

**NATIONAL COUNCIL
FOR THE AGED**

**CARING FOR
THE ELDERLY
PART II**

**THE CARING PROCESS:
A STUDY OF CARERS IN
THE HOME**

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五十年來紀念
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NATIONAL COUNCIL FOR THE AGED

The National Council for the Aged was established by the Minister for Health in June 1981. The terms of reference of the Council are:

"To advise the Minister for Health on all aspects of the welfare of the aged, either on its own initiative or at the request of the Minister, and in particular

on methods of ensuring co-ordination between public bodies at national and local level in the planning and provision of services for the elderly,

on ways of meeting the needs of the most vulnerable elderly,

on ways of encouraging positive attitudes to life after 65 years and the process of ageing,

on ways of encouraging greater participation by elderly people in the life of the community,

on models of good practice in the care of the elderly

and

on research required to plan and develop appropriate services for the elderly."

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THE CARING PROCESS: A STUDY OF CARERS IN THE HOME

By

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Helen Ruddle

with the assistance of

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NATIONAL COUNCIL FOR THE AGED. 1988
REPORT NO. 19

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for

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Cover Design by Declan Buckley

£5.80

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Foreword

This study, *The Caring Process: A Study of Carers in the Home* is Part 2 of a research programme, ("Caring for the Elderly"), on family carers of elderly people in the Republic of Ireland which was initiated by the National Council for the Aged in 1985.

Part I of the programme, *A Study of Carers at Home and in the Community*, was published in June 1988. It provided a profile of carers and the database for this study of the process of caring for elderly people within households. It found that there are 66,000 elderly people receiving a significant amount of care at home from a relative, which is more than three and a half times the number of elderly people in institutional care. It identified the nature and extent of the care required of families and relatives of those elderly people who continue to live at home, in their own communities, rather than in an institutional environment.

This second volume of the study examines the caring process and focuses primarily on the family carers of elderly people living at home rather than on the recipients of care themselves. The study shows clearly that family carers are the unrecognised backbone of community care — inadequately supported by State and other agencies in the task they have undertaken with such dedication and very often carrying out the task at great personal sacrifice. Without the commitment and dedication of the family carers the demands on the State for institutional care of the elderly would be very much higher.

The question "Who cares for the carers"? is given added urgency as a result of the findings of this study and needs now to be seriously addressed. The Council in its preface to the study has sought to identify the main areas where this support is required and has made recommendations for changes in policy and practice. There is a great need for information and support services for the carers of the elderly. Such supports as respite care, better home help and day care services, information, training and counselling services would all help to ease the burden on the carer as would better co-ordination of community medical and nursing services. The Council also believes that a strong case can be made for the introduction of a special scheme of financial assistance

by the State for the carers of certain elderly people and this proposal is outlined in the Council's preface.

The Council would like to thank the authors of the report, Professor Joyce O'Connor, Director of the project, and Dr. Helen Ruddie, Research Officer, together with Marie O'Gallagher and Eileen Murphy and other members of the research team at the Social Research Centre, N.I.H.E. Limerick. We also wish to gratefully acknowledge the contribution of the staff of the Research Unit of the ESRI and in particular Professor Brendan Whelan. We are indebted to the respondents in various parts of the country without whose co-operation and goodwill the study could not have been carried out.

The Council also wishes to acknowledge the contribution of the members of the Consultative Committee established to advise on the preparation of the report, Dr. Michael Hyland (Chairman), Dr. Ruth Barrington, Mrs. Iris Charles, Mr. Jim Cousins, Mr. Fred Donohue, Ms. Aileen O'Connor, Mr. Joseph Rowe, and Mr. Seamus Shields.

The Council would also like to thank Mr. Bob Carroll, Secretary of the Council, and Mr. Michael Browne, former Research Officer with the Council, for their considerable contributions to the production and publication of the report.

We hope that the publication of this study will lead to a greater awareness of the major role played by families and relatives in the care of the elderly and of the problems they face in carrying out this task. We hope too that the issues raised and the recommendations we have made will be addressed by central government, by health boards, by voluntary and statutory agencies and by professionals with responsibility for the care of the aged and will lead to significant and early improvements in the position of family carers whose contribution is so vital to the dignity and well-being of so many elderly people living in the community.

Mr. L. J. Tuomey, Chairman
National Council for the Aged,
Corrigan House,
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September 1988.

Comments and Recommendations by the National Council for the Aged

1. INTRODUCTION

Despite the impact of various social factors (e.g. higher marriage rates, lower fertility rates, greater geographical mobility, less closely-knit communities, increased levels of female participation in the labour force and increased life expectancy, particularly for women), the family continues to be the strongest and most reliable source of care for elderly persons. The majority of the ill elderly and handicapped continue to be cared for at home rather than in institutions — living either with their spouse or children, with another relative or occasionally with non-relatives. Families tend to show a high degree of adaptability to the needs of dependants and increasing levels of disability can be catered for within the natural caring network. There is a body of impressive evidence which indicates the variety of ways in which family members seek to maintain elderly dependents at home despite having to simultaneously discharge other familial and work responsibilities.

The National Council for the Aged has recently published a report *Caring for the Elderly Part I: A Study of Carers in the Home and in the Community* (National Council for the Aged, Report No. 18) which estimated that 66,300 elderly persons in the Republic of Ireland receive some level of care from family members. Some 36 per cent of these were described as needing a lot of care and almost 77 per cent received their care from a household member. This study also estimated that 39 per cent of the elderly have carers who are aged fifty-five years and over, and that almost 80 per cent have female carers.

The present study, *Caring for the Elderly Part II. The Caring Process: A Study of Carers in the Home*, explores the family caring process and identifies some key issues relating to it. The Council hopes that the study will make an important contribution in creating an increased recognition of the central and vital role played by families in the community care of elderly persons.

The following are the main findings of the study:

(a) Main Characteristics of Carers of Elderly Persons

- Half of the carers are aged between 40 and 60 years; approximately one-quarter are themselves elderly.
- One-fifth of carers have given up work to care for the elderly person.
- One-third are members of households totally dependent on State benefits.
- The majority of carers have had occasion to visit the doctor about their own health in the last year. One-third are suffering from ongoing health problems.
- Twenty-nine per cent have been caring for more than 10 years.
- Two-thirds are caring for a parent or parent-in-law and one-quarter are caring for their spouse.

(b) Main Characteristics of Elderly Persons being Cared-for

- Many have some physical problems typically of long-term duration of 5 years or more — disease of the joints is a very common complaint.
- The majority depend on the carer for the essentials of cooking and preparing meals.
- Over a quarter are dependent with regard to bathing — a further 52 per cent require some help with this task.
- Thirty-one per cent are housebound; 15 per cent are bedridden.
- Memory loss, angry outbursts, mood swings, confusion, depression and sleeplessness each affect 15 per cent of elderly people cared-for on a regular basis.
- Twenty-four per cent are incontinent of urine and 20 per cent have problems with soiling.

(c) Main Caring Tasks

- Fifty per cent of carers devote 4-7 hours a day caring for the elderly person; 35 per cent spend more time than this.
- Over half are required to be "on call" 24 hours a day always or almost always.

- Over half of carers help the elderly person in and out of bed on a daily basis.
- Over 80 per cent have responsibility for administration and supervision of medication.
- The majority prepare meals for the elderly person.
- Over two-thirds give some help with washing and bathing the elderly person.
- A quarter dress the elderly person daily.
- Tasks related to toileting are carried out daily by 22 per cent and are carried out on a less regular basis by a further 22 per cent.

(d) Restrictions of Caring Role

- Seventy-one per cent of carers feel confined all or some of the time: 58 per cent believe that caring puts constraints on their social life; 82 per cent of carers have not had a holiday in the past year.
- The majority of carers say that they find caring very tiring — 57 per cent feel overwhelmed by caring some or all of the time.
- Many carers feel unable to relax when out socially because of worry about the elderly person or because of being limited in the amount of time away from the home.
- Many carers find it emotionally draining and upsetting seeing an elderly relative change from his/her former self.
- Carers sometimes experience strains on relationships — with, for example, spouse and children competing for attention with the elderly person and/or conflict with other family members whom the carer feels are not carrying their share of the caring burden.

There are a number of issues arising from the study which the Council wishes to highlight, as follows:

- (i) Family carers make an enormous contribution to the care of elderly persons in the community.
- (ii) Despite this major contribution to the care of the elderly, the services of carers receive scant recognition and are not financially recompensed.

- (iii) Support to carers from statutory sources in the form of practical services and advice is almost non-existent.
- (iv) Family carers of elderly persons do not form a homogeneous group. The elderly being cared-for differ greatly in terms of physical, psychological and medical well-being and functioning. The carers vary in age, level of income, access to services, physical health and emotional well-being and also in terms of the level of support available from family, friends, and neighbours.
- (v) For some people the caring burden is enormous, e.g. those who have to provide care on a twenty-four hour basis.
- (vi) In some instances the financial burden associated with caring is great not only in terms of extra costs on items like food and heating but also in terms of lost employment opportunities and related pension rights.
- (vii) Services in general do not seem to be meeting the needs of carers for temporary respite from demanding behaviour which frequently causes stress and strain on the part of the carer.
- (viii) The lack of statutory support services for carers is likely to result in:
 - (a) a breakdown in the family caring system and a consequent unnecessary admission to institutional care;
 - (b) serious physical, emotional and/or financial problems for the person/family carrying out the caring function.

2. COMMUNITY CARE AND THE FAMILY

The underlying and frequently articulated philosophy of community care is that elderly people should be enabled to live in their own homes, and supported in so doing by a combination of formal and informal service provision for as long as possible. The Council takes the view that the strong social obligation and commitment of families to care for their elderly is overstrained in many instances.

If old people are to remain in the community, support and assistance must often be directed to the whole family of which they are members. (Seeböhm Committee, 1968, p. 96)

Provision of community and home-based care for older persons, in

the spheres of health, housing and social welfare are central measures for supporting the family. Professional assistance, financial aid and counselling services need to be made available to families caring for disabled or chronically ill ageing members. Respite care is required as well to provide periodical relief to such families, and economic policies must ensure that they are not indirectly penalised for carrying out their caretaking role. Income tax incentives, allowances and housing subsidies are concrete measures implemented thus far in various contexts in support of the family. Clearly, a combination of service and financial policies is required to strengthen the capacities of the family to respond to the needs of its ageing members and to permit the continued integration of the ageing in family life. (United Nations, 1985, p. 74)

While there may be a strong ideological bias towards family care of the elderly, such care is not necessarily more desirable than care provided formally by the State — "Both may be narrowly or expansively conceived and operated, they may enhance or reduce dependency, deny or facilitate rights and restrict or enhance freedom". (Walker, 1982. p. 5)

A question which is frequently raised by policy researchers is who cares for the carer? This question requires to be seriously addressed in the overall context of community care services for the elderly in Ireland.

3. SUPPORT SERVICES FOR CARERS

In addition to general improvements in basic community care services for the elderly and more effective co-ordinating and information mechanisms, as discussed in Section 4 below, the Council considers that there are a number of other specific areas where changes could be brought about which would enhance the family caring system, particularly during periods of intensive caring.

These areas are:

- (i) Respite care
- (ii) Information, training and counselling
- (iii) Home help services
- (iv) Day care services
- (v) General practitioner services
- (vi) Prescribed relative allowance

- (vii) Basic payment for family carers
- (viii) Carers' support groups.

(i) Respite Care

The provision of respite care for carers of elderly persons is not a new concept but for various reasons has not always fulfilled its promise of sharing the responsibility of caring between formal services and the family. Some of these reasons include lack of relevant knowledge on the part of carers, pressure on hospital/nursing home staff to use every available bed, fear of the elderly person that the admission might prove long-term and fear by hospital staff that the family would be reluctant to resume the responsibility of caring.

The present report identifies a number of possible respite interventions for carers, *viz.*

- week-end live-in companions to relieve the primary carer;
- day care centres;
- short-term boarding-out with other families on a planned intermittent basis;
- intermittent hospital admissions (geriatric and district hospitals);
- intermittent beds in designated nursing homes.

The need for planned respite facilities is paramount and every effort should be made by health boards not only to provide a range of respite options but also to ensure that carers are aware of such options. It is also important to ensure that the availability of respite care facilities allows for some choice by carers and elderly persons about the time and duration of the respite service.

(ii) Training, Counselling and Information

People embarking on a caring role require information on the nature of the elderly person's illness and on support services available. They also require practical training and advice on lifting, bathing, changing beds and clothes. Health boards should ensure that such services are available as required.

Carers may also require help in coping with a caring role which in some instances impinges significantly on the carer's life, with major

implications for their physical, emotional and financial well-being. Health boards should make available social work personnel to whom people requiring counselling and advice could be referred. The following areas should be covered by the social worker:

- (a) taking on the caring role;
- (b) the role of other family members in supporting the carer;
- (c) the need for the carer to look after his/her own physical and emotional well-being;
- (d) the nature and progression of illness/disability;
- (e) the post-caring situation;

The social worker also has an important role to play in developing and facilitating carers' support groups at local level.

Carers also need information on available support services in the community and how to go about availing of such services. Health boards should develop a system of making such information readily available, through the information officer referred to in Section 4 (iii) below, but also, for example, through the general practitioner service, the public health nursing service and the home help service. It is also possible that some of this work could be undertaken by health education officers where such posts exist.

The Council considers that the media, particularly television and radio, has much to contribute in providing information and advice to carers of elderly persons at home. The Council therefore recommends that the Health Promotion Unit of the Department of Health should engage in a sustained use of the media to promote the concept of care in the home and to provide appropriate information and advice to carers.

(iii) Home Help Service

The home help service should not only be protected from the impact of current cutbacks in the health services but should be developed and expanded so as to provide a higher level of support for persons caring for highly dependent elderly relatives. In particular health boards should explore the possibility of developing the home help service to:

- provide night-sitting services for elderly persons at home requiring twenty-four hour care;
- assist carers in all daily caring tasks;

- provide week-end cover.

Home helps should be appropriately trained and remunerated for the provision of these services.

(iv) Day Care Services

The Council has already highlighted the need for a more comprehensive system of day care services for the elderly (Convery, 1987). Day centres are particularly relevant in the context of supporting carers especially in the case of elderly people suffering from dementia or Alzheimer's disease. Voluntary organisations providing high quality day care services should receive increased grant aid as a matter of priority. The acute need for adequate transport to day care centres has already been emphasised by the Council and should be provided as an essential aspect of day care services.

(v) General Practitioner Services

The general practitioner plays a key role in the care of elderly persons at home and consequently in supporting the carer. The general practitioner makes a significant contribution by:

- (a) communicating to carers basic information about the nature of illnesses and treatment, related behaviour patterns and progression of disability;
- (b) informing carers of the range of support services and options available and encouraging the carer to avail of such services;
- (c) making appropriate referrals and acting as an advocate when necessary;
- (d) encouraging the carer to look for support from other family members, friends and neighbours;
- (e) identifying for the carer where and how he or she can get basic training in caring.

General practitioners should receive special training to equip them to carry out the above tasks. The role of the general practitioner in disseminating information on services is obviously dependent on the availability of adequate and appropriate statutory support services for carers.

(vi) Prescribed Relative Allowance

(a) The prescribed relative allowance should be extended to include instances where full-time care for eligible elderly persons is provided by prescribed relatives who are married and instances where the care is provided by other relatives, e.g. cousins.

(b) The Department of Social Welfare should implement immediately the recommendations of the Commission on Social Welfare that eligible prescribed relatives (i.e. people who have no personal income and are caring for an elderly or infirm relative) should have entitlement in their own right to a social assistance payment.

(vii) Constant Care Attendance Allowance

It is the view of the Council that the enormous contribution made by full-time carers to the care of the elderly in the community and the consequent saving to the exchequer should be recognised by the State in the form of financial reward or compensation over and above any social welfare payment to which the carer may be entitled. It can be estimated (National Council for the Aged, Report No. 18) that out of a total of 66,000 elderly persons in the population as a whole who are receiving care at home, there are some 24,000 who are very dependent and require such care on a full-time basis. The savings to the exchequer are likely to be considerable in that such care in an institutional setting would be quite expensive to provide. Thus every effort should be made to support the concept of full-time care of the elderly at home for financial as well as for ideological reasons.

Consideration should, therefore, be given by the Department of Health to the possibility of developing a scheme whereby people caring full-time for elderly relatives would receive a Constant Care Attendance Allowance from health boards for such a service, similar to the successful Domiciliary Care Allowance* payable in respect of severely handicapped

*This is a monthly allowance designed to make some contribution toward the cost of maintaining a severely physically or mentally handicapped child at home. It is paid in respect of a severely mentally or physically handicapped child between the ages of 2 and 16 years. The child must be maintained at home, needing constant care and supervision which is deemed to be substantially greater than that which would normally be required by a child of the same age and sex. The handicap must have been present for at least six months prior to the application and likely to continue for at least one year.

The allowance is paid regardless of the parents means. However, if the child has means in his/her own right, this is taken into account. 'Means' in this context would include payment of compensation for injuries sustained in an accident.

children. This payment should be made regardless of the carer's means, but should be subject to professional medical certification of the elderly person's dependency on constant care which would be carried out in accordance with criteria drawn up by the Department of Health for this purpose.

Consideration should also be given to extending the tax-free allowance given to an incapacitated person who employs a housekeeper to cover situations:

- (a) where full-time care is provided by a relative;
- (b) where the tax-payer is a relative of the incapacitated person and is providing full-time care for the incapacitated person either directly or through his/her spouse.

(viii) Carers' Support Groups

Local carers' support groups have an important role to play in the areas of information-sharing, emotional support and respite for carers, and also in the area of advocacy on behalf of carers. Such groups should be encouraged and supported by statutory personnel and voluntary bodies.

(ix) Innovative Developments

In the foregoing context of providing increased support services for carers the Department of Health should make special additional funds available to health boards for innovative development in the areas referred to, especially in the areas of co-ordination, respite and intermittent care, day care and night-sitting services (See 3 (ii), 3 (iii), and 3 (iv) above and 4 (i), 4 (ii) and 4 (iii) below).

4. CO-ORDINATING SUPPORT SERVICES FOR THE ELDERLY

The Council considers that the issue of family care of the elderly must be viewed in the context of a need for a much more comprehensive community care system for the elderly than that which currently exists. In particular, there is an urgent need to provide more resources in the areas of public health nursing, home helps, respite and intermittent care facilities, and day care services. Simultaneously, there is a need to develop and expand social work, chiropody, physiotherapy and occupational therapy services provided for the elderly in the community.

There is also a need to maintain adequate, appropriately located hospital and long-term care facilities for the elderly so as to enhance the community care network.

(i) Joint Planning for the Elderly at Local Level

It is the considered view of the Council that, even with the increased availability of resources, an effective community care system for the elderly can be brought about only if appropriate co-ordinating mechanisms are introduced. Such mechanisms would include the setting up of a structure for joint planning for the elderly at local level, involving health authorities and housing authorities, hospital programmes and community care programmes, the statutory sector and the voluntary sector. Such a structure would aim to integrate and to fully support the work of voluntary bodies, neighbourhood networks and the family caring system. The Council is currently engaged in the evaluation of two such co-ordination projects which have been established on a pilot basis. These projects consist of (i) a steering committee at community care level which has responsibility for co-ordinating services and (ii) local area committees which co-ordinate services at district level and make recommendations on the planning and development of services for the elderly to the steering committee.*

(ii) Co-ordinator of Services for the Elderly

The co-ordination of health and welfare services for the elderly would, in the Council's view, be greatly enhanced by the availability of a person at community level with responsibility for co-ordinating all services for the elderly in the area. The Council wholeheartedly supports the recommendations of the Working Party on Health and Welfare Services for the Elderly that a co-ordinator of services for the elderly be appointed in each community care area (Department of Health, 1988). This co-ordinator of services should have statutory responsibility for ensuring that support services, e.g. respite and intermittent care facilities, day centres, home helps and public health nursing, were provided at a consistent level throughout the community care area and at a level adequate to meet the needs of the elderly. In addition to his/her general responsibilities the co-ordinator of services for the elderly should have

*Further information on these pilot projects can be obtained from the National Council for the Aged.

the following specific responsibilities in respect of family carers of elderly persons.

- (a) As well as maintaining a register of elderly persons at risk, the co-ordinator of services for the elderly should ensure that a register is kept of all elderly persons being cared for at home by a relative.
- (b) As the general practitioner is the professional with whom carers have most contact and the professional who is most likely to be involved with a family when an elderly person begins to need full-time care, the co-ordinator of services for the elderly should ensure that general practitioners are well informed of the services available to carers in the area.
- (c) The co-ordinator of services for the elderly should ensure that local authorities are made aware of the repairs and adaptations to homes which are necessary to enable the carer to look after their elderly relative as comprehensively as possible.
- (d) The co-ordinator of services for the elderly should ensure that any person providing a heavy level of care for an elderly relative is offered a range of support, including day care attendance for the elderly person, respite care, assistance in the home, and/or a night-sitting service.

(iii) Liaison and Information Officers

The work of the co-ordinator of services for the elderly would be greatly enhanced by the availability of one person at local district level who would have responsibility for liaising between those caring for elderly people and the support services available in the community. The co-ordinator of services for the elderly should, therefore, nominate an officer in each district (population 25,000-30,000) who would have responsibility for such liaison and for providing information on support services available to elderly persons and their carers. This officer should be readily identifiable and regularly available to the public.

5. SUMMARY OF RECOMMENDATIONS

Carers of elderly persons are, in the Council's view, the key to community care of the elderly and, therefore, require to have their needs and

requirements seriously addressed by the advocates of such care and particularly by national health policy. Carers are, however, often the 'forgotten army' who receive scant attention or support from the State. The factual position is that in order to carry out their caring role effectively carers need a wide range of supports from the statutory services, particularly in the areas of respite care, day care and practical help with difficult daily tasks such as lifting, bathing and night attendance. Every care should also be taken by health boards to ensure that carers are not put under excessive pressure due to the lack of appropriately located acute hospital places and long-term places for the elderly.

The Council considers that there is an urgent need for a general improvement in community care services for the elderly and their carers and an urgent need for more resources in the area, particularly in the light of various cutbacks in services in recent years. The Council wishes to make the following specific recommendations in respect of developing a comprehensive range of support services for family carers of elderly persons.

1. Co-ordinator of Services for the Elderly

Health boards should appoint a co-ordinator of services for the elderly at community care level.

2. District Liaison and Information Officers

The co-ordinator of services for the elderly should nominate a person at local district level (population 25,000-30,000) to liaise with the co-ordinator of services for the elderly and, also, with people involved in the delivery of services at district level. This person should be required to make available comprehensive information on statutory support services provided to elderly people and their carers in the area.

3. Respite and Intermittent Care Facilities

Health boards should develop as a matter of priority a range of respite services for family carers including short-time boarding out schemes with families and intermittent/floating institutional bed facilities.

4. Information, Training and Counselling Services

Health boards should provide for an organised system of training, counselling and information for family carers of elderly persons and should make personnel available for this purpose.

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Acknowledgements

The authors wish to thank most sincerely all those who, by proffering suggestions, ideas and information, made the planning and execution of this study possible. The National Council for the Aged funded and initiated the study.

First, we wish to thank the Chairman and the members of the National Council for the Aged for their support, encouragement and advice. Special thanks are due to the Research Advisory Committee: Dr. Michael Hyland (Chairman), Mr. Michael Browne, Dr. Ruth Barrington, Mrs. Iris Charles, Mr. Bob Carroll, Mr. Jim Cousins, Mr. Fred Donohoe, Ms. Aideen O'Connor, Mr. Joseph Rowe and Mr. Seamus Shields for their guidance, advice and support. This Committee provided an invaluable platform for discussion bridging the gap between practitioners, carers, policy makers and researchers. Their comments and constructive criticisms of the various stages of the earlier drafts of the study were most helpful.

Mr. Michael Browne gave of his time without question and we would like to thank him sincerely for his ideas and suggestions.

Appreciation is also given to the staff of the Computer Services Division in NIHE Limerick, in particular Mr. Martin Leonard, whose expertise and help proved an invaluable aid to the study.

We are especially grateful to Ms. Martina Curtin, Ms. Karen McCarthy and Ms Grainne O'Connell. They managed to read our writing and their patience and skill with the redrafting of the text deserve special mention.

The staff of the Survey Unit of the ESRI. Professor Brendan Whelan and Mrs. Colbert Stanley helped and contributed with their ideas and advice. Our appreciation of the work of other members of the ESRI and SRC teams should be recorded, especially that of the ESRI interviewing personnel who carried out the fieldwork and the coding and data preparation staff in the SRC Survey unit. Eileen Humphreys contributed to the development of the interview schedule and her administrative and organisational role in the study is acknowledged.

Mrs. Esther O'Connor, Mrs. Mary Donoghoe and Mrs. Barbara

Crowley of the SRC Survey Unit helped in the preliminary testing of the questionnaires developed for the study.

The key contributors to the study are, of course, the carers who of necessity must remain anonymous. We would like to acknowledge their generous co-operation and contribution to the study.

None of the above mentioned is responsible for the final manuscript: any errors or omissions are the sole responsibility of the authors.

We particularly wish to acknowledge the help of Mr. Rory Hearne. Before his untimely death, which we deeply regret. Rory acted as statistical consultant to the project and provided expert advice and guidance throughout all stages of the study. We remember Rory as a dear friend and colleague.

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CHAPTER ONE

Introduction

Focus of the Study

This study — *The Caring Process: A Study of Carers in the Home* — focuses on carers who look after elderly persons in their own homes and is the first study of its kind in the Republic of Ireland. Based on a nationwide study of carers this book sets out to explore, describe and analyse the life experiences of those who provide home-care for the elderly. Its purpose is to present an in-depth picture of all aspects of carers' lives: how do people come to be carers?; what factors influence them in making such a decision?; what does daily caring involve for them and what help do they get from family, friends and neighbours? The role of statutory bodies and of voluntary organisations in providing back-up assistance to carers is also explored. The impact of caring on the carer's social, psychological, physical and material well-being is documented and the carers' own reactions to their situation and how they define their lives as carers are described.

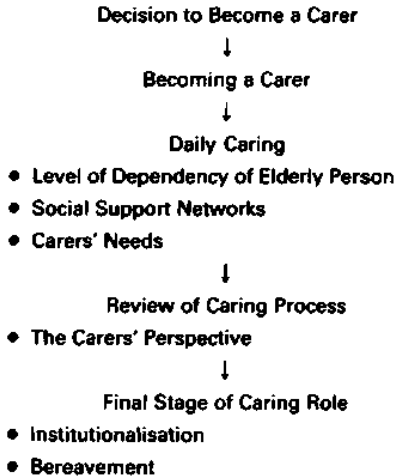
Focus on Carers in the Home

In recent times there has been considerable concern and detailed research on the situation of the elderly in Ireland. However, relatively little attention has been given to those who are caring for the elderly and who maintain them in the community — *the carers*. The position of those who care for the elderly within their own homes is a central concern of the National Council for the Aged and knowledge of their numbers, characteristics and life experiences is a major aspect of the Council's research programme. The research programme — initiated in 1985 — in its first phase focused on establishing a general profile of carers in the home and in the community: *Caring for the Elderly Part 1: A Study of Carers at Home and in the Community*. This second phase provides a more in-depth picture of all aspects of caring within the home.

Aims of the Study

This study is designed to contribute to greater knowledge and understanding of the lives of carers. It explores the process of caring within a framework which views caregiving as a complex behaviour involving different stages (Figure 1.1):

FIGURE 1.1: THE CARING PROCESS



Objectives of the Study

The specific objectives of the study are:

- to establish a profile of family carers of elderly persons — their number; demographic characteristics; socio-economic status; and relationship to the persons being cared-for.
- to explore how and why they became carers.
- to describe the nature and extent of care provided in the context of the elderly person's physical and mental well-being, level of functional ability and degree of dependency.
- to detail the daily routine of caring.
- to examine the extent of practical help and support provided through the carer's informal social support network and through voluntary and statutory bodies.
- to examine the costs of caregiving to the carer.

- to identify the primary needs of carers at the different stages of the caring process.

BACKGROUND TO THE STUDY: CARE IN THE HOME AND IN THE COMMUNITY

The vast majority of the elderly living in the community do not require care. Research shows that in Ireland 66,300 old people are partially dependent on help and require some level of care. These dependent elderly tend to be older, are more likely to be women, to live in rural areas and to be in households headed by farmers.

Who Cares?

The first study of carers of the elderly showed that in Ireland, as in other countries, families are the main carers of their dependent elderly relatives. People in households of professional or managerial class are less likely than farm households to care for an elderly person within their own home, although they do give elements of care to people outside the home. Furthermore, these households are more likely than other households to be involved in low intensity caring situations. Irrespective of social class, more women than men tend to be carers and women provide more intensive care. While over 15 per cent of sons give some level of care, responsibility for caring falls mainly on women whether wives, mothers or other relatives. Women carers also look after the more dependent elderly. The majority of carers are between 20-54 years of age but one-quarter are elderly themselves being 65 years or more. The range of help given with ordinary day-to-day activities was highlighted in this earlier study with over 18 per cent of carers providing help with all aspects of living, thus enabling the elderly person to live within a family setting in the community.

Care from Outside the Home

In the first study of care of the elderly, information from the carers themselves indicated that 12 per cent of households give care to an elderly person outside the home. This represents a considerable number of people who are involved in informal support within the community. Here again women emerge as being the principal carers — whether or

not they are relatives of the elderly person needing care. Outside carers are younger than those providing care within the home and fewer are relatives of the elderly person. The descriptions of care given involve routine daily activities and emphasise the importance of social contact to the elderly. The vast majority (86%) of carers provide company and over half (57%) undertake shopping and collection of pensions. Approximately one-quarter of carers perform household tasks such as cooking, ironing and fire-making, indicating their essential role in integrating and supporting elderly persons in the community. According to the elderly receiving care, the kind of help given is concentrated on laundry, ironing and transport. Almost half of those being cared-for by someone outside the home live alone and are substantially less dependent than those being looked after by family members in their own homes.

The first part of the research programme on carers of the elderly raises some important issues in regard to the social definitions of care, gender differences in caring patterns and differences between socio-economic groups in their extent of caregiving. Furthermore, the preliminary report raises many questions which are examined in greater detail in this second report: how people come to be carers; what factors influence them in making such a decision; what caring involves for them and what influence do social support networks have on their lives. The present study also investigates the consequences which must be borne because of caring and it describes the carers' own reaction to their situation. An important distinction which must be made between the first and second phases of the research programme is that this present study focuses on an examination of the lives of those carers who are caring for an elderly person who is living within the household and does not consider those who are providing care outside the home.

RESEARCH DESIGN AND METHODOLOGY

The study was conducted in a series of stages as outlined in Figure 1.2. The first stage involved background research using documentary sources, in-depth qualitative interviews and empirical research. The main study was preceded by a pilot study the objective of which was to test the comprehensiveness and usefulness of the research questionnaire. A brief outline of the main stages of research follows.

FIGURE 1.2 RESEARCH STAGES

Stage	Objectives
Preliminary Background Research: Literature Review Meeting with Advisory Committee Discussions with statistician and fieldwork organiser	To explore the conceptual arena of the study. To define the focus of study. To structure the interviews for the qualitative pre-tests. To structure the in-depth interviews with the carers
Qualitative Pre-tests: 10 in-depth interviews	To explore experiences of the caring process and conceptual arena To explore practical fieldwork issues.
Pilot Study	To pre-test the questionnaires to be used in main study. To test organisation and sample selection.
Fieldwork Organisation	Selection of interviewers. Training of interviewers. Fieldwork.
Main Study: survey of 200 carers	To provide an in-depth picture of the different stages of the caring process.
Data Preparation and Analysis	Coding and inputting of data. Data checking and validation. Preliminary analysis, frequency counts. Tabulation of data. Data reduction. Detailed analysis.
Summary Report	Discuss policy issues with Advisory Committee
Main Report	To communicate the findings of the study.

Sample Selection

A representative sample of 200 carers was selected from among all those providing a minimum of occasional care and living in the same household as the elderly person being cared-for. The sample was derived using the data collected in the first study of the research programme on care of the elderly *Caring for the Elderly: A Study of Carers at Home and in the Community*. A complete description of the sampling procedure used is contained in the report of that first study.

Essentially, the procedure involved the identification of carers by means of the AFT/ESRI Quarterly Consumer Survey of households in the Republic of Ireland. All households in the Consumer Survey sample reporting either that they provided some care to an elderly person outside the home or that they contained an elderly person receiving care

formed the basis for the analysis presented in Part I of the research programme. This first study found that the most intensive forms of caring occurred where the carer and the elderly person being looked after lived together in the same household and it was, therefore, decided to concentrate exclusively on those households in the present study. Of the 325 households identified in the first study as containing an elderly person receiving care, in 73 cases the elderly person was being looked after by someone outside the household (many of these were old people living alone) and a further six declined to participate in further studies at the time of the first interview. Accordingly there were 246 households which were appropriate for inclusion in this present study. Of this group 12 were involved in a pilot study and 95 could not be interviewed for various reasons detailed in Table 1.1.

In order to increase the overall sample size to the required number of 200, an additional group of 165 carers within the home was identified from the January, February and March 1987 rounds of the Consumer Survey. Since cost considerations precluded interviewing more than about 200 respondents overall, 34 of the obtained 165 addresses were omitted at random from the sampling procedure. Sixty-one carers from this group were finally included in the study (Table 1.1). Overall, 200 interviews were obtained (Table 1.1) with the main reason for non-response being changes in the circumstances of the household. Of those interviewed 164 were females with 36 being male.

Table 1.1: Composition of study sample

	Sift 1 (1985)	Sift 2 (1987)	Total
Total identified as willing to participate	246	165	411
Used in Pilot	12	—	12
Not Contacted	—	34	34
Deceased	7	1	8
Moved	11	1	12
Temporarily Absent	2	2	4
Vacant House etc.	3	1	4
Refused	7	6	13
Ill/Senile	2	0	2
Not possible to contact	25	21	46
Other reason (e.g., care no longer required. carer moved away, etc.)	38	38	76
Interviewed	139	61	200

The data presented in this report, unlike those in Part I, are not weighted since the main interest in this enquiry is to build up a detailed picture

of the carers and their life-styles and not to present overall national estimates. The data are, of course, subject to the usual caveats regarding sampling error. It was not possible to calculate exact estimates of the standard error of this phase of the survey. As a rule of thumb, however, it can be assumed that each percentage reported has a margin of error of at most 10 percentage points¹. Thus, a figure of 43 per cent obtained in the survey indicates that the true figure lies between 33 and 53 per cent.

Pilot Study

Following an intensive series of pilot interviews, a broad-ranging interview schedule was developed. The pilot study was regarded as an integral part of the research design and many changes were made to the questionnaire on the basis of its findings. The general approach used was to consider each main area of investigation separately and to formulate numerous questions or items referring to it. Procedures and indices used in previous research were also investigated. The items were then judged, tried out and modified. In this way the questionnaire went through many stages of revision. During these early stages, consultations and discussions were held with the Advisory Committee as well as with relevant agencies and individuals. These proved to be of major benefit to the study.

Interview Schedule²

The interview schedule which was finally developed was structured and pre-coded with a fixed sequence of topics to be followed by the interviewers. The following are the main areas covered by the schedule:

- Details on the elderly person for whom respondent is caring.
- Whether respondent is caring for any mentally and/or physically handicapped persons.
- Household composition.
- Motives and factors related to becoming a carer.

¹ This rule of thumb is derived by assuming a "design effect" of 1.5. i.e.. it is assumed that the standard error for a simple random sample of the same size must be multiplied by 1.5 to allow for the effects of clustering, etc.

² See Appendix Two for outline of the questionnaire design.

- Physical health of elderly person.
- Mental health of elderly person.
- Receipt of advice on caring.
- Daily routine of caring
- Carers' physical health.
- Carers' mental health.
- Housing circumstances that may make caring difficult.
- Contact with family, friends and neighbours.
- Practical help from carers' family and friends.
- Emotional support from carers' family and friends.
- Provision of services assisting carer.
- Provision of advice to carers.
- Financial circumstances.
- Caring: constraints on social life.
- Caring: effects on relationships.
- Experiences of respite from caring.
- Needs of carers.
- Relationship between carer and elderly person.
- Best things about caring.
- Worst things about caring.
- Life-satisfaction of carer.
- Needs of carers where elderly person is in long-term care or no longer lives with carer.
- Any further comments of carer.

Fieldwork

The interviewing team consisted of members of the ESRI Survey Unit and was comprised of 12 interviewers and a fieldwork supervisor. A detailed training programme was undertaken, the main objectives of which were to impart a common approach, to enable the interviewers to become familiar with the questionnaire and to achieve a full understanding of the project. The training programme was centred around the following areas:

- familiarity with the design of the study.
- detailed briefing on and knowledge of the questionnaire.
- simulated interviewing for standardisation of approach.
- discussion group after trial interviews.

Fieldwork was completed between mid-March and the end of May 1987. All those interviewed were assured of the confidentiality of the interview information. The non-response rate was 3 per cent. The quality of the interviews obtained was high.

Processing and Analysis of the Data

All the interviews were checked thoroughly before being prepared for computer analysis. The coding and checking was undertaken by a team based at the Social Research Centre's Survey Unit. The reduction of the considerable quantity of data was facilitated by the use of cluster analysis and the SPSS Computer Package.

Format of the Report

This report is organised into thirteen chapters. Chapter One provides an introduction to the study and describes its design and research methodology. The main themes to emerge from recent research related to the elderly and their carers are presented in Chapters Two and Three. Chapter Four outlines the characteristics of those elderly people who get home-care and describes the nature of the care they require in terms of their physical and mental well-being, level of functional ability and degree of dependency. The characteristics of those who provide home-care for the elderly are presented in Chapter Five. Chapter Six explores the process of becoming a carer and the factors that influence the decision to take up the caregiving role. The daily dimensions of caring are described in Chapter Seven. The nature and extent of the support provided by family, friends and neighbours is the subject of Chapter Eight while Chapter Nine details the support given by voluntary and statutory bodies. The impact of caring and the costs it exacts in different aspects of the carers' lives are documented in Chapter Ten. The needs of carers form the focus of Chapter Eleven and Chapter Twelve describes the carers' personal experiences of caregiving. The final chapter — Chapter Thirteen — reviews the main findings of the study and outlines a plan for the development of a comprehensive range of services for carers. References follow at the end of Chapter Thirteen. Two Appendices accompany the main text. Appendix One contains tables referred to but not included in the main text. An outline of the questionnaire design is contained in Appendix Two. A copy of the questionnaire, together with a description of indices and measures used in the study, are available on request from the National Council for the Aged.

CHAPTER TWO

Carers of the Elderly at Home: Literature Review

Introduction

Despite evidence to the contrary, the dominant popular image of old age is still one of inevitable decline, dependency and senility. Research carried out in Ireland and the USA clearly shows that the vast majority of the elderly, even in advanced old age, function independently. Recently, more emphasis is being placed on the elderly as a resource within the community and on the concept of old age as a time of opportunity. Present-day demographic and social changes offer rich new possibilities and challenges both to the elderly and to the community in general.

The increase in life expectancy brought about by advances in medicine and improved living conditions has led to a growth in the proportion of elderly people living in our society. The relatively recent changes in mortality, work patterns, educational levels and family lifestyles present the possibility of new horizons for family life and for the potential of individuals in society. While recognising the importance and potential of the elderly in society the research literature very often focuses on ageing as a problem. Recently the focus has begun to shift to encompass family care and care of the elderly in their homes and in the community. Over the past number of years, researchers and policy makers, particularly in North America and the United Kingdom, have highlighted the importance of family and friends in providing long-term care to the elderly. Much of this literature has focused on the composition of the informal caring network, the variety of sources of care and the commitments of caregivers. Researchers, support groups and carers themselves have focused in particular on the complexity of caregiving and the caregiving process. They have raised questions about the capacity of informal caregivers to continue to provide the bulk of long-term care. A number of themes have emerged from the literature. Horowitz¹

identified four successive but overlapping phases in the development of knowledge pertaining to the family caregiver:

- Family abandonment of the older person.
- The elderly person as a family member.
- The family as caregivers.
- The relationship between formal and informal care.

This chapter reviews the findings related to how people become carers; who are the people who care for the elderly; the cycle of caring; and the role of social support networks. The next chapter focuses on the consequences for the carers of providing home-care for the elderly. It is important to emphasise that when we are discussing caregiving and carers that we are talking about help given to individuals by nuclear and extended families and by neighbours and friends. This help covers a wide spectrum including physical care, emotional support and guidance, non-financial as well as material help. This and the following chapter draw together some of the main themes to emerge from the research findings and document the different aspects of the caring process.

HOW PEOPLE BECOME CARERS

Availability and Proximity

Many factors come into play in deciding who becomes a carer. Studies highlight the importance of distance and availability as factors associated with the decision to become a carer. While geographical proximity does not guarantee either willingness or ability to provide direct assistance, the number of family members geographically available to an older individual does set parameters for the amount of care potentially available². Studies have shown that assistance with such activities as home and garden maintenance, transport, meal preparation, and personal care can be provided only by those living near enough for weekly, in some cases daily, face-to-face interaction³. The importance of proximity is reaffirmed by studies which have looked at whether the rural aged maintain more frequent personal contact with children and family than do older people living in a metropolitan community⁴. These studies showed that because of the greater physical separation between children and their aged parents in the rural setting, compared to the urban aged, the opportunity for the maintenance of frequent contact was reduced⁵.

Relationship Between Carer and Elderly Person

Research has established that caregiving support is given most often by one family member at a time — mainly by a spouse. Shanas and his co-workers have referred to this as the "principle of substitution"⁶. In the absence of a spouse, a child assumes the role; in the absence of a child, another relative and so on⁷. While adult children usually remain in contact, they provide less care to a parent whose spouse is still alive than to a widowed parent. Childless and unmarried people may turn to brothers and sisters or more distant relatives such as nieces, nephews or cousins, but these relatives rarely provide a high level of care⁸. Research in the U.S. indicates that widowed, divorced or elderly people who have never married prefer to live near to but in separate quarters from their relatives — what has been termed by Rosenmayr as "intimacy at a distance"⁹.

The point at which family members define their role as carer differs for spouses compared to children, as does the point at which the role is terminated: compared to children, spouses retain care of the dependent person for a longer time¹⁰. Over the years, then, researchers have clearly established that the elderly are part of family networks¹¹ and that they maintain close contact with relations, friends and neighbours¹⁻⁴ and that a pattern of intergenerational reciprocity prevails among family units.

Factors Related to the Decision to Care

Three broad areas of importance have been identified when looking at traditional and cultural influences on who cares for an elderly person¹³:

- Demographic Imperatives
- Antecedent Events
- Situational Factors

DEMOGRAPHIC IMPERATIVES

In relation to demographic imperatives, research has shown that one can more easily predict who will be the carer when the parent has only one child or when there is only one female child. Similarly, it is easier to predict if there is only one child in the vicinity, or in some cases only one unmarried child¹⁴.

ANTECEDENT EVENTS

Parental age and household composition are antecedent events that have a strong influence on the subsequent emergence of the carer¹⁵. Childrens' freedom to give responsibility to others for caring is greatest while the parental unit is still intact and/or before dependency becomes an issue. Leaving an old widowed parent alone with no other children living in the area is obviously more unacceptable than leaving when the elderly person's spouse is still alive.

Filial Obligation toward Ageing Parents

The persistence of attitudes of filial obligation among adult children has been indicated by studies of family support systems for ageing parents¹⁶. Researchers have also highlighted the role of attitudes to 'obligation' in predicting contact with elderly parents and the caregiving that is provided to them¹⁷. Finley and his co-workers point out however that:

Attitudes of filial obligation are a product of the social and structural world in which a person lives. For some persons norms of filial obligation may be very costly; abandoning the norms may seem costly to others....This analysis is a beginning in understanding the variation in attitudes of filial obligation¹⁸.

Their analysis revealed that obligation is not simply a product of affection but that the degree of obligation is also explained by such structural and demographic factors as role conflict and distance. Filial obligation can vary by the type of relationship, for example, mother, father, mother-in-law, father-in-law or by gender of the adult child¹⁹.

Children of parents widowed at a young age are destined early on for their caretaking role and gradually assume it. In other cases, however, children reach middle age with healthy parents and with no one overtly destined to assume caretaking responsibilities. When a parent becomes vulnerable in these circumstances, children have to make quick decisions about who will care. Proximity then exerts influence on those decisions. If there is only one child in the area at the time of the crisis, the decision is made. When there are several children close by, other practical considerations arise. For example, the child who owes the parent a special debt is a likely candidate. All other things being equal, the child with the fewest competing obligations is also a likely candidate. A child with a disabled spouse, dependent children or responsibility for parents-

in-law would be exempted. If the children are employed, the one with the least well paying job or the most marginal participation in the labour force becomes the carer in most cases²⁰.

Influence of Employment Status

Research findings have shown²¹ that many working caregivers experience conflict between the demands of employment and their caregiving responsibilities. However, findings of studies on the degree to which employment impinges on caregiving have not been consistent. Some work²² has shown that female labour force participation is a significant factor influencing rates of institutionalisation of elderly persons. Others have shown that while a son's assistance in the caregiving role can be decreased by his employment status, employment is not a significant predictor of caregiving hours among daughters²³.

SITUATIONAL FACTORS

With respect to situational factors, brothers and sisters themselves may have to co-operate in determining and/or justifying their relative involvements in the caregiving role. Sometimes these decisions can be arrived at logically by careful evaluation of each child's circumstances and previous contributions. At other times a particular child will volunteer to assume the caregiving role²⁴. The Equal Opportunities Commission (EOC) in England notes 'rationing' of resources as one influence on people's decision to become carers.

Given scarce resources, social services departments tend to put priority on providing for the old and severely handicapped living alone. This may well mean that regardless of their ability to cope, the family — or the nearest female relative — are left with no alternative but to provide for their dependent relatives on their own²⁵.

Whilst this policy may be economically expedient for local authorities, its implications can be severe for the families caring for dependants who, without adequate support, may find it difficult to cope.

However as Hagestad notes it is important to put the issue of parent care in perspective:

Families have always been caregiving units. The most significant

difference between today's families and families of the past is not likely to be in the number of hours spent on the provision of care, but in the focus of care²⁶

WHO ARE THE CARERS?

Demographic Characteristics

Research shows important gender differences in the provision of care. Not only are women more likely than men to be caregivers but women offer significantly higher levels of care and the nature of the care which they give is also different²⁷. While it is predicted that in the future more men, especially husbands, will be assuming the caregiver role, at the moment informal care usually means care by women²⁸. A survey by the EOC in Britain found that three times as many women as men were looking after elderly or handicapped relatives²⁹. Research shows that though women constitute the majority of carers the proportion of husband/wife carers is almost equal. Of those looked after by relatives, findings indicate that the men are predominantly cared for by male relatives (mostly sons) and the women by female relatives (mostly daughters). Since the majority of elderly people who require help from carers are women, the effect of this pattern is to place a disproportionate responsibility on female relatives³⁰. A recent study undertaken for the National Council for the Aged found that women act as carers in the majority of Irish cases. Male carers are in a minority and in the main are the husbands of elderly or disabled women and they are, on average, rather older than female carers³¹. Not only are carers mainly female, but the experience of caring is very different for men and women. For example, in Britain, it was found in an EOC study that it is more common for female than for male relatives to share the same household³². This means that the women are more likely to continue coping with increasing dependency for a longer period, since they are more readily "available" at all hours of the day and night.

Research has also found that women assume more of the intensive all day caring than men³³. Females are more likely than males to attend to the personal hygiene needs of the elderly and to engage in household tasks and meal preparation. Males, on the other hand, tend to focus their help on activities such as home repairs, financial management and the provision of transport. Women carers are likely to give up paid

employment³⁴, or otherwise adjust their working lives in order to care for dependent relatives³⁵. In addition, caregiving may discourage the resumption of paid employment among those who already had found it necessary to take a break from the labour market to bring up children³⁶. Although as indicated above this is not necessarily the case.

Because of a substantial body of evidence indicating that women are the principal carers, there is an increasing awareness that 'community care' means care by women, usually female relatives. Several writers raise the issue of the exploitation of women involved in caring and highlight the danger that women may find themselves being pushed back into bearing a burden which is unjustified³⁷. The Irish Council for the Status of Women have found that, whatever the reason, once the woman has accepted the job of carer, it is invariably an open-ended commitment; 20 years not being uncommon. It was found that the duration of care ranges from 7 — 30 years and by the time the relative has died, most women are in their 40s and 50s³⁸. But there would seem to be indications that the composition of carers is going to change. Changes in society are affecting the amount of support that is available. These changes include a decrease in family size, a reduction in what is referred to as 'the caretaking poor' (women aged 35 — 49 years) and a decrease in the number of single daughters. Another general demographic factor influencing the composition of carers is the earlier age of marriage and the increased number of married women doing paid work³⁹. On top of these factors there is the growing mobility of the population; nearly one household in ten moves every year in the United Kingdom⁴⁰.

Cycles of Caring

It seems too that not only are women usually the carers but often they have cared for more than one person in their lifetime. For example, in one study it was established that among women looking after widowed mothers, this often is only one phase of these women's experience as carers. Almost half had helped an elderly father before his death, and one-third had helped look after other elderly relatives. Twenty-two per cent were providing help to another relative at the same time and almost two-thirds had children living at home. It was concluded that, given the discrepancy in life expectancy for men and women, it is inevitable that many of these women will care for dependent husbands in future⁴¹.

Age of Carers

Because carers include spouses, adult children, other relatives, friends

and neighbours, the age range amongst them varies quite considerably. In the United Kingdom, a study carried out by the EOC found that 42 per cent of carers were themselves over 60 years of age and only 8 per cent were below the age of 40 years. All spouse carers were over 50 years of age, and so also were 78 per cent of friends and neighbours. The ages of adult child carers ranged between 25 and 69 years. A high proportion of male carers were over 70, reflecting the predominance of spouses among this group⁴². Other research has found that the age of carers ranged from 20 to 85 years: the carer could be a grandmother or she could have young children at home⁴³.

SOCIAL SUPPORT NETWORKS

The advantages of social networks for the elderly have been well documented⁴⁴. What is now becoming clear, however, is that support networks also provide a service for the carers in relieving them of some of the stress and strain and in relieving some of the burden of 'round-the-clock' watch. Social supports have two components: the physical or instrumental component which includes activities such as assistance with bathing, cleaning, cooking and the tasks involved in day-to-day care, and the emotional component. Support can be informal coming from family, friends and neighbours, or formal coming from social services, health agencies, counsellors or support groups⁴⁵.

In a discussion of the effect of social supports on the carers' burden, one study distinguishes between the quantitative and the qualitative aspects of social networks:

Typically, the quantitative aspects of social resources are referred to as the individual's social network; whereas a more qualitative dimension implies perceived support or satisfaction from the network (a subjective appraisal) ... For example, social networks are not always able nor willing to be helpful to members in need during times of stress. It is entirely possible that social "support" may in fact be harmful or have negative psychological consequences for the recipient⁴⁶.

The importance of the distinction between the quantitative and the qualitative aspects of social networks has been confirmed by some of the studies on caregivers' burden which have shown that many carers of Alzheimer patients reduce their social contacts as the burden of care increases. According to one group of authors:

There is a tendency for caregivers to become quite isolated, receiving fewer and fewer visits and going out less⁴⁷.

Similarly, in a recent study in the United States which compared Alzheimer's patients with healthy elderly, it was found that:

Caregivers report much less contact with neighbours and friends than do families of healthy elderly in the comparison group. Thus, 46% of Alzheimer's families have no contact with neighbours compared with only 24% of the comparison group⁴⁸.

However, other research evidence reveals that it would be unwise to assume that the larger a carer's social network, the less stress they are likely to experience. In a recent study of 72 carers of disabled relatives in the United States, it was found that "the total number of people in the caregivers'support networks was unrelated to their level of stress"⁴⁹.

Informal Support

The degree of help that carers receive from family, neighbours and friends has been found by some studies to be an important influence on the degree of stress they experience and their freedom to take up other activities. Studies have highlighted that activity and friendship patterns are sometimes disrupted among carers, often quite suddenly. For example, one study found that among wives who were carers there was little planning for the future and beneath the surface were feelings of resentment as the wives recalled things they would have done if their husbands had not become disabled. Wives seemed to miss the activities they previously enjoyed outside the home, such as visiting friends and seeing films. Sense of isolation was heightened during the winter months with increased compulsion to stay indoors⁵⁰. This study showed clearly that having support from friends, sympathetic children or relatives was of enormous help⁵¹. With respect to whether or not carers receive such support from family, friends and neighbours, it became clear that when the elderly relative lived in a separate household there was some sharing of tasks between the members of the extended family, but once the dependant was established in the carer's home there was a noticeable decline in support from other relatives. Only in one case were relatives cited as giving "frequent" help; more commonly it was "hardly ever" or "none at all". Help from voluntary organisations or neighbours was reported to be even more rare, and where given, it was on a fairly casual

basis. Ironically, it appears from research that the greater the degree of dependency, the smaller the amount of external help offered⁵². It has been noted that, especially among adult child carers, lack of social support is the factor contributing most to burden⁵³.

Role of Neighbours

While neighbours have an important role in support networks, their part is usually secondary to that of family members. Neighbours meet different needs and complement the support provided by the family. The kind of help provided by neighbours does not constitute a homogeneous resource and can range from intensive regular care to little more than passing contact. Typically, however, neighbours, when they are involved, are more likely to help with routine household chores. They appear to be of particular importance in times of crisis when their assistance can be quickly mobilised. While it sometimes happens that a neighbour can also be a best friend and one whose friendly ear is preferable to confiding in close relatives, more often nowadays the 'good' neighbour is seen as someone who is at once friendly, helpful and distant⁵⁴. Research has identified that in most localities it is a small number of neighbours who are deeply involved with one or several households and who give a great deal of care every day. This help is usually given to neighbours who are old, handicapped or sick and usually alongside care given by kin. It has also been discovered that the presence of kin actually encourages the involvement of neighbours in giving care as this means they do not have to carry the major burden for caring⁵⁵.

Formal Support Services

The promotion of a community care policy requires support for carers not just through help from friends and neighbours but also through interaction with both voluntary and statutory agencies. It has been shown that carers face problems at four levels. First, the practical level: giving the elderly person help with household and personal care poses problems. Carers also experience problems because of the behaviour of the elderly person, for example, incontinence, repetitive questioning, wandering, etc.. At the interpersonal level, carers may feel sadness at the changes in their elderly relatives and socially there are restrictions in getting out and in working and seeing family and friends. While services are relevant to some but not all of these problems, it has been

found that most carers place a high value on the particular service they receive and many would like them more often. Services promote the capacity of the carers to continue to care. The build up of strain is less if carers are receiving the services of a home-help, community nurse, day relief care or attendance allowance⁵⁶.

One study examined the perceived need for formal services among carers of dementia patients. Carers who experienced higher levels of anxiety were found to have a significant positive need for counselling services. A significant positive need for community services was indicated by a combination of the severity of patient impairment, the carer's experience of higher levels of anxiety and carer levels of expressive support. These findings imply that carers are able to identify the types of services they need as they strive to maintain their patient at home⁵⁷. Feelings of well-being are also related to levels of social support⁵⁸.

Integration of Formal and Informal Care: A Key Issue

The balance between family and community help and state intervention needs to be addressed. The importance of the family is now seen as central and the debate in the literature is on the willingness and commitment of the statutory services to embrace both the voluntary and the informal sector of family, friends and neighbours. The Wolfenden and Barclay Reports⁵⁹ highlight the need to recognise and work with the needs and natural helping resources that exist. A central concern of the literature in recent years is the nature of the relationship between formal and informal care and the necessity of building bridges between the two systems. Horowitz⁶⁰ and Simmons *et al*⁶¹ and Offer *et al*⁶² in keeping with the above have suggested that a partnership between the formal and informal support networks can ensure effective care for the elderly persons while also helping the caregivers. Carefully planned services may effectively relieve some of the burden carers experience⁶³. Programmes that focus on improving the carers' ability to cope with everyday problems and on providing opportunities for respite, may have considerable impact on subjective burden. However, it has been found in one study that the regular support services provided are often of little relevance to carers and need to be carefully examined to ensure that they are meeting the real needs of carers⁶⁴. The study suggested that the home-help service, for example, did not give the required relief as it merely substituted for carers in an area that they liked to preserve for themselves and that gave them a break from caring. Also, the carers"

use of day centres was found to increase if these were made available at times which would allow carers freedom and relaxation — evenings, weekends and holidays. Nursing care was found to be unsatisfactory, with infrequent visits being made. Also, many complained about the services¹ inability to give an estimated time of arrival. Since particular services are not always appropriate, the study suggests that in an attempt to improve services to the elderly and their carers, carers should have the status of co-workers in the caring team and should be involved in designing support programmes specific to the elderly person's needs.

There is still a lot to know about the relationship of different patterns of caregiving and the diversity of needs within the different types of dependency groups. As Offer and his co-workers note⁶⁵:

to understand the dynamics of informal help, the contexts in which it is given or not given — need to be carefully explored. Second and not entirely unrelated, what counts in informal help is "a good outcome".

Froland also points out that:

In everyday practice, professionals and informal caregivers have to grapple with different assumptions and expectations about what "support" means and how it should be provided.... In many ways, trying to combine the effort of professional service providers with those of family members, concerned neighbours, and devoted friends is like trying to link two cultures in which very different beliefs, customs and norms of exchange prevail⁶⁶.

Support Groups for Carers

Spouses providing care to demented and physically ill patients report experiencing considerable stress, primarily due to the perceived lack of social support. Support groups can play a major role in providing support and eliminating loneliness⁶⁷. A study of support groups for carers of Alzheimer patients mentions three types of such groups: educational; educational/mutual support; and ventilation of feelings⁶⁸. In this study it was found that the most frequently identified benefits of support groups for carers were the knowledge received, the feelings of universality and the group cohesiveness⁶⁹. Viewing these three benefits in evolutionary perspective, the authors state that:

By conceptualizing support group dynamics in an evolutionary

perspective it is possible that many caregivers may then "drop out" because they have received what they wanted out of the group. Many others may stay on wanting more mutual/peer support from other caregivers (i.e. universality and group cohesion)⁷⁰

The study also revealed that the main criticisms of support groups by the carers were logistics (i.e. the scheduling, location and physical setting of meetings), the content of meetings (i.e. the lack of information on community services) and emotions/feelings (i.e. the depressing and discouraging nature of the subject matter)⁷¹. As regards emotions/feelings, the authors add:

Caregivers who had left the demanding situation of caregiving at home, then sought respite and support at group meetings, only to find themselves participating vicariously in emotional caregiving again⁷².

INSTITUTIONALISATION

The decision to institutionalise is a major step for both the elderly person and the carer. Sometimes the decision is precipitated by the physical and mental decline of the patient. More frequently, however, it appears to occur because the family and particularly the carer have become physically, financially and emotionally exhausted from providing care. However, Zarit cautions against the notion that institutionalisation is a panacea because, in addition to being financially burdensome and traumatic for the patients, he argues that:

Nursing home placement only shifts the burden families experience, rather than relieving it. The family members will continue to have to visit their relative in the nursing home, and to deal with staff and doctors to try to assure the best care available. Seeing their relative in an institution is in itself stressful, and the family has less control over care with nursing homes than in their own home. Finally, since there is only limited third party payment for nursing home care, placement can be devastating financially, placing even more stress on the family⁷³.

Carers of Alzheimer's patients tend to be spouses or children. One of the implications of this is that the marital status of the patient is an

important determinant of whether s/he is cared for in the community or in an institution. This was shown in a longitudinal study of demented patients which revealed that:

Undoubtedly the most important factor which affected the patient's viability in the community was that of family support ... Patients living with just an elderly spouse were more vulnerable, while those who lived alone were the most vulnerable of all⁷⁴.

This result is quite consistent with Townsend's earlier work in England in 1957 which found that, among old people, it was the unmarried, the childless married, and those whose children were living too far away who were the most likely to enter institutions⁷⁵. More recent evidence from the United States also confirms this pattern:

Older persons admitted to long-term care institutions are less likely to be married and less likely to have living children. Before entering an institution, many elderly have tried a number of other alternatives, including living with their families ... Contrary to the myth of the nursing home as a "dumping ground" for elderly abandoned by their families, social gerontological research has consistently demonstrated that institutionalisation is usually a solution of last resort, selected only when other approaches to caring for the older person have failed⁷⁶.

One of the factors which often precipitates institutionalisation is the ill-health of the carer rather than that of the patient. In one study it was found that carers of Alzheimer's victims were "suffering from serious illnesses themselves, including cancer and chronic heart disease"⁷⁷. In this case, institutionalisation was precipitated by the ill-health of the carer rather than that of the victim⁷⁸.

In a longitudinal study, Colerick and George identify a number of factors which, in their estimation, "can reliably predict within a one-year interval the caregivers who will make institutional arrangements for their patients and those who probably will not"⁷⁹. They summarize the predictors of institutionalisation as follows:

Those who subsequently institutionalised their patients were most often female, employed, and were among the youngest in the sample. In addition, they reported above average incomes, high levels of stress, and dissatisfaction with time spent in recreational pursuits. Caregivers exercising the institutional option were more

often children than spouses of the patient. It is reasonable to assume that those caregivers who are more stressed, have more competing role responsibilities (e.g. employment), and are less central to the patient (e.g. child rather than spouse) would move more quickly to the decision to seek help outside the home⁸⁰.

One study of the reasons for resorting to institutionalisation suggests that for a small number of carers incontinence can be a major factor. It should be borne in mind, however, that the more frequently given reason of "24 hour care was too-difficult" may also have included incontinence as an element of care. Other reasons mentioned were combative behaviour or angry outbursts or that the carer was simply worn out, especially through not getting enough sleep. Twenty-one per cent of carers became ill or injured; all but one of whom was a spouse in his 60's and 70's. Thirteen per cent said a doctor's recommendation convinced them it was time to consider institutionalisation. In some cases this opinion was resented, in other cases it was appreciated as the carers felt that they had lost their own perspective and ability to make decisions. In some instances other family members persuaded primary carers to institutionalise and this was generally appreciated⁸¹. Other research found that the single most important variable underlying the decision to institutionalise an elderly person is the carer's attitude towards nursing home care. The second most powerful is the carer's perception that the tasks being performed for the elderly are burdensome. The third factor is the carer's perception of the quality of care which the elderly person would receive in a nursing home. The least important variables are carer's health and stress effects⁸².

SUMMARY

The review of the literature presented in this chapter has shown how factors such as availability and proximity influence who it becomes the carer when the elderly person becomes dependent. Demographic imperatives, antecedent events and situational factors have emerged as playing a significant role in the decision to become a carer. Gender differences in the provision of care and the importance of social support in relieving the burden of caregiving have been highlighted. Finally the chapter has raised issues related to the decision to terminate caregiving and place the elderly person in institutional care. Later chapters of the report explore the relevance of these findings in the Irish context.

CHAPTER THREE

Consequences of Providing Home-Care: Literature Review

Introduction

The costs and, to a lesser extent, the benefits of providing informal care have been examined in many studies. Burden has been defined by researchers as the extent to which carers perceive their emotional and physical health, social life and financial status as suffering as a result of caring⁸³. Stress or strain can result from this. Many attempts have been made to measure this burden/stress/strain. The following sections describe the different costs involved in caregiving which are seen to contribute to the burden of the carer. The demands placed on carers vary enormously and, accordingly, so too does the level of burden a carer experiences: elderly people being cared for range from those who are independent in virtually all aspects of daily life to those who are bedfast and thus dependent on others to wash, dress, toilet and feed them.

Financial Costs to Carers

One of the most basic costs of caring is the financial cost. While costs vary according to circumstances they can sometimes be very severe. The Equal Opportunities Commission (EOC) cites two factors which are important in determining the financial cost of caring for an elderly person: the restriction of employment opportunities for the carer and the extra costs to the household as a result of the needs of the dependent person⁸⁴. Various studies are quoted by the EOC to show that people looking after the elderly are less likely than others to work and, if working, are more likely to be working part-time. The most typical extra costs incurred in caring are heating, special diets, the management of incontinence (which can include additional washing or laundry costs, additional bedding and clothes, incontinence pads and items such as

family from all informal and formal networks⁹⁷. In turn this isolation increases the pressures already mentioned. The caring process can also lead to social isolation⁹⁸.

Emotional Demands of Caring

Many studies show that despite the arduous nature of physical care and consequent continual tiredness it is the emotional demands of caring which are often the most severe⁹⁹. Emotional strain has been found to be pervasive among all groups of carers apart from friends and neighbours. This latter group appears to be the least involved and registers the least amount of strain in the role of primary caregiver¹⁰⁰. Since caring can have a number of emotional effects on both parties, it has been pointed out that where there has always been a poor relationship it is unwise for carers to undertake the caring role in a one-to-one situation¹⁰¹.

Although many carers feel that they both want and have a duty to care for their elderly relative, it is not always a rewarding task. It can demand considerable patience, since the confused elderly and seriously handicapped in particular can become critical of the carer as they struggle to retain a sense of independence. In addition, the carers can find themselves acting as mediators between difficult dependants and their own families. Husbands may get irritated at the dependant's demands on the woman's time and children may resent being unable to bring friends home. This conflict of loyalties can be a constant pressure for many women¹⁰².

Even when relations are harmonious, the predictability of the daily grind, the need for constant planning to cover all eventualities and the consequent lack of spontaneity in the lives of both carers and dependants take their toll emotionally. Everyday activities which most people take for granted — such as shopping, visiting a friend, catching a bus, gardening, making a telephone call from a coin box, or in extreme cases, simply going into another room in the house — can become impossible or extremely complicated for the carer¹⁰³.

Psychological Costs of Caring

Research has established that there is three times as much stress among carers compared to others in the community. Carers' level of life satisfaction is also considerably lower. This may be due, at least in part, to the fact that carers appear to be, on average, less able than others in the

community to pursue social activities^{1*4}. In one study, carers were asked a series of questions about worry, strain, and the impact of caregiving in eight areas of private life. The overriding worry for all carer groups was the health of the dependent elderly person. For spouse carers the next greatest worry was finances and the elderly person's morale. Children, on the other hand, worried about obtaining sufficient help while anxiety about financial matters was less¹⁰⁵. Depression and anxiety are the single most frequently noted problems among carers¹⁰⁶.

Physical Costs of Caring

With respect to the physical costs of caring, in one study it was found that, in most cases, carers attributed a general deterioration in their health to the strains of caring. But there were specific problems too, such as back-pain resulting from lifting non-ambulant people¹⁰⁷. Other studies support these findings. Some carers report a number of symptoms of acute stress sufficient to suggest a need for specialised attention. Significant associations have been established between physical strain in the carers and particular problems involved in looking after their relatives. These problems include heavy incontinence in the elderly person, having to cope with a lot of trying behaviour, disturbance during the night, inability to have ordinary conversations with their elderly relatives and restrictions on their own leisure activities and on time with friends and family¹⁰⁸.

Research also indicates that closeness of kinship ties influences the physical costs experienced by carers. Spouses report significantly more visits to the doctor and poorer health than other groups of carers. With respect to mental health indicators, spouse carers exhibit lower levels of well-being than do the other groups¹⁰⁹.

Costs to the Family

Fragile family relationships may be broken by the demands of the caring task¹¹⁰. Many caregivers cite neglect of familial responsibilities as a major concern¹¹¹ and others report some evidence of family conflict¹¹². Instead of welding a nuclear family together, a caring situation often generates tension and conflict and this in turn makes the burden of care more onerous. Carers' children often feel uneasy about dependent grandparents and in some cases this may manifest itself in disrespect and resentment. Because of changes that have overtaken the household,

husbands (of carers) may feel angry towards the elderly person. The carer/mother/wife, trying to fulfil a number of competing roles, is often caught in the middle, both as a worker and family mediator.

Any suggestion that family care means "care through an integrated family network" is not supported by research evidence. "Family care" most often means that one particular family member is "selected out" to care because her/his circumstances lend themselves more conveniently to caring. The burden of care therefore falls unevenly within the family. Normal family tensions are often heightened with the resentments which come when carers believe other family members are not doing their share. This is exacerbated when the carer is unmarried and other brothers and sisters are married. Carers often feel that their unmarried status allows them to be placed under greater pressure¹¹³.

Research indicates that the family is affected by caring because of interference with its life-style, privacy, socialisation patterns, vacations, future plans and income. The diversion of the carer's time from other family members and the negative effects on the carer's health are further indications of the costs to the family of caring. Emotional support from spouses, family members and other relatives mitigates the carer's strains. However, when changes in the family stimulate interpersonal conflicts, relationships are affected negatively between husbands and wives, among adult family members and across the generations¹¹⁴.

Influence of Relationship Between Carer and the Elderly Person on Burden

Research findings indicate that the most important factor relating to strain is the carer's relationship with the elderly person¹¹⁵. One study established that while the majority of carers felt 'very close' to those being cared for, getting on well with them was another matter¹¹⁶. An inverse correlation appeared between closeness of kinship and ability to get on well. Friends and neighbours as a group got along best with the elderly person, followed by "other" relatives. In the case of spouses, only 60 per cent reported getting along very well with the person cared for and among children the proportion dropped to 53 per cent. This may be related to the strains involved in caring because usually the intensity of care by spouses and adult children is greater than that provided by others¹¹⁷.

Further findings show that the extent of the impact of caring on the everyday life of the carer is related to closeness of kinship and the

availability of the carer for continual involvement. Thus, spouses were most affected and neighbours/friends were least affected¹¹⁸. This greater impact of caring on close kin compared to friends and neighbours may account for the finding that the latter group of carers get on better with the elderly persons. Other research has indicated that the best explanation for perceived burden is the subjective quality of the relationship; for example, the child's affection for the parent, the parent's affection for the child and extent of value consensus between them¹¹⁹.

Influence of Living Arrangements on Burden

Living arrangements have also been found to have an effect on caregiver burden. Carers who reside with their charges are more likely to use psychotropic drugs; they report the highest level of stress symptoms and report the lowest levels of life-satisfaction. Carers who live with their charges also report significantly lower household incomes than other caregiver groups and show the lowest levels of participation in and satisfaction with social activities¹²⁰.

Influence of Duration of Caregiving on Burden

For many carers, long-term care frequently develops from a short-term crisis, with the individual assuming the role of carer in the belief that it will be temporary. *Ad hoc* arrangements made to cope with the short-term crisis may be unsuitable for long-term care, creating pressures on the carer when care is extended¹²¹.

If caring lasts just weeks or months, although the disruption to the carer's life may be severe, the period may be short enough for the carer's long-term opportunities to be unaffected. However, many crises precipitating the need for care are initially open-ended and carry with them particular stresses — emotional and financial — stemming from uncertainty as to how long caring will last. This often leaves the short-term carer in a vulnerable position, without any of the back-up services and benefits which are sometimes available when the need for long-term care has become recognised¹²².

On the other hand, if responsibility for the personal and emotional care of the dependent person continues for years rather than months, then the burden of care and its impact on the life opportunities of the carer can be very severe. The EOC's survey found that 44 per cent of carers had been caring for upwards of 5 years, and almost 25 per cent

for over 10 years. Only 12 per cent of the sample had been doing so for less than a year¹²³.

Variations in Burden between Male and Female Carers

Based upon cultural stereotypes, it is often assumed that men and women will respond differently to the caregiving role. For example, the finding that women form more intimate relationships with others and have stronger social support systems than men¹²⁴ suggests that male carers might be more likely than females to be socially isolated. Studies on women and moral development also suggest that women put a stronger emphasis than do men on their personal relationships¹²⁵. Women also are considered to have a stronger 'ethic of caring' than men, and to have stronger social supports¹²⁶. However, research suggests that assumptions that women carers find caring easier may need to be questioned. Women when they become middle-aged undergo a role shift away from full-time caregiving and begin to pursue new interests and may resent a return to a full-time caregiver role¹²⁷. Men, on the other hand, may enjoy taking on the role of caregiver because it is new and is a means of expressing their nurturing feelings. Moreover, a study carried out for the EOC in Britain found that while men and women were coping with broadly the same range of dependency, in some respects women perceived more adverse effects¹²⁸.

Findings indicate that different levels of support are made available to women and men. Both informal and service support are more likely to be provided for male carers. Male carers are more likely to receive home-help, meals-on-wheels, rehabilitation and assessment services and long-stay care. Females are more likely to receive day-care and short-stay care. Community nursing is the only service provided equally¹²⁹. The fact that elderly people being cared for by men are more likely to receive rehabilitation and assessment services suggests that the need to restore the elderly person's ability to cope independently is seen as being more urgent where a male is the carer rather than where a female carer is involved¹³⁰. One study found that, apart from spouse carers, those elderly people looked after by men were more likely to be admitted to institutions and that those cared for by men who went into long-stay care were more able¹³¹. In view of such findings of higher support for males it is not altogether surprising that studies have consistently shown that females experience more burden. Stresses and strains have also been shown to vary among men and women. The findings indicate

that subjective factors are more important than severity of illness in determining burden. Husbands report less burden than wives — this is thought to be related to husbands' greater tolerance of memory and behaviour problems. For wives, both the quality of the past relationship and the number of behaviour problems are significantly associated with burden¹³².

Influence of Carer's Personal Perception of Caring Tasks

Some models of stress propose that the impact of harmful events is mediated by whether the person actually perceives them as harmful and by the person's own coping responses. Research with carers supports this model. One study found that carers feel burden when the dependent person manifests deficits in behaviour and carers have difficulty tolerating these behaviours¹³³. This finding underscores the point that individual carers react differently to problem behaviours and vary in their skills for managing these problems. Further, all carers do not find the same problems to be troublesome. Studies of elderly persons suffering from Alzheimer's disease suggest that carers' ability to tolerate problem behaviours actually increases, even as the disease of the elderly progresses. Carers frequently explained their responses by stating that they had learned to manage problems more effectively, or they simply did not let problems 'bother' them any more¹³⁴.

Burden of Caring for Victims of Senile Dementia

Physically, carers of the demented elderly suffer a huge burden. The need for constant supervision is exhausting. Troublesome physical care problems include inability of the person to feed her/himself, incontinence and sleep disturbance. Carers of dementia patients often have a very difficult time because of the total inability of the patient to look after him/herself.

Many studies of burden, stress and strain have focused almost exclusively on carers of those who suffer some form of dementia. While some kinds of dementia are of short duration and are reversible, approximately 10 per cent of those over 65 years and 20 per cent of those over 80 suffer chronic and irreversible loss of intellectual functions. The most usual cause of chronic dementia is Alzheimer's disease. This disease can have devastating effects not only on the sufferer but also on the victim's carer

and family. This is so because not only is it incurable but it causes very distressing symptoms including confusion, forgetfulness, depression, disorientation and agitation. The victim can no longer carry out the simplest tasks of living and in later stages may no longer recognise familiar family faces and may be incapable of managing eating and toileting.

At the emotional level, carers of dementia patients undergo great strain. They have to watch the person they love disintegrate little by little, which can be agonising. Adjustment to the perceived reversal of parent/child roles in the family may be especially difficult for young adults to accept. All social life is often completely disrupted¹³⁵.

One study which was designed to explore the experiences of families from the time of the early recognition of symptoms of dementia throughout the course of the illness found that the most frequently mentioned first symptoms were related to problems with memory, confusion and disorientation¹³⁶. First symptoms were also manifested in work-related problems, personality changes and a general inability to function. It was memory related problems which caused a majority of friends, relatives and victims themselves to seek help. Personality and physical changes also influenced seeking professional help¹³⁷. Families in this study reported difficulty articulating subtle changes to their doctor, so that in many cases dementia went undetected for several years. Moreover, the families had a problem convincing the doctor that something was wrong even when they were certain that the changes were serious. Others struggled with demented relations who did not understand or agree that a medical consultation was necessary. Once a diagnosis was made, families had difficulty learning how to care for their relative. Explanations received were perceived as focusing almost entirely on the hopeless nature of dementia. Families were told the disease was progressive, incurable and its causes were unknown. They were also told that the relative would gradually deteriorate, finally becoming helpless. Few families reported that a factual, adequate explanation of Alzheimer's disease was given, including a description of the progressive nature of the illness. Some families could not recall any information or explanation at all being given. In some cases, families only remembered being advised not to bring the patient back because nothing could be done. The manner in which diagnosis was presented to families caused additional stress. Some families were given a curt, brief explanation of the disease in a waiting room or in an elevator. In a few cases the diagnosis and prognosis were given in the presence of the patient as if s/he were not there¹³⁸.

Until families received thorough explanations of the progression of the disease, they tended to believe that reasoning and past means of communication would still work. With few exceptions, families were astonished when they realized the extent of impairment in thought, judgement and reasoning. Only 16 per cent received specific suggestions for handling behavioural problems or coping with personality changes. This made attempts to provide care at home extremely difficult¹³⁹.

Recent attempts at alleviating the burden of caregiving for victims of Alzheimer's disease, such as the 'stress management model'¹⁴⁰, focus on information-giving as a primary component together with problem-solving techniques.

Information Needs: Useful Interventions

The stress-management model is designed to be used flexibly so that in some cases the focus of intervention would be on information, while in others it would be on problem-solving. According to its authors:

In some cases, a caregiver can solve immediate problems but does not understand the disease. The intervention is then focused on providing information. In other situations the caregiver has plenty of information but is ineffective in dealing with day-to-day realities of the disease. We then focus on teaching the caregiver the process of problem solving. Ultimately, outcomes of managing problem behaviour and increasing support to the caregiver can be either easy or difficult to achieve, depending on the patient's condition and the potentially available resources¹⁴¹.

The information needs of carers are seen to vary enormously depending on their access to information and their ability to absorb it. Two types of information are believed to be particularly required for carers of patients with diseases such as Alzheimer's: information about the disease and information about the behaviour problems it causes. In the case of incurable diseases, the transmission of information is seen to require considerable skill and delicacy so that the carer is given accurate information without being overburdened or losing all hope.

The other dimension of information to be conveyed to families and the carers of Alzheimer's patients concerns the problem behaviours which the disease causes. These problem behaviours include such things as asking repetitive questions, memory loss, accusations, lowered inhibitions in social settings, and so on. These problem behaviours can be

particularly distressing for the carer who is likely to be a spouse or a close family member.

Giving information in this context can take the form of explaining and refraining the problem behaviour. According to one study¹⁴², "a key component of these explanations should be to explore the patient's perspective". For example, a carer who interprets the patient's repetitive questions as being done to annoy or attract attention may be led to view it as the patient not remembering he has already asked the question or not having appropriate skills to get the attention needed.

Level Of Dependency and Its Relationship To Strain

One common assumption is that, over time, the strain on a carer increases, culminating in the decision to place the patient in institutional care. However, some studies indicate that, for example, the magnitude of strain is not significantly different according to the stage of senile dementia of the elderly person¹⁴³. It has also been found that measures of dependency show no relationship to burden¹⁴⁴.

Another study, contrary to expectations, found that feelings of burden were not related to the extent of behavioural impairment, nor to the duration of the illness¹⁴⁵. It was also found that the level of burden was less than expected considering the complexity of many of the cases of dementia¹⁴⁶. However, at least one study has established a connection between the objective condition of the patient and the burden of the carer¹⁴⁷.

Coping Styles

While the burden or stress of caregiving has been widely documented in the literature, it has been pointed out that little attention has been given to the ways in which carers cope with, or manage, demands of caregiving that are appraised as taxing or exceeding their personal resources¹⁴⁸. Coping, as the term is used in the literature, is defined as any emotional, cognitive, or behavioural response which aims to adapt to a particular situation. A recent study in the United States identified four basic coping styles which are: acceptance of the situation; emotion-focused styles such as depression, anger, resentment; problem-focused styles, such as finding solutions to problems, being creative, learning to deal with problems through literature; and inspirational styles, such as resorting to religion and prayer. Findings show the predominant mode of coping

for both patients and carers was acceptance (60% and 68% respectively). However, carers reported using more emotion-focused coping responses than did patients¹⁴⁹.

SUMMARY

The research reviewed in this chapter reveals that caregiving can have negative consequences in many aspects of the carer's life. Caregiving can involve quite severe financial costs both in terms of lost employment opportunities and expenses incurred. The social life of the carer is often restricted and loneliness and social isolation are not infrequent. There are also costs to the psychological and physical well-being of the carer. The relationship between the carer and her/his elderly charge and the carer's living arrangement emerge as important influences on the experience of strain or burden in caregiving. The findings reviewed highlight important variations in the experiences of burden between female and male caregivers and underline the particular difficulties experienced by carers looking after victims of Alzheimer's disease. Later chapters of the report explore whether the costs and burden of caregiving described in the research literature are also part of the experience of carers in the Irish context.

CHAPTER FOUR

Who Gets Home Care?

Introduction

Who are the elderly cared-for at home? What age are they? Can they manage to dress and feed themselves? Do they suffer from depression or confusion? Are men and women equally likely to get home care? This chapter is designed to answer such questions. It provides a general profile of the elderly being cared-for at home and describes what is involved in caring in the light of the elderly person's physical health, level of functional ability and psychological state. The chapter investigates the extent to which the elderly people are perceived by their carers as being dependent on them. The answers to questions such as those raised above greatly influence the nature of what is involved in caring for any particular carer. Accordingly, the chapter ends with the carers' own personal perceptions of the amount and extent of care given and their experiences of the demands placed on them through caregiving.

Age and Sex of the Elderly Persons Receiving Care

The elderly person being cared for at home is more likely to be female (59%) than male (41%). The people receiving care range in age from 65 to 99 but the highest percentage (43%) are in their 80's with a quarter aged between 81 and 85 years. A sizeable group (15%) are 90 years of age or over. Just 9 per cent are less than 70 years. The women receiving care tend to be older than the men: 61 per cent of females are over 80 years compared with 46 per cent of males (Table A4.1).

Occupational History of the Elderly

Over a third (35%) of the elderly had not been in paid employment outside the home, these for the most part having been housewives (30%) (Table A4.2). Among those who had worked outside the home, 38 per

cent had been employees and 24 per cent had been farmers. A small group (4%) had been self-employed. Those who had been farmers typically worked between 30 and 100 acres (Table A4.3). Elderly who had been employees were most often in semi-skilled (21%) or unskilled jobs (29%) with 23 per cent having been skilled workers. A small percentage (12%) had been in the lower professional or managerial class (Table A4.4).

Physical Health of the Elderly Persons Receiving Care

The vast majority (84%) of the elderly people being cared-for at home suffer some physical disability or other (Table 4.1). The type of disability suffered varies greatly but disease of the joints is particularly common with close on a third (31%) of the elderly persons having a disability in this area. The other most frequently noted health problems are diseases of the cardio-vascular or renal systems (16%) and neurological disease (12%). Visual or hearing defects are present in one of every 10 of the elderly. Typically, the elderly person's health problem is of long-term duration of five years or more (67%) (Table A4.5) and the condition has been deteriorating over the years (59%). Many of the elderly receiving care suffer not just one but two (55%) or even three (20%) or four (2%) health problems.

Table 4.1 : Physical health problems of elderly persons receiving care (Q.24)

Type of Health Problem:	Number	Percentage
Endocrine	3	1.5
Cardiovascular/Renal	32	16.0
Respiratory	15	7.5
Neurological	24	12.0
Skin	3	1.5
Malignancy		1.5
Gastro-Intestinal	9	4.5
Joints	61	30.5
Visual/Hearing	19	9.5
No Disability	31	15.5
Total (N)	200	

EXTENT OF DEPENDENCY OF THE ELDERLY

The extent to which the elderly person is dependent on her/his carer is explored in relation to three aspects of life: personal care, medical

condition and psychological state. In order to determine levels of dependency in relation to personal care, the elderly people's perceived ability to look after themselves is assessed in the following areas: washing and bathing, dressing, feeding, cooking, and mobility. The elderly person's ability to manage these different tasks is described in the following terms: without difficulty, with difficulty, only with help or not at all. Dependency in relation to the medical aspect is investigated in terms of whether or not the elderly person is housebound and whether or not there are problems with incontinence or soiling. Dependency arising from the elderly person's psychological state is explored in terms of whether s/he suffers memory loss, depression, angry outbursts, sleeplessness, confusion, wandering and failure to recognise family.

Perceived Ability to Manage Washing and Dressing

A sizeable percentage of the elderly are perceived by their carers as not being able to manage at all by themselves in many aspects of their personal care. One of the tasks which causes most difficulty and which is yet a necessary part of the elderly person's daily life is washing and bathing: over a quarter (27%) are totally dependent on the carer in this area and a further 52 per cent require help to wash (Table 4.2). Again, 15 per cent cannot manage the everyday tasks of shaving or hair-care while 27 per cent need help in this area. The task of cutting toe-nails is an important area of personal care where the majority of the elderly being cared-for are either completely dependent (45%) or require some help (49%) (Table 4.2).

Table 4.2: Ability of elderly person to manage personal hygiene tasks (Q.25)

Degree of Ability	Washing and Bathing		Shaving and Hair-Care		Cutting Toe-Nails	
	N	%	N	%	N	%
Without Difficulty	42	21.0	115	57.8	14	7.0
With Difficulty	36	18.0	26	13.1	21	10.5
Only With Help	67	33.5	28	14.1	76	38.0
Not at All	53	26.5	30	15.1	89	44.5
Not Applicable	2	1.0	0	0.0	0	0.0
Total (N)	200		199		200	

Non-respondents excluded

With respect to dressing, putting on shoes and stockings presents the greatest difficulty for the elderly: 13 per cent cannot manage this aspect

of dressing at all while a further 20 per cent can manage to do so only with help. Likewise with buttons and zips: 13 per cent are dependent on their carers to do up their clothes and 17 per cent need help in managing. In terms of other aspects of dressing, 12 per cent cannot dress themselves at all with a further 15 per cent needing help if they are to get dressed (Table 4.3).

Table 4.3: Ability of elderly person to manage dressing (Q.25)

Degree of Ability	Shoes and Stockings		Buttons and Zips		Other Aspects of Dressing	
	N	%	N	%	N	%
Without Difficulty	66	33.0	84	42.0	98	49.0
With Difficulty	65	32.5	52	26.0	44	22.0
Only With Help	39	19.5	34	17.0	30	15.0
Not at All	25	12.5	26	13.0	24	12.0
Does Not Apply	5	2.5	4	2.0	4	2.0
Total (N)	200		200		200	

Where help is required with personal hygiene tasks, in more than three-quarters of cases help is provided in the first instance by the carer. In most cases there is no other person apart from the carer who helps with washing (60%) or hair-care (68%) or nail-cutting (60%). Where help from a second person is available, most usually the assistance is given by another household member (Table A4.6). Where dressing is concerned, again with few exceptions it is the carer who accepts primary responsibility for providing any help that is required. In most cases, nobody else but the carer gives any help with dressing. In the few instances where back-up help is available, that help is more likely to be given by another household member (Table A4.7).

Perceived Ability to Manage Feeding and Cooking

The majority of the elderly persons being cared-for (79%) are capable of feeding themselves but 17 per cent require at least some help and 5 per cent are completely dependent on their carers in this area (Table 4.4). Close on three-quarters of the elderly (73%) are dependent on others in the essential task of cooking and preparing meals and a further 21 per cent need at least some help in this area. Just 6 per cent can manage cooking by themselves without difficulty. Where help in feeding or cooking is required it is the carer who in more than 95 per cent of

Table 4.4: Ability of elderly person to manage feeding and cooking (Q.25)

Degree of Ability	Feeding Self		Cooking Meals	
	N	%	N	%
Without Difficulty	158	79.0	11	5.7
With Difficulty	20	10.0	19	9.8
Only With Help	13	6.5	22	11.3
Not at All	9	4.5	142	73.2
Total (N)	200		194	

Non-respondents excluded

cases provides that assistance. In the majority of cases there is no second person to help with feeding (74%) or cooking (78%). Where there is a second source of help it is most likely to be another household member (Table A4.8).

Degree of Mobility

Getting out of bed unassisted is impossible among 9 per cent of the elderly while a further third need at least some help (Table 4.5). Almost 20 per cent are totally dependent on others in managing steps or stairs or walking about (Table 4.5).

Table 4.5: Degree of mobility of elderly person (Q.25)

Degree of Ability	Getting out of Bed		Climbing Steps/Stairs		Walking	
	N	%	N	%	N	%
Without Difficulty	116	58.3	46	23.0	78	39.0
With Difficulty	40	20.1	47	23.5	60	30.0
Only With Help	26	13.1	45	22.5	19	9.5
Not at All	17	8.5	36	18.0	37	18.5
Does Not Apply	0	0.0	26	13.0	6	3.0
Total (N)	199		200		200	

In the vast majority of cases, it is the carer who has primary responsibility for giving any assistance required with getting out of bed (93%), with climbing stairs (92%) and with walking (85%). Typically, there is no second person to assist the elderly person in being mobile. In those cases where back-up assistance is available, the second helper is most likely to be another household member (Table A4.9).

Ability to Manage Toileting

Ability to manage toileting requires a number of other abilities on the part of the elderly person — dressing, mobility, ability to control urination and defecation. As already noted, approximately 13 per cent of those being cared for are totally dependent on others in managing to dress themselves. With respect to their ability in getting to and using the toilet, 12 per cent of the elderly are dependent on others in this area and a further 29 per cent require at least some help (Table A4.10).

Level of Dependency in Relation to Personal Care

Of the different aspects of personal care investigated, the following areas were identified as being the key indicators of dependency:

- whether the elderly person can wash and bathe her/himself;
- whether the elderly person can get to and use a toilet;
- whether the elderly person can get in and out of bed;
- whether the elderly person can feed her/himself;
- whether the elderly person can dress her/himself;
- whether the elderly person can make her/his own meals; and
- whether the elderly person can walk unaided.

An overall measure of dependency in the area of personal care was computed from the above 7 factors in the following manner. The elderly person was considered to be very highly dependent if s/he could not manage at all by her/himself in relation to 6 or 7 of the areas described above; a high level of dependency was indicated if there was an inability to manage in relation to 4 or 5 of the areas; inability to manage 2 or 3 of the areas was considered to reflect a medium level of dependency and a low level of dependency was indicated if the elderly person was unable to manage in relation to just one area.

Table 4.6: Level of dependency in relation to personal care

Level of Dependency	Number	Percentage
No Dependency	20	10.5
Low Dependency	50	26.3
Medium Dependency	74	38.9
High Dependency	15	7.9
Very High Dependency	31	16.3
Total (N)	190	
Non-respondents excluded		

Using this measure it emerges that almost a quarter of the elderly being cared-for at home are either very highly (16%) or highly dependent (8%) (Table 4.6). Thirty-nine per cent of the elderly exhibit a medium level of dependency. A small group (11%) are independent in relation to all aspects of personal care.

Level of Dependency in Relation to Medical Aspects of Care

Three indicators of dependency were investigated in connection with medical aspects of care: incontinence of urine, soiling and whether the elderly person was bedridden. A sizeable group of the elderly being cared-for (14%) were bedridden at the time of interview; this being a permanent condition among 6 per cent (Table 4.7). Many cannot get out of the house without help (41%), while 17 per cent are permanently housebound.

Table 4.7: Degree of house-boundness of elderly person (Q.28)

Degree	Number	Percentage
Bedridden Permanently	11	5.5
Bedridden Temporarily	17	8.5
Housebound Permanently	33	16.5
Able to get out only with Help	81	40.5
Able to get out unassisted	58	29.0
Total (N)	200	

Incontinence is recognised as one of the most difficult and disturbing problems facing those who care for the elderly. In this light a noteworthy finding of this study is that close on a quarter (24%) of elderly persons cared-for at home are incontinent of urine and again a large percentage (20%) have problems with soiling. Many of those with a problem in this area are incontinent both of urine and faeces (39%).

Consideration of overall level of dependency across the 3 medical indicators used, reveals that 8 per cent of the elderly cared-for at home may be regarded as being highly dependent in this area in that they are incontinent both of urine and faeces and are bedridden (Table 4.8). A

Table 4.8: Level of medical dependency

Level of Dependency	Number	Percentage
No Dependency	137	68.5
Low Level	27	13.5
Medium Level	20	10.0
High Level	16	8.0
Total (N)	200	

further 10 per cent exhibit 2 of the 3 problems investigated and thus may be regarded as having a medium level of dependency. Among 14 per cent the level of dependency in the medical area is low; these people exhibiting just one of the problems investigated. According to the measure used the majority of the elderly may be considered as being independent in relation to the medical aspects of care studied.

MENTAL WELL-BEING OF THE ELDERLY

The emotional and physical strains of caring are greatly increased where the elderly person exhibits symptoms of mental infirmity. Mental infirmity can result from a variety of causes, the most common being organic brain disease. One such disease is Alzheimer's disease. Alzheimer's disease is a particular form of dementia associated with ageing which expresses itself in symptoms such as confusion, forgetfulness, depression, angry outbursts, wandering and disorientation. While in the early stages of Alzheimer's disease the affected person can lead a moderately independent life, severe dementia virtually disables its victims so that, for example, s/he no longer recognises the faces of family members and cannot manage even routine activities. Thus, the physical care involved can be exhausting. In addition, there is the need for constant supervision. At the emotional level the carer has the added suffering of seeing someone s/he loves deteriorate by degrees.

Incidence of Symptoms of Dementia

According to the carers' descriptions of the elderly people in their care, a substantial percentage appear to be suffering some degree of dementia. A group of approximately 15 per cent are seen by their carers as continuously exhibiting such symptoms as memory loss, angry outbursts, mood swings, confusion and sleeplessness (Table 4.9). Depression is an on-going problem among a slightly larger group of the elderly (17%). In addition to those who continuously manifest such symptoms of dementia, there is a further group of between 24 to 36 per cent who suffer these difficulties occasionally. More severe indications of dementia are evident among a smaller group of the elderly: for 6 per cent wandering is an on-going problem and among a similar sized group (6%) mental state has deteriorated to the point where the elderly person no longer recognises members of the family.

Table 4.9: Whether elderly person exhibits different symptoms of Dementia

Symptoms	Yes		Sometimes		No		Total
	N	%	N	%	N	%	
Memory Loss	29	14.6	59	29.6	111	55.8	199
Angry Outbursts/ Mood Swings	29	14.6	50	25.2	119	60.1	198
Confusion by Day	28	14.0	48	24.0	124	62.0	200
Confusion by Night	23	11.5	25	12.5	152	76.0	200
Sleeplessness	29	14.7	62	31.5	106	53.8	197
Depression	34	17.0	72	36.0	94	47.0	200
Wandering	11	5.6	25	12.8	159	81.5	195
Failure to Recognise Family	12	6.0	20	10.0	168	84.0	200
Non-Respondents Excluded							

In the great majority of cases problems associated with dementia have become evident within the last 5 years. There are instances, however, where the carer has been coping with such distressing symptoms for between 10 to 30 years (Table A4.11).

Level of Dependency in Relation to Psychological State

Of the different aspects of psychological state investigated the following factors were identified as the key indicators of the level of dependency of the elderly person in relation to this area of care:

- Memory loss
- Wandering
- Confusion by day
- Confusion by night
- Angry outbursts/mood swings
- Failure to recognise family.

Based on these 6 indicators of psychological state, an overall measure of dependency was derived. The elderly person who exhibits one of these symptoms is considered to have a low level of dependency. Where 2 or 3 of these symptoms are present a medium level of dependency is indicated; 4 or 5 symptoms reflect a high level of dependency; and the person who exhibits all 6 symptoms is considered to be very highly dependent.

Using this measure of dependency, it emerges that 3 per cent of elderly people being cared-for at home are very highly dependent in terms of

their psychological state. A further 18 per cent may be regarded as highly dependent in this area. Among a quarter of the elderly their psychological state is such that a medium level of dependency is indicated. According to the measure used, almost a third of the elderly may be regarded as being independent in terms of their psychological state (Table 4.10).

Table 4.10: Level of dependency in relation to psychological state

Level of Dependency	Number	Percentage
No Dependency	62	32.5
Low Level	40	20.9
Medium Level	48	25.1
High Level	35	18.3
Very High Level	6	3.1
Total (N)	191	

Non-respondents excluded

OVERALL LEVEL OF DEPENDENCY

In order to determine the elderly person's overall level of dependency across different areas of care, a measure was derived based on the degree of dependency identified in each of the following areas: personal care, medical situation, psychological state. According to this measure 17 per cent of the elderly cared-for at home may be regarded as showing a very high overall level of dependency in that they are very highly dependent in at least one of these three areas. A further 22 per cent may be considered to be highly dependent. Thirty-five per cent show a medium level of dependency and 19 per cent show a low level of dependency. Using this measure only a small group (8%) may be regarded as being independent in relation to all 3 aspects of care investigated (Table 4.11).

Table 4.11: Overall level of dependency

Level of Dependency	Number	Percentage
Very High Dependency	34	17.0
High Dependency	44	22.0
Medium Dependency	70	35.0
Low Dependency	37	18.5
No Dependency	15	7.5
Total (N)	200	

DURATION OF PROVISION OF CARE

Consideration of the length of time for which the carer has been providing care gives an idea of the commitment that is involved in caring for an elderly person at home. While the length of time for which the carers under study have been providing care varies greatly from one year or less to 31 years (Table 4.12), the general picture is that caring is a long-term commitment. Fifty-four per cent of those studied have been carers for more than 5 years while 29 per cent have been providing care for more than 10 years. A small group have been carers for a period of 21 to 30 years and one carer has been providing care for over 30 years.

Table 4.12: Number of years for which care has been provided (Q.15a)

Number of Years	Number	Percentage
0 - 5 Years	93	46.5
6 - 10 Years	49	24.5
11 — 15 Years	24	12.0
16 — 20 Years	18	9.0
21 — 25 Years	6	3.0
26 — 30 Years	9	4.5
Over 30 Years	1	0.5
Total (N)	200	

EXTENT OF CARE PROVIDED

Apart from the level of dependency of the elderly person, a further indication of the nature of the demands which caring imposes is the extent to which care is constant. With respect to the constancy or extent of care provided, 20 per cent of the carers are looking after the elderly person on a 24-hour basis (Table 4.13). For a further 30 per cent, care

Table 4.13: Extent of care provided (Q.29)

Extent of Care	Male		Female		Total	
	N	%	N	%	N	%
24-hour care	5	13.9	34	20.7	39	19.5
Constant care except at night	12	33.3	47	28.7	59	29.5
Occasional care during the day for specific tasks	19	52.8	83	50.6	102	51.0
Total (N)	36		164		200	

is constant during the day but not at night. In the remaining cases, care is given on an occasional basis for specific tasks throughout the day. No great differences emerge between male and female carers with respect to the extent of care which they provide; this being particularly true in relation to the numbers providing occasional care or constant day care. With respect to round-the-clock care, females are more likely than males to be providing this kind of care (Table 4.13).

Not surprisingly, those elderly persons with the highest level of dependency are also those who require the most constant care. Among those exhibiting a very high dependency level (34) half require round-the-clock care while a further 14 need constant care throughout the day. Just 3 of this group receive occasional care (Table 4.14). Likewise, of

Table 4.14: Relationship between extent of care given to elderly person and the elderly person's overall level of dependency

Extent of Care	Level of Dependency				
	Very High Dependency	High Dependency	Medium Dependency	Low Dependency	No Dependency
Needs 24-Hour Care	17	16	5	1	0
Needs Constant Care	14	13	24	5	0
Care Needed Occasionally	3	15	41	31	1
Total (N)	34	44	70	37	15

the 44 elderly persons who are highly dependent, 16 need 24-hour care and 13 need constant daily care. The majority of those exhibiting medium (70) or low levels (37) of dependency require occasional care.

Whether or not the elderly person is housebound has implications for the extent of care required: over half (54%) of those needing 24-hour care are housebound or bedridden (Table A4.12).

As might be expected, the extent of care needed is also greater among those elderly with incontinence problems: of those requiring 24-hour care, 54 per cent are elderly persons who are incontinent of urine and 46 per cent are people who have difficulties with soiling (Tables A4.13 and A4.14).

PERCEIVED AMOUNT OF CARE PROVIDED

As a further indication of what is involved in caring for the elderly at home, more than half (57%) of the carers feel that the elderly person

being looked after needs a lot of care. According to 38 per cent the elderly person needs a little care. Among a small group (5%) the kind of care required is seen as being just occasional.

Many (32%) of the elderly persons needing a lot of care, need this kind of looking-after not just during the day but at night also. Among 41 per cent a lot of care is needed constantly throughout the day. There are some (27%) who, though they require a lot of care when the need arises, require to be looked after only occasionally during the day. In the case of those elderly people requiring a little care, the great majority (80%) need to be looked after just occasionally. There are some (16%) however, who need only a little care but yet require constant attention during the day (Table A4.15).

The relationship between level of dependency and the work involved in caring is evident from the fact that almost all of those exhibiting very high or high levels of dependency require a lot of care (Table 4.15). Of the 70 elderly people exhibiting a medium level of dependency, 31 require a lot of care and 38 a little. Those with low levels of dependency typically require just a little care.

Table 4.15: Relationship between the amount of care required and the elderly person's level of dependency

Amount of Care	Level of Dependency				
	Very High	High	Medium	Low	None
A Lot	32	39	31	10	2
A Little	2	4	38	22	10
Occasional	0	1	1	5	3
Total (N)	34	44	70	37	15

Cycles of Caring

Clearly, the nature of what caring involves is influenced by whether the carer has just one person to look after or whether s/he has responsibility for the care of a number of persons. Research shows that carers often look after more than one person in their lifetime. In the present study, while the vast majority of the carers (94%) are looking after just one elderly person, there are, however, 10 individuals who are providing care for 2 elderly persons and in 2 cases 3 elderly people are being looked after. In addition to looking after an elderly person there are 8

carers who are also providing care for a handicapped person. Five of the 8 handicapped persons being cared-for are living in the carer's own home. In 3 cases the handicapped person is a child of the carer, in another 3 cases the cared-for person is a brother and in the remaining 2 cases it is some other relative who is being looked after. Apart from looking after an elderly or handicapped person, more than a third of the carers (37%) have the added responsibility of looking after children under 18 years of age.

SUMMARY

Who Gets Care at Home?

Those elderly persons cared-for at home are more likely to be female than male. Typically, they are in their 80's or 90's with few being less than 70 years of age. Women cared-for at home tend to be older than the men. In their working lives, these elderly people for the most part had been small farmers or semi-skilled or unskilled workers. The vast majority receiving home-care suffer some kind of health problem. Disease of the joints is most usual but diseases of the cardio-vascular and renal systems are also not uncommon and visual or hearing defects are present in one of every 10. Many of the elderly suffer not just one but several health problems. Investigation of the kind of care which the elderly people require reveals that there are many who are highly dependent on their carers particularly in the area of personal care but also in relation to medical and psychological aspects of care.

Level of Dependency: Personal Care

Consideration of the ability to manage tasks such as washing, dressing, feeding, cooking, toileting, getting out of bed and walking unaided indicates that many cannot fend for themselves at all in relation to personal care. Sixteen per cent may be considered as being very highly dependent in that they cannot manage at all by themselves in at least 6 of the areas noted. A further 8 per cent may be regarded as being highly dependent in that they have to depend on others in at least 4 aspects of personal care.

Level of Dependency: Medical

A sizeable group of the elderly are bedridden; in some cases this is a

temporary condition (8%) but among 6 per cent this condition is permanent. Many cannot get out of the house without help (41%) and 17 per cent are permanently housebound. Incontinence is a problem among almost a quarter (24%) of those being cared-for at home and again a large percentage (20%) have problems with soiling. Consideration of the findings across these different aspects of medical care reveals that 8 per cent may be regarded as being highly dependent in that they are incontinent both of urine and faeces and are also bedridden. A further 10 per cent exhibit at least 2 of these problems and thus may be regarded as showing a medium level of dependency.

Level of Dependency: Psychological

Apart from physical and medical dependency a substantial percentage of those cared-for at home are exhibiting symptoms of dementia. Approximately 15 per cent are seen by their carers as continuously suffering memory loss, angry outbursts, mood swings and confusion. A similar percentage are perceived as being depressed and suffering from sleeplessness. There are, in addition, many elderly (between 24% and 36%) who manifest symptoms of dementia occasionally. Among a group of 6 per cent the elderly person's psychological state has deteriorated to the point where s/he is continuously wandering and no longer recognises family members. Overall, almost a quarter (21%) of the elderly may be regarded as being very highly (3%) or highly dependent (18%) in psychological terms in that they exhibit 4 of 6 symptoms of dementia.

Overall Level of Dependency

Consideration of level of dependency across all areas of care reveals that 17 per cent of those cared-for at home may be regarded as being very highly dependent and a further 22 per cent may be considered to be highly dependent.

Who Provides the Care?

In all areas where the elderly person is dependent on others to manage, the carer is the one most likely to provide the necessary assistance. Typically, the burden of helping is borne alone by the carer without back-up assistance from a second person. A striking aspect of the care provided at home is that, for most, caregiving is a very long-term

commitment: over half of those studied (54%) have been carers for 6 years or more while 29 per cent have been giving care for more than 10 years.

Level of Care Provided

Given the numbers of elderly who are very highly or highly dependent it is not surprising that the majority of the carers (57%) specify that they provide 'a lot' of care. Thirty-eight per cent see themselves as providing 'a little' care while a small group (5%) regard their care as being occasional. Caregiving is a 24-hour commitment for many (20%) and for a further 30 per cent care is constant throughout the day. In the remaining cases, care is provided on an occasional basis for specific tasks when required.

Cycle of Caring

For some carers, caregiving is not confined to just 1 person: 12 are looking after more than 1 elderly person and 8 are also providing care for a handicapped person. In addition, more than a third of carers (37%) have responsibility for children under 18 years of age.

CHAPTER FIVE

Who Provides Home Care?

Introduction

Who are the carers of the elderly? Do men and women equally provide care? Are carers single or married? What age are they? Do they come from particular socio-economic backgrounds? What is their employment status? This chapter documents the demographic and socio-economic characteristics of carers. In addition, their financial circumstances are described and details of home-ownership and household composition are provided. The current state of carers' physical health and psychological well-being is also described.

DEMOGRAPHIC CHARACTERISTICS OF CARERS

Age and Sex of Carers

In common with previous research findings, in the present study the vast majority of the carers are female. Among the 200 carers interviewed, there are 36 men compared to 164 women; a ratio of approximately 4.5 times more females than males. The age range of the carers varies greatly from some who are in their 20's (4) to those who are in the 80's (3). Most, however, are middle-aged or elderly with just 17 per cent being younger than 40 years. Half of the carers are in the age-range of 40 — 59 years. It is noteworthy that many are themselves elderly with 22 per cent in their 60's and 10 per cent in their 70's (Table 5.1). No marked differences are evident in the age-ranges of male and female carers.

Marital Status

Overall, carers are much more likely to be married than single. At the time of interview 67 per cent were married (Table 5.2). A further 10 per cent had been married at some stage but are now widowed (14) or

Table 5.1 : Age-group of male and female Carers (Q.6)

Age-Group (In Years)	Male		Female		Total	
	N	%	N	%	N	%
23 — 29		0.0	4	2.4	4	2.0
30 — 39	7	19.4	23	14.0	30	15.0
40 — 49	9	25.0	46	28.0	55	27.5
50 — 59	10	27.8	34	20.7	44	22.0
60 — 69	6	16.7	38	23.2	44	22.0
70 — 79	3	8.3	17	10.4	20	10.0
80 — or more	1	2.8	2	1.2	3	1.5
Total (N)	36		164		200	

Table 5.2: Marital status of carer (Q.7)

Status	Male		Female		Total	
	N	%	N	%	N	%
Married	11	30.6	122	74.4	133	66.5
Widowed	0	0.0	14	8.5	14	7.0
Divorced/Separated	2	5.6	2	1.2	4	2.0
Deserted	1	2.8	1	0.6	2	1.0
Single	22	61.1	25	15.2	47	23.5
Total (N)	36		164		200	

divorced/separated (4) or deserted (2). Less than a quarter (24%) of the carers are single. However, when male and female carers are considered separately very clear differences emerge. Male carers are more likely to be single (61%) than married (31%); by comparison close on three-quarters of the female carers are married and only 15 per cent are single.

SOCIO-ECONOMIC CHARACTERISTICS OF CARERS

Educational Attainment

Just over half (51%) of the carers had left full-time education before 16 years of age (Table A5.1). A further 47 per cent left school between the ages of 16 and 18 years. A very small group (3%) were still involved in full-time education while in their 20's. With regard to the level of education attained on leaving school, those with primary certificate account for 46 per cent of all the carers under study. Just over one-third (35%) have the Intermediate or Group Certificate. A small group (15%) have been

educated to Leaving Certificate standard and a few (3%) have attended third-level institutions (Table A5.2).

Employment Status and Occupation

Very few (16%) of the carers work outside the home and of the 31 who do 12 are working part-time. Male carers are more likely than female carers to be working in paid employment: only 10 per cent of the women are working outside the home compared to 42 per cent of the male carers (Table A5.3). Among those who had been or are currently working, the majority are employees (88%); 9 per cent are farmers and 3 per cent are self-employed. Except for one case, all of the 14 who are farmers have holdings of less than 100 acres (Table A5.4). The most typical sized farm is between 50 and 99 acres (5). Of those in occupations other than farming, over half (56%) are semi-skilled or unskilled workers (Table 5.3). Close on a quarter (21%) are non-manual workers. Only a small percentage (14%) are in the professional or managerial classes.

Table 5.3: Main occupation of carer when working (Q.10a)

Occupation	Number	Percentage
Higher Professional and Higher Managerial	3	2.1
Lower Professional and Lower Managerial	17	12.1
Other Non-Manual	30	21.4
Skilled Manual	11	7.9
Semi-Skilled Manual	51	36.4
Unskilled Manual	28	20.0
Total (N)	140	

Based on those who had ever worked, excluding farmers.

Reasons for Leaving Employment

While only 16 per cent of the carers are currently working, the majority (77%) had been in employment at some time. Among those who had been employed but who had left work for one reason or another, many (39%) had not worked for over 20 years and two-thirds had not worked for over 10 years (Table A5.5). Over half (59%) had left work in order to get married and raise a family (Table A5.6). Others left employment because of redundancy (7%), retirement (6%) or other reasons (8%) such as illness. However, 20 per cent left work specifically in order to take up the role of carer. Men (38%) were more likely than women (17%) to have given up work for this reason.

FINANCIAL CIRCUMSTANCES OF CARERS

Receipt of Pensions, Benefits, Allowances

In the case of most carers (83%) there is at least one member of the household receiving an old-age pension. The amount received varies greatly from £20 to £131 per week but the most typical amount is between £45 and £55 (Table A5.7). In a small number of households there is someone receiving a social welfare retirement pension (10%) or invalidity pension (3%). In a few instances some member of the household gets some other kind of statutory payment such as disability benefit (6%), widow's pension (6%), disablement benefit (1%) or deserted wife's allowance (2%). It is of note that in 38 households there is at least one person in receipt of unemployment benefit, the amounts received varying from £13 per week to £110 per week (Table A5.8).

Wages and Salaries

It is striking that in almost one-third (32%) of the households studied there is no income from wages or salaries and the family is wholly dependent on State benefits or allowances (Table A5.9). Among 40 per cent of the carers in this group, caregiving is experienced as causing financial strain (Table A5.10). Where the household does have income from a wage or salary, the disclosed amounts vary enormously from less than £20 per week to over £400. Typically, however, income from this source amounts to between £80 and £200. Few carers from households where someone earns over £200 per week experience any financial strain as a result of caregiving. However, in those households where there is less than £200 in earned income, caregiving causes financial difficulties (Table A5.10).

Overall Weekly Income

Consideration of the overall amount of money in the household per week reveals a range from £31 to £490 (Table 5.4). While the figures provide some indication of the variations in carers' circumstances, it should be noted that the sum of different incomes calculated for every household every week may not be truly representative as some people disclosed some but not others of their sources of household income. Accordingly, data for some carers are incomplete. From the information available, it appears that among the majority of carers (68%) household

Table 5.4: Overall amount of weekly income (Q.76)

Amount	Number	Percentage
No Household Income Revealed	9	4.5
£31-£50	21	10.5
£53-£100	47	23.5
£103-£150	40	20.0
£157-£200	28	14.0
£202-£250	25	12.5
£250-£303	17	8.5
£306-£403	12	6.0
£490	1	0.5
Total (N)	200	

incomes amount to £200 or less per week. Experience of financial strain due to caregiving is most prevalent in households with this amount of weekly income (Table A5.11).

Prescribed Relative Allowance

The Prescribed Relative Allowance is an increase in pension payable to incapacitated old-age and invalidity pensioners in respect of a prescribed relative who is living with them and is providing them with full-time care and attention*. Although this allowance is specifically for caregiving, just 8 of the carers under study actually benefit from this provision. This is so because of the eligibility requirements which have been laid down. With respect to eligibility requirements on the part of the pensioner, s/he must either be receiving an old-age pension, a blind person's pension, invalidity pension or be over 66 and receiving a widow's pension, retirement pension, deserted wife's benefit, deserted wife's allowance or prisoner's wife's allowance from the Department of Social Welfare. S/he must be so incapacitated as to require full-time care and attention and s/he must be receiving full-time care and attention from a prescribed relative who is residing with her/him for that purpose. Apart from the prescribed relative, s/he must be living alone or only with children under 18 or persons aged 18 and over and who are mentally/physically incapacitated.

In the case of the prescribed relative, s/he must not be engaged in employment outside the home, s/he must not be entitled to any other benefit, pension or allowance from the Department of Social Welfare

* Note, the allowance is paid to the elderly person and not to the carer.

and, most significantly, s/he must not be a married person who is maintained by her/his spouse.

Given these conditions, it is not surprising to discover that only 8 of the carers in the study (3 males and 5 females) are in receipt of the Prescribed Relative Allowance, as it rules out married women and, as indicated previously, these are precisely the people most likely to be providing care. Also, a son or daughter who is working on her/his land to even a limited degree is deemed as being outside the scope of this scheme as it is taken as evidence that the prescribed relative is not devoting full-time care and attention to looking after the elderly person in question. An interesting point is that only 4 of the 8 consider themselves to be giving a lot of care to the elderly person; the remainder describing the amount of care they are giving as 'a little'. However, in order to be eligible for the Prescribed Relative Allowance the prescribed relative is supposed to be giving full-time care and attention.

HOME OWNERSHIP AND HOUSEHOLD COMPOSITION

Many more carers (60%) live in rural areas than in towns (28%) or cities (12%). Most (86%) own their own homes with 72 per cent owning their house outright and 14 per cent still paying mortgages or loans (Table A5.12). A small number are renting houses either from local authorities (5%) or from the private sector (1%). Some (7%) are living in the homes of relatives. While almost all carers have houses, there are 3 who are living in bedsitters or flats and 2 described their accommodation as a caravan or mobile hornet.

Carers come from many different sized households ranging from 2 to 10\$, (Table A5.13). However, small households of 2 or 3 persons are the most usual. Over a quarter (28%) are living in households comprising 4, 5 and 6 persons, and a substantial percentage (11%) live in 7 person homes. A small group (8%) live in large households with 8, 9 and 10 people. Where the household is comprised of one other member besides the carer and the elderly person, typically that other person is a spouse (66%). While larger households are comprised mainly of children, there

* In one of these cases the carer's home had been burned out and she was taking temporary refuge in a mobile home. The two elderly people being looked after by this carer were being cared for temporarily by other relations.

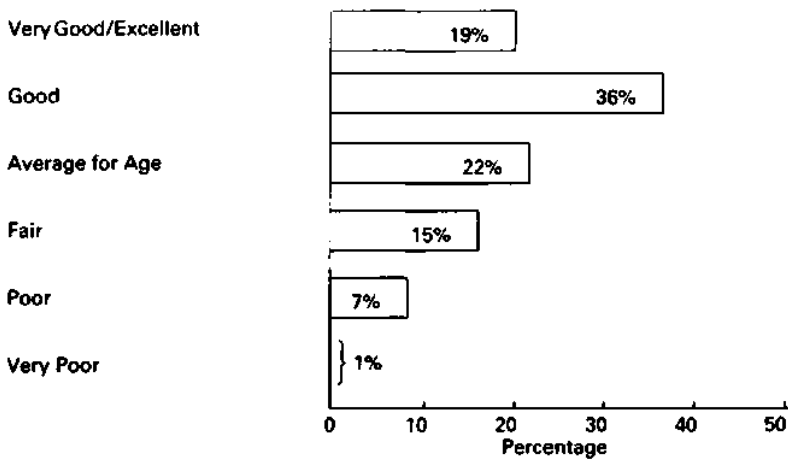
**Households comprised of two people means that there is just the carer and the elderly person.

are some carers who share their homes with parents (4), parents-in-law (4), brothers (18) or sisters (5), or some other relative (18). The head of the household is typically the spouse of the carer (42%) or the carer her/himself (30%), although in a substantial percentage of cases (22%) the head of the household is the elderly person for whom care is being provided.

HEALTH OF CARER

Over half the carers (55%) rate their health as excellent (19%) or good (36%) with a further 22 per cent regarding their health as average for their age (Figure 5.1). However, close on a quarter of carers (22%) perceive themselves as having only fair (15%) or even poor health (7%) and in two cases the health of the carers is rated by them as being very poor.

Figure 5.1: Carers' Ratings of Personal Health



Many (33%) of the carers experience some on-going health problem which is more likely to be permanent (58%) rather than temporary (13%). The most common problems are diseases of the cardio-vascular

or renal systems (33%) (Table 5.5). A sizeable percentage (18%) are suffering from disease of the joints. In many cases (33%) the health problem of the carer is so severe that her/his activities are continuously being limited and among a further 42 per cent the health condition prevents the carer from carrying out certain activities at least sometimes.

Most (72%) carers had had occasion to visit a doctor in the year prior to interview. Between one and 3 visits was the most usual pattern (50%) but some had had to attend the doctor 12 times or more (Table A5.14). Over a third (38%) had suffered an illness requiring medication in the year prior to interview while among 7 per cent the illness was so severe as to require hospitalisation. Apart from physical health problems, a small number of carers are taking medication for a nervous condition (7) or to induce sleep (4).

Table 5.5: Nature of health problem of carer (CL43b)

Nature of Problem:	Number	Percentage
Endocrine	2	2.4
Cardio-Vascular/Renal/Blood	29	33.3
Respiratory	5	5.9
Neurological	9	10.7
Skin	2	2.4
Malignancy	1	1.2
Gastro-Intestinal	8	9.5
Joints	15	17.9
Visual/Hearing	5	5.9
Colds/'Flus etc.	7	10.7
Total (N)	83	

SUMMARY

Who Provides Home Care?

In answer to the question: who are the carers of the elderly? the findings indicate that females are 4.5 times more likely than males to be the caregivers. Many carers are themselves elderly persons. Most carers are currently married (67%) or have been married at some time (10%) with less than a quarter (24%) being single. Female and male carers differ in that female carers are most likely to be married (75%), whereas males are typically single (61%).

Socio-Economic Characteristics

The findings indicate a relatively low level of educational attainment on the part of many carers. Over half (51%) had left school before the age of 16 and 46 per cent have no formal educational qualifications. Just over a third (35%) have the Intermediate or Group Certificate while 15 per cent have obtained Leaving Certificate standard. Very few carers are in paid employment (16%) with males (42%) more likely than females (10%) to be working outside the house. Many of those in paid employment work part-time. Among those who have been or are currently in paid employment, most (88%) are employees with small numbers being farmers (9%) or self-employed (3%). The most typical sized farm is 50-99 acres. Those in occupations other than farming are typically in semi-skilled or unskilled jobs (56%). A small group (14%) are in the professional and managerial class. One in 5 of carers gives up work to take on the role of caregiving with men (38%) being more likely than women (17%) to leave work when they become carers.

Financial Circumstances

In most households (83%) there is at least one person in receipt of the old-age pension, the amount varying from £29 to £178. Between one and 19 households receive some other type of weekly benefit such as invalidity pensions (5), widows' pension (11), deserted wives' (3) and unmarried mother's allowance (1). In several households (19%), there is at least one person receiving unemployment benefit. Income from wages or salary is typically £200 per week or less. Almost one-third (32%) of the households are totally dependent on State benefits or allowances. Households with a weekly income of £200 or less — which is the most typical situation — are most likely to experience financial strain as a result of caregiving. Very few (8) of the carers receive the Prescribed Relative Allowance which is the only provision specifically for caregiving.

Home Ownership and Household Composition

The vast majority of carers (86%) live in their own homes with 6 per cent being in rented accommodation. The typical household is small, consisting of 2 or 3 persons (53%). However, over a quarter share the household with 4, 5 and 6 persons and 19 per cent of the carers live in large households of up to 10 people.

Health of Carer

Close on a quarter (22%) of carers rate their health as fair or poor. Two carers see themselves as having very poor health. A large percentage (33%) suffers some on-going health problem which in many cases (33%) is severe enough to limit activity. The most common problems involve cardio-vascular or renal complaints — both of which are frequently associated with stress. Many also suffer from disease of the joints (18%). Most of the carers (79%) have had some illness in the past year and again the majority (72%) have had occasion to visit the doctor. In 7 per cent of the cases their illness was severe enough to require hospitalisation. Apart from physical health problems, a small group of carers are taking medication for a nervous condition (7) or to induce sleep (4).

CHAPTER SIX

Becoming a Carer

Introduction

How does one become a carer? Is it a matter of choice or due to pressure of one kind or another? What are the factors that influence who in the family takes on the role of carer? What choice does the elderly person have regarding who gives the care? Typically, carers find themselves in that particular role as a result of a variety of factors. Research identifies three general types of influence: demographic imperatives, antecedent events and situational factors. Demographic imperatives which might influence the decision to become a carer include the relationship of the carer to the elderly person, family size and composition, and marital status. Antecedent events which exert influence might include age and state of health of the elderly person and the possibility of institutionalisation. Among the situational factors which determine who becomes the carer, the more important are proximity and availability. The purpose of this chapter is to explore the different kinds of influence which affected the carers of the present study in arriving at their decision to become carers.

DEMOGRAPHIC INFLUENCES ON BECOMING A CARER

Relationship of Carer to Elderly Person

Among those studied, the most usual relationship between the elderly person and his/her carer is that of parent and child (46%) (Table 6.1). Spouses account for almost a quarter (24%) of those being cared-for and a sizeable percentage (19%) are parents-in-law. Male carers, with few exceptions, are taking care of a parent or wife. Women carers, by comparison, look after a greater variety of people including not just parents and spouses but parents-in-law, brothers, sisters, other relatives and friends.

Table 6.1 : Relationship of carer to the elderly person (Q.16)

Relationship	Male		Female		Total	
	N	%	N	%	N	%
Spouse	9	25.0	38	23.2	47	23.5
Parent	23	63.8	68	41.5	91	45.5
Parent-in-law	1	2.8	37	22.6	38	19.0
Brother	0	0.0	2	1.2	2	1.0
Brother-in-law	0	0.0	1	0.6	1	0.5
Sister	0	0.0	3	1.8	3	1.5
Sister-in-law	0	0.0	2	1.2	2	1.0
Other Relative	3	8.3	7	4.3	10	5.0
Friend	0	0.0	6	3.7	6	3.0
Total (N)	36		164		200	

Of the 10 people caring for 2 elderly persons, typically the second person being cared for is a parent (6). The remaining carers are looking after a parent-in-law (2) or other relative (1) and in one case the second person being cared-for is a friend or neighbour. In the 2 cases where the individual is caring for 3 elderly persons, the third person is a relative of the carer in one case and a friend in the second case.

Household Size

Just under one-third of the carers (32%) are on their own in the home with the elderly person. In these cases decisions about who provides care are likely to have been based solely on availability. While carers living in larger households might be expected to have had greater choice about the provision of care, it should be noted that more than a third of carers share their homes with children under 18 years of age who are not available as carers.

Gender and Marital Status

As indicated previously, women are far more likely than men to become carers. Adoption of the role of carer by women is, very likely, influenced by the traditional caring role of women. Availability, however, also plays a role in that many more women than men are not in paid employment outside the home or are more marginally involved in the labour force than men.

In the present study, women are at least four times more likely to be carers than men. The women appear to have been more available than

the men in the sense that a higher percentage of the women (27%) than men (6%) had never worked outside the home and also many of the women carers who had worked had already given up employment for reasons of marriage and child-rearing (72%) (see Chapter Five).

Marital status appears to exert a different influence on adoption of the caregiving role depending on the sex of the candidate. Three-quarters of the female carers, in the present study, are married. Because the women tend to give up work on getting married, marriage makes them more available as care givers. On the other hand, the male carers are more likely to be single (61%) than married (31%). It may be that married men are perceived as being less available for caregiving because of the competing obligations of providing for wife and family.

INFLUENCE OF ANTECEDENT EVENTS

Deterioration in the health of the elderly person (79%) or onset of illness (70%) are frequently noted by the carers as reasons for taking on the role of caregiver. Among three-quarters of the carers, incapacity of the elderly persons to look after themselves was the original motivation for taking on caregiving. Worry (64%) about the elderly person or fear that lack of care would lead to institutionalisation (58%) led some of the carers to take up that particular role (Table 6.2).

Table 6.2: Antecedent events influencing decision to become carer (Q.15b)

Antecedent Event	Influence			
	Yes		No	
	N	%	N	%
Illness of Elderly Person	140	70.0	60	30.0
Elderly Person Unable to Look After Self	150	75.0	50	25.0
Deterioration of Health of Elderly Person	157	78.5	43	21.5
Elderly Person Living Alone	39	19.5	161	80.5
Worry About Elderly Person	127	63.5	73	36.5
Possibility of Institutionalisation	116	58.0	84	42.0
Elderly Person Dying	22	11.1	177	88.9
Non-Respondent Excluded				

INFLUENCE OF SITUATIONAL FACTORS

For the vast majority of the carers (84%), part of the reason for taking on the role was that they felt they had a responsibility to do so (Table 6.3). Availability is also clearly an important influence. In almost three-quarters of cases (73%) there is nobody else available to provide the necessary care. In some cases there are others available but the carer is the only one willing to take on the task (59%) or others actually refuse to give the necessary care (11%). In over a third of cases (38%) the elderly person her/himself had specifically requested the help of the carer. Proximity to the elderly person obviously exerts an influence on becoming a carer. While the present study does not have information on how close the elderly person and the carer lived prior to dependency it does, however, show that 71 per cent of the elderly were already living with the carer before becoming dependent and in these cases there may have been little choice in the matter of providing care.

Table 6.3: Influence of situational factors on decision to become carer (0.20a)

Situational Factor	Influence			
	Yes		No	
	N	%	N	%
Carer Only Person Available	146	73.0	54	27.0
Carer Only Person Willing to Take on Role	117	58.5	83	41.5
Other Relatives Refused	21	10.5	179	89.5
Carer Felt It Was His/Her Responsibility	168	84.0	32	16.0
Elderly Person Requested Carer	76	38.4	122	61.6

KEY INFLUENCES ON BECOMING A CARER

Examination of all the different demographic, antecedent and situational influences at work in determining who it is becomes the carer reveals six key factors: a feeling of responsibility; being the only one available to care; having the elderly person already in the home prior to dependency; inability of the elderly person to look after self; and illness or deterioration of health of the elderly person.

Among 36 per cent of the carers studied, every one of the above factors had an influence on their decision to become a carer and among a further quarter their decision had been influenced by 5 of the 6 factors.

Three (12%) or 4 factors (14%) were influential among others (Table A6.1). Thus, it can be seen that for the majority of carers it was a combination of factors rather than any single influence which determined their decision to take on the role of caregiver.

DECISION-MAKING PROCESS IN BECOMING A CARER

For the majority (79%), becoming a carer was a gradual process whereby the elderly person began to need more and more care over time. Typically, the elderly person had already been living with the carer prior to becoming dependent (71%).

Over 60 per cent of carers report that they made a specific decision to become caregivers. Among those who did not make a specific decision (35%), an important factor appears to be whether or not the elderly person had been living with the carer before becoming dependent: 87 per cent of those who had not made a specific decision to care had been sharing the household with the elderly person prior to dependency.

Where the elderly person and the carer had been previously living in separate homes, in more than half the cases (59%) when the elderly person became dependent s/he moved into the home of the carer rather than vice versa. Most (81%) carers were happy with the new living arrangements but a small group had felt 'reluctant' (4) or actively unhappy (3) about the new situation. In a few cases (4) the carer feels there had been no other choice (Table A6.2). Typically, the elderly person her/himself does not have a say in who becomes the carer: just over a third (37%) of the elderly persons had had a choice about who would provide the care.

UNDERSTANDING OF AND SATISFACTION WITH THE ROLE OF CARER

While the majority of the carers had either understood exactly (20%) or had had a fairly accurate idea (51%) of what caring entailed when they took on the role, over a quarter (28%), however, had no idea of what it would involve.

Typically, caring has turned out to be no better or worse than had been expected (53%). Indeed, for a small percentage (7%) it is even better than expected. However, a large group of more than one-third

(39%) find the task of caring worse than had been anticipated. Of this latter group, the majority (56%) had had no idea of what caring would entail when they took on the role.

In the main, the carers have a positive attitude towards the role they have taken on: typically they 'do not mind' being carers (52%) while many (38%) declare themselves to be 'very happy' with the role (Table A6.3). There is a group however who describe themselves as 'reluctant' (5%) or actively 'unhappy' (4%) about having to be carers.

The level of care provided seems to be an important influence on the carers attitude to caregiving. It is noteworthy that over half of those who are unhappy or reluctant about caring are providing 'a lot of care' compared to 41 per cent who are providing 'a little care' and just one person who is providing 'occasional care'.

SUMMARY

Who Cares?

Most usually, it is an adult child who is the carer of the elderly person looked after at home (46%). Spouses account for almost a quarter of those providing care and a sizeable percentage are sons or daughters-in-law (19%). By comparison with male carers, women look after a greater variety of people including not just parents and spouses but parents-in-law, brothers, sisters, other relatives and friends. Just under one-third of the carers (32%) are on their own in the home with the elderly person. It is likely that in these cases the issue of availability was a significant influence on decisions about who should provide the required care. This study shows that a woman who is married is more likely than a single person to become a carer; perhaps because women tend to give up paid employment with marriage and thus are seen as being more available. By comparison, the man who becomes a carer is more likely to be single.

Becoming a Carer: Key Factors

Examination of different antecedent and situational influences at work in determining who it is becomes the carer reveals six key factors: a feeling of responsibility; being the only one available to care; having the elderly person already in the home before dependency; inability of the elderly person to look after self; and illness or deterioration of health of

the elderly person. For the majority of carers it is a combination of these factors rather than any single influence which determined their decision.

Making the Decision

The process by which the decision is made regarding who becomes the carer is typically a gradual one (79%) rather than a sudden response to a crisis. In most cases (71%) the elderly person had already been living with the carer before becoming dependent. However, while the process may be gradual, the majority of carers (63%) nevertheless report that they had made a specific decision to take on caregiving. Typically the elderly person involved does not have a choice about who becomes the carer.

A substantial percentage of carers take on the role without having any idea of what caring involves (28%) and for many (39%) the task turns out to be worse than anticipated. While, in the main, carers are 'very happy' (38%) or at least 'do not mind' (52%) being caregivers there is a group who describe themselves as 'reluctant' (5%) or actively 'unhappy' (4%) about being in the job. Carers who are unhappy or reluctant about caregiving are more likely to be providing a lot of care (53%) rather than a little (41%) or occasional care (1 person).

CHAPTER SEVEN

Daily Dimensions of Caring

Introduction

The purpose of this chapter is to provide an understanding of what is involved in day-to-day caring of the elderly at home. What tasks do the carers have to carry out? What is their daily routine? How many hours do they give to caring? This chapter explores such questions. The level of dependency of the elderly person and her/his physical and psychological state will of course greatly influence the precise tasks associated with daily caring and the intensity of care required. The attitudes of the carer towards her/his role will also affect how performance of daily tasks is experienced, so that what for one carer is an onerous or distasteful task may be experienced quite differently by another. The support and assistance available to the carers is another factor which affects the experience of their daily lives. Because of such influences, wide differences will exist between carers with respect to personal experiences of caring. Nevertheless, it is possible to describe a general picture of the daily dimensions of caring. In looking at the daily lives of carers it should be remembered that in some cases (10%) more than one elderly person is being looked after or a handicapped person is also receiving care. Moreover, more than a third of the carers (37%) also have responsibility for children under 18 years of age. There is also the fact that a sizeable percentage of carers are themselves elderly.

Daily Routine

Most carers (69%) do not have a particular daily schedule to which they strictly adhere although there are tasks which they perform routinely every day. However, a substantial number of the elderly (31%) insist on a particular routine which is experienced as unhelpful and demanding by their carers. For the majority (68%), the day begins between 8.00 and 10.00a.m. Many (19%), however, take up their job even earlier

(Table A7.1). Typically (50%), carers devote 4 to 7 hours each day to caring, although for many (35%) caring takes up many more hours than this. Only 15 per cent of carers spend less than 4 hours each day in caring (Table 7.1).

Table 7.1: Number of hours spent in caring: (Q.39a)

Number of Hours	Number	Percentage
0*	6	3.1
1	3	1.5
2	8	4.1
3	13	6.7
4	20	10.3
5	24	12.3
6	23	11.8
7	30	15.4
8	17	8.7
9	10	5.1
10	7	3.6
11	3	1.5
12	3	1.5
13	4	2.1
14	11	5.6
15	2	1.0
16	2	1.0
17	4	2.1
18	2	1.0
24	3	1.5
Total (N)	195	

Non-respondents excluded

*No specific time allocated to caring; attention given as needed.

It is noteworthy that while none of the 6 per cent of carers who spend between 16 and 24 hours in caring are in paid employment, there are however, some who are working outside the home but who still give 10-12 hours (10%) and even up to 15 hours (14%) to caregiving (Table A7.2).

It is important to note that rather than being confined to a particular period of the day, which might allow the carer some personal freedom in structuring her/his own time, caring tasks are most often spread throughout the day (Table 7.2). The only period that is free for most carers is night-time. The typical pattern is one to two hours spent in caring throughout the morning, again in the afternoon and again in the evening time.

Table 7.2: Hours spent caring in different periods of the day (Q.39a)

Number of Hours	Period of the Day							
	Morning		Afternoon		Evening		Night	
	N	%	N	%	N	%	N	%
0	13	6.7	18	9.4	17	8.9	136	77.7
1	61	31.6	40	20.8	55	28.6	2	13.1
2	63	32.6	90	46.9	59	30.7	7	4.0
3	28	14.5	18	9.4	25	13.0	6	3.4
4	23	11.9	11	5.7	20	10.4	2	1.1
5	5	2.6	1	0.5	9	4.7	0	0.0
6	0	0.0	14	7.3	7	3.6	1	0.6
Total (N)	193		192		192		175	
Non-respondents excluded								

Being on Call on a Twenty-four Hour Basis

While carers may spend a limited number of hours each day directly involved in caring tasks, they may still, however, not be free to become involved in other activities through having to be 'on call' should the elderly person require assistance. Indeed, the finding of the present study that approximately a quarter of the elderly need help in getting to and using the toilet means that many of those being cared-for need someone to be around constantly. More than a third of the carers studied (36%) are required to be always on call, 24-hours per day. For a further 17 per cent this is also usually the situation and for 14 per cent 24-hour presence is sometimes required. Just over a third (34%) say they are never required to be on 24-hour call. Whether or not the carer is required to be on 24-hour call does not appear to be influenced by the number of people in the household. Carers in homes comprised of several people are just as likely to be on 24-hour call (37%) as are carers in homes where there is nobody else but the elderly person (32%) (Table A7.3)

Daily Tasks in Providing Care

Ordinary domestic tasks, such as preparing and cooking food (91%) and making cups of tea (80%), form part of the daily routine for practically all carers. In some cases (19%) the elderly person is on a special diet and has to have meals specially prepared for him/her (Table A7.4). In addition to these tasks, many carers find that every day they are involved in such tasks as washing and bathing the elderly person (33%) or helping her/him to get dressed (27%). Among approximately a further third,

these tasks, while not required daily, have to be carried out at least sometimes (Table A7.4). Helping the elderly person in getting to and using the toilet are always part of daily life for 22 per cent of carers with almost a further quarter (22%) sometimes having to perform these tasks.

Given that almost a quarter (24%) of the elderly are incontinent of urine and 20 per cent have problems with soiling (see Chapter Four), the tasks involved in this area are clearly onerous. In addition to the care involved directly in toileting, there is also the added burden of laundering of clothing and bed-linen.

Problems associated with physical mobility (see Chapter Four) mean that over half of the carers (55%) have to help the elderly person in getting in and out of bed; for some (32%) this is an occasional rather than a regular task, but for almost a quarter it is always part of the daily routine (Table A7.4). Again, helping the elderly person in and out of chairs is always part of daily life for almost a quarter of carers (23%) and is also involved in caring — if on a less regular basis — for a further 24 per cent.

Apart from the tasks involved in physical care and in helping the elderly person get about, most carers have responsibility for the daily administration and supervision of medication (Table A7.4). For some carers, caring also involves tasks not related to practical needs such as sitting with the elderly person or reading to her/him (15%), or taking the elderly person for a walk or drive (16%) (Table A7.4).

Experience of Tiredness

Given the duties involved in caregiving, it is not surprising that most carers admit to feeling tired at least sometimes (35%) with many (40%) being constantly tired. However, almost half (49%) of the carers never get a chance to rest during the day. Moreover, when the elderly person requires attention at night, it is the carer who typically gives that help (50%). Clearly, where the household is comprised of just the carer and the elderly person, the carer has no option but to attend when help is required. However, in 55 per cent of those instances where the carer is the only one to give help to the elderly person at night, there is another option, seldom availed of, in that several other people are living in the home but do not help out when that situation arises (Table A7.5).

SUMMARY

Daily Routine

For the majority of carers, the daily routine of caring begins between 8.00 and 10.00a.m. Typically, carers devote between 4 to 7 hours each day to caring. Rather than being confined to a particular period of the day, the most usual pattern is that caring tasks are spread throughout the day with one or two hours spent in caring in the morning time, again in the afternoon and again in the evening time. The only period that is free for most carers is night-time.

Being on Call

Although the time directly involved in caring tasks may be limited to a number of hours each day this does not always mean that the carers are then free to pursue their own activities. More than a third of the carers (36%) are required to be always 'on call' round-the-clock should the elderly person require attention and for a further 17 per cent this is also usually the situation. Carers in homes with several other people are just as likely to be on 24-hour call as are carers in homes where there is nobody else but the person being cared-for.

Daily Tasks

In addition to the ordinary domestic chores of cooking and preparing meals, the daily routine of many carers involves difficult and time-consuming tasks such as washing and bathing the elderly person (33%) or helping her/him to get dressed (27%). More intimate tasks related to toileting are part of daily life for almost a quarter of carers (22%). For those caring for elderly people who are incontinent (24%) or have problems with soiling (20%), there is the added burden of laundering of clothing and bed-linen. Some of the elderly cared-for at home always need to be assisted in getting in and out of bed (24%) or in and out of chairs (23%). Most carers (67%) have responsibility for the daily administration and supervision of medication.

Tiredness

Given the tasks involved in caregiving it is not surprising that most carers experience tiredness at least sometimes (35%) if not constantly (40%).

Many (50%), however, never get a chance to rest during the day. Moreover, if the elderly person requires attention at night it is the carer who, most usually, gets up to give that care even in those households where there is someone else who might substitute for the carer.

CHAPTER EIGHT

Who Helps the Carers?

The daily round of domestic and physical activities involved in the care of an elderly person at home can consume an enormous amount of time and effort and can be both emotionally and physically taxing. If carers are to continue providing the level of care indicated in previous chapters, and for such a long period of time, it is very important that they should have sources of support to draw on to relieve them of some of the burden of caregiving. But do carers get help and support in providing care from other family members or from friends and neighbours in the community? This chapter outlines the nature and extent of the support which the carers of the present study get from informal sources. Two aspects of this informal support are investigated. First, the quantitative aspect of support is described in terms of the number of people in the carer's social network and the amount of contact with different network members. The qualitative aspect of support is outlined in terms of the actual help provided, whether of a practical or emotional kind.

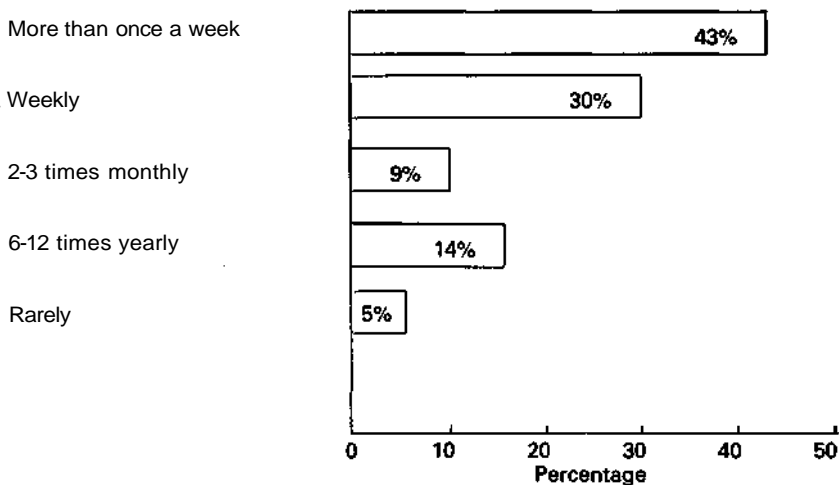
EXTENT AND COMPOSITION OF CARERS' SOCIAL NETWORK

Carer's Contact with Immediate Family Members

Forty per cent of the carers of the study have children living away from home; the most usual number being between 1 and 3 (66%) (Table A8.1). Typically the carer's children are aged between 21 and 35 (60%) (Table A8.2), are married (54%) and working full-time (61%) (Table A8.3). Most of these carers (73%) have a visit from at least one of their children once a week (43%) or more (30%) (Figure 8.1). Not surprisingly, the distance between the carer and her/his child is an important influence on the frequency of contact between them: the great

majority (89%) of those who visit more than once weekly live within 5 miles (Table A8.4).

Figure 8.1 : Frequency of Visits by Carer's Children*

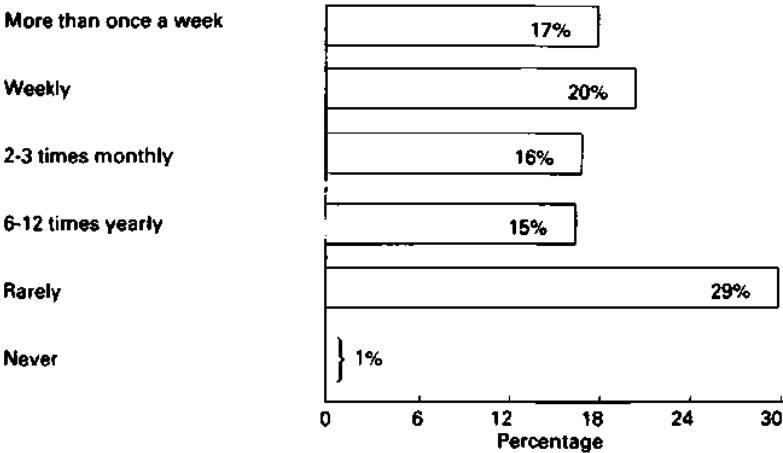


There is no difference in visiting patterns between sons and daughters (Table A8.5). Most of the carers (87%) feel satisfied with the amount of contact which they have with sons and daughters (Table A8.6) and almost all (92%) see their relationship with their children as being 'very close and friendly' (Table A8.7). The majority of the carers (81%) have brothers or sisters living in different homes; the most typical number being between 1 and 3 (66%) (Table A8.8). These brothers and sisters are mostly over 40 years of age (77%) (Table A8.9). Some carers (37%) receive a visit from at least one brother or sister once a week or more often (Figure 8.2). However, it often happens that carers rarely or never (30%) have a visit from a brother or sister. Geographical distance is clearly of issue here as many live at a distance from the carer with 49 per cent being more than 50 miles away. The majority (78%) of those who rarely or never visit are living at a distance of more than 50 miles from the carer whereas those who visit most frequently are no more

"Degree of contact with children is based on the frequency of visits of that child who, among all the carer's children (from 1-6), visits the carer most frequently.

than 5 miles away (Table A8.10). While carers, typically, see their relationships with brothers and sisters as "very close" (49%) or "reasonably close" (37%) (Table A8.11), almost one-third (32%), however, would like more contact.

Figure 8.2: Frequency of Visits by Carer's Brothers and Sisters*

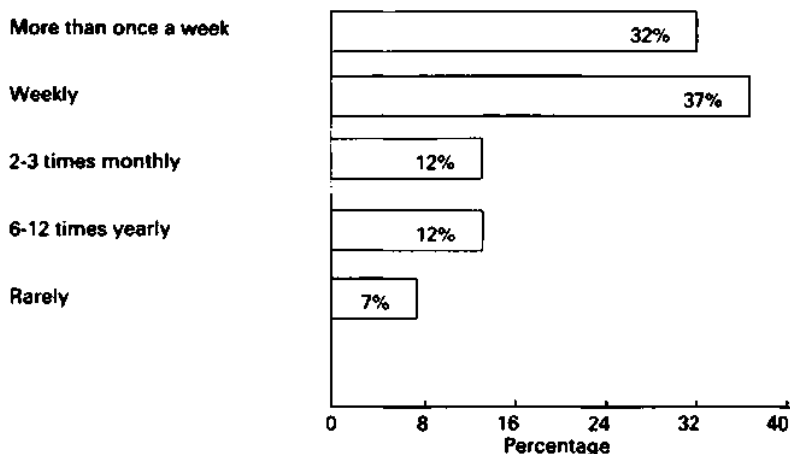


In general, as one would expect, grandchildren do not form part of the carer's social network (28%). Of those carers who have grandchildren living in a separate home, most have at least weekly visits (69%) (Figure 8.3); a level of contact which is satisfactory to most (89%).

Neither do parents (14%) or parents-in-law (12%) figure frequently as part of the carer's support network — which might be expected given the typical age of the carers. While parents and parents-in-law, for the most part (88%), live within 15 miles of the carer (Table A8.12), almost all are elderly and contact is often infrequent (Figure 8.4). However, the majority of the carers are satisfied with the frequency of visits; this interestingly being more evident in the case of fathers (73%) than mothers (59%) (Table A8.13).

*Degree of contact is based on the frequency of visits by that sibling who, among all the carer's brothers and sisters (1-6), visits most frequently.

Figure 8.3: Frequency of Visits from Grandchildren



Consideration of the overall level of contact between the carers and all of their immediate family members, whether children, brothers and sisters, parents or grandchildren, reveals that 36 per cent of carers may be considered to have a very high level of contact in that they have visits a number of times each week from one or more persons (Table 8.1). A

Table 8.1: Overall level of contact with members of immediate family

Level of Contact	Number	Percentage
Very High Level	65	35.9
High Level	53	29.3
Medium Level	19	10.5
Low Level	43	23.8
No Contact	1	0.6
Total (N)	181	

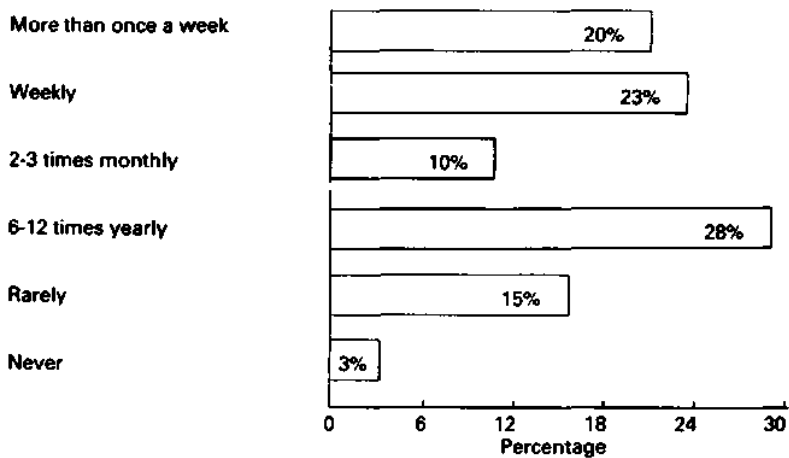
Non-respondents excluded

further 29 per cent have a high level of contact with at least one family member paying a visit once weekly. However, among almost a quarter (24%) of carers the extent of contact may be considered low as they receive a visit from a family member just once a month or less.

Visiting patterns, particularly among children (81%) and grand-

children (87%), have mostly remained unchanged since the carer began looking after the elderly person but where changes have taken place visits are likely to have become more frequent rather than less frequent. Parents are the exception to this general pattern with over a third (34%) of this group now visiting less frequently than had been the case before the carer took on caregiving.

Figure 8.4: Frequency of Visits by Parents/Parents-in-Law*



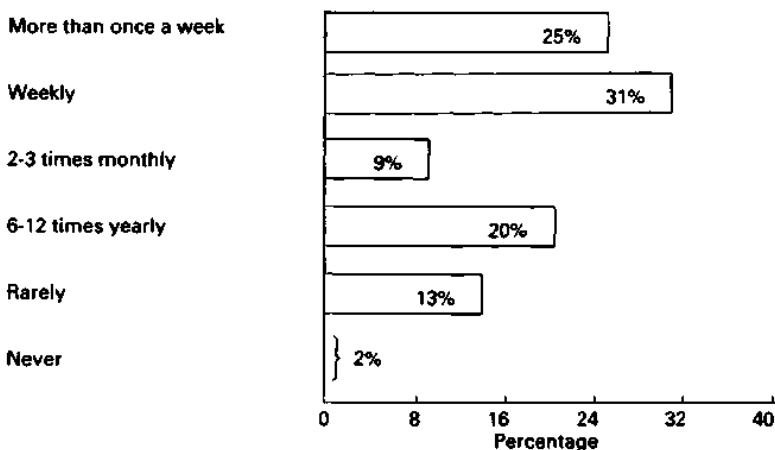
Involvement of Other Relatives and Friends in the Carer's Social Network

Apart from immediate family, just over half of the carers (56%) have at least one other person in their social network, while 31 per cent have at least 2 other members. Very few have contact with 3 (16%) or 4 (8%) people outside of family. Contact with others outside of the family circle is most likely to be with cousins (28%) or friends (35%) (Table A8.14). Relatives and friends in the carer's support network vary greatly in age, reflecting the fact that different kinds of relations are involved from aunts and uncles to nephews, nieces and cousins. Some of the carer's contacts are under 10 years of age while others are over 90. However,

*Degree of contact based on the number of visits by that parent or parent-in-law who visits most frequently

the majority (63%) are aged between 30 and 60 years of age (Table A8.15). Many carers (56%) enjoy a high level of contact with relatives and friends having a visit from one or more of them at least weekly. However, among over a third of carers (35%) the extent of contact appears to be low with a relative or friend visiting once a month or less (Figure 8.5). As with other people in the carer's network, geographical

Figure 8.5: Frequency of Visits from Close Relatives or Friends* -



distance is an important influence on frequency of contact: the majority (76%) of those who visit rarely are living at a distance of more than 50 miles (Table A8.16). It is noteworthy that over a third (35%) of relatives and friends in the carer's social network have increased their visits to the carer's household since the elderly person became dependent. Most carers (81%) are satisfied with the existing level of contact with relatives and friends.

Involvement of Neighbours and Clergy in Carer's Social Network

Most of the carers (84%) have neighbours living close-by (Table A8.17). Neighbours pay daily visits in the case of over a quarter (27%) of carers which may be regarded as a very high level of contact (Figure 8.6). A

*Degree of contact is based on the number of visits from that relative or friend who visits most frequently

Figure 8.6: Frequency of Visits from Neighbours

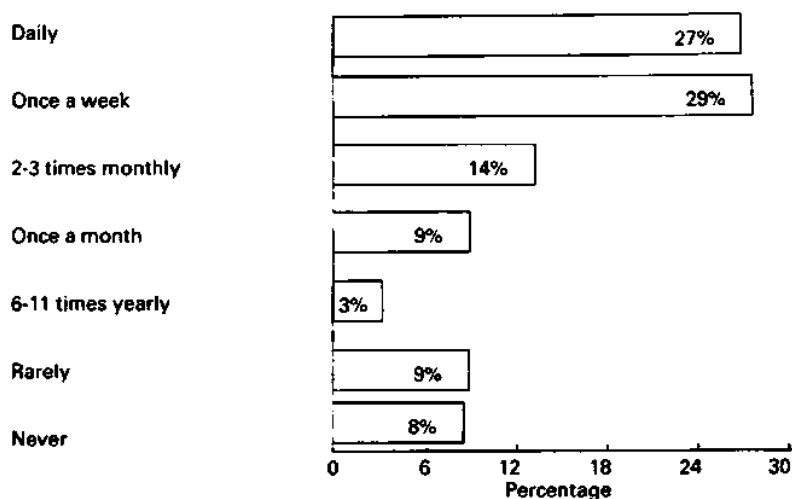
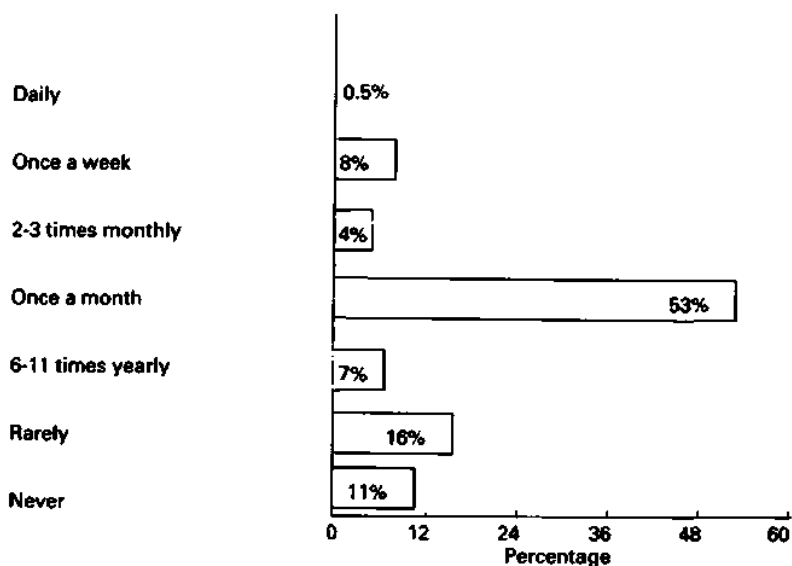


Figure 8.7: Frequency of Visits by Members off the Clergy



further 29 per cent have a high level of contact enjoying at least weekly visits from some neighbour. However, among 21 per cent of carers the extent of contact is low with visits from neighbours occurring once a month or less and in some cases (8%) neighbours never call. The majority of carers (73%) have visits from members of the clergy. The extent of contact is typically low, the most usual pattern of visiting being once a month (53%) (Figure 8.7).

Overall Level of Contact with Different Social Network Members

Consideration of overall frequency of visits to the carer from different social network members — whether immediate family, other relatives and friends, neighbours or members of the clergy — indicates that 53 per cent receive a visit from one person or more a number of times each week which may be regarded as a very high level of contact. A further third enjoy a high level of contact in that they have a visit from at least one person once a week. Among a small group of carers (9%) the level of contact is low with someone paying a call just once a month or less (Table 8.2).

Table 8.2: Overall level of contact with different social network members

Level of Contact	Number	Percentage
Very High Level	105	52.5
High Level	65	32.5
Medium Level	13	6.5
Low Level	17	8.5
Total (N)	200	

Carer's Access to Means of Contact

Given the nature of the caregiving task it would seem important that the carer has access to a telephone. Yet less than half of the carers studied (46%) actually own a telephone and among those who do not have one installed many (20%) have to travel between a quarter of a mile to 2 miles, or even further (7%), to reach one.

Among almost a third of the carers (32%) there is no car in the household and where there is a car it is more usually the property of another household member (66%) rather than of the carer (31%). Many carers find public transport in their area either very poor (25%) or poor (23%).

PRACTICAL HELP GIVEN BY SOCIAL NETWORK MEMBERS

Just over half of the carers (52%) receive any practical help from someone outside the home including family, friends or neighbours. A smaller percentage (32%) receive back-up assistance from a second helper while a minority (17%) have help from a third person. Friends and neighbours are the most likely to give assistance (27%), followed by brothers and sisters (26%) and then children (23%) (Table A8.18). The kind of practical support offered through the carer's informal support network varies greatly. The two tasks most likely to be carried out are shopping (32%) and supervising the elderly person while the carer is out (29%) (Table 8.3). Little help is given with personal tasks such as washing or bathing (2 helpers) or dressing the elderly person (1 helper).

Table 8.3: Main activity which helper carries out (Q.55)

Kind of Help	Helper						Total %	
	1st	2nd	3rd	4th	5th	6th		
Shopping	45	14	7	1	0	1	68	32.4
Cooking	6	4	1	0	0	0	11	5.2
Laundry	2	2	0	0	0	0	4	1.9
Making Fires	3	1	0	1	0	0	5	2.4
Collecting Fuel	2	0	0	0	0	0	2	0.9
Bringing in Fuel	3	4	1	0	0	0	8	3.8
Gardening	2	1	0	1	0	0	4	1.9
Cleaning	1	4	2	0	0	0	7	3.3
Decoration	1	4	3	0	0	0	8	3.8
Household Repairs	1	0	2	0	0	0	3	1.4
Looking after Elderly Person	25	21	12	1	2	0	61	29.0
Bathing/Washing Elderly Person	2	0	0	0	0	0	2	0.9
Lifting/Helping Elderly Person	2	0	0	0	0	0	2	0.9
Dressing Elderly Person	1	0	0	0	0	0	1	0.5
Taking Elderly Person Out for A Walk	6	5	4	2	0	0	17	8.1
Other	2	3	2	0	0	0	7	3.3
Total (N)	104	63	34	6	2	1	210	

The great majority of the helpers (82%) provide assistance with more than one task. Compared to the primary help given, there is less consistency among helpers in the second task carried out. Four activities account for half of the assistance provided by helpers: bringing the

elderly person for a walk or drive (17%), looking after the elderly person while the carer is out (15%), cooking (11%), and cleaning (8%). Apart from these 4 tasks, the kind of assistance given varies greatly among helpers (Table A8.19).

Where practical help is given it is likely to be regular rather than intermittent with the majority of those involved (69%) helping out at least once per week. Typically, a visit from a helper lasts 1 to 2 hours (56%) with 32 per cent staying for 3 to 4 hours (Table A8.20). It is of note that, over time, most helpers (68%) have increased the amount of assistance they give (Table A8.21).

Support in Dealing with Common Problems

As part of the investigation of the kind of assistance that family, friends and neighbours provide, the carers were presented with a list of 6 different common problems and were asked to indicate to whom, if anyone, they would turn should they experience any of these problems. The kind of problems investigated include the carer becoming ill, needing advice about financial matters, needing to borrow different things, needing a lift or needing someone to talk to about different matters. With 4 of these 6 common problems, the person most likely to provide the needed support is a spouse (Table 8.4). Where the carer needs a lift or needs to borrow something, s/he is most likely to turn to a friend or neighbour. Neighbours and friends also play an important role when the carer is feeling down and needs someone to talk to. Many carers look to brothers and sisters and other relatives (44%) if feeling ill and unable to leave the house. Sizeable numbers have nobody to turn to for help with 3 of the 6 problems investigated: needing financial advice (22%), needing to borrow something (17%) and being worried about a personal problem (16%).

For the purposes of the present study, a carer who has someone to depend on in the case of each of the common problems described is considered to have a very high level of support. Using this criterion, it emerges that the majority of carers (64%) may be regarded as getting a very high degree of support from family, friends and neighbours. A further 16 per cent have a high level of support having someone to call on in the case of 5 of the 6 problems. Among 3 per cent of carers the level of support is low, these people having no-one to depend on except

Table 8.4: Person who helps with different common problems (Q.62)

Problem	Person To Whom Carer Would Turn											
	Spouse		Parent		Brother/ Sister		Other Relative		Friend/ Neighbour		Other	
	N	%	N	%	N	%	N	%	N	%	N	%
If Ill and Couldn't Leave Home	67	33.7	2	1.0	32	16.1	56	28.1	31	15.6	8	4.0
If Advice Needed											3	1.5
About Money	83	42.3	4	2.0	26	13.3	23	11.7	6	3.1	11	5.6
If Worried About											43	21.9
Personal Problem	69	34.8	5	2.5	28	14.1	29	14.6	22	11.1	14	7.1
If Feeling Down and											31	15.7
Needing Someone to Talk to												
If Needing Lift											4	2.0
Somewhere	57	25.8	2	1.0	16	8.2	39	20.1	65	33.5	4	2.1
If Needing to Borrow	50	2.0	2	1.0	9	4.5	23	11.6	127	64.1	0	0.0
Food, Tool, etc											33	16.7

Non-respondents and carers for whom questions are non-applicable excluded

in the case of 1 or 2 difficulties (Table 8.5). In two cases the carer has no-one s/he can turn to for help with any of the problems described.

Table: 8.5 Level of informal support with common problems

Level of Support	Number	Percentage
Very High Level	122	64.2
High Level	30	15.8
Medium Level	30	15.8
Low Level	6	3.2
No Support	2	1.1
Total (N)	190	

Support in Dealing with Crisis Situations

In addition to help received with common problems, carers were asked if they had people whom they could depend on in times of more serious difficulty. The kind of difficulty or crisis investigated included needing the loan of a car or a sizeable amount of money, needing somewhere to stay for an indefinite period of time, needing someone to look after children for a few days or needing to be collected at the airport late at night.

In the case of each type of crisis situation, many carers have nobody to turn to for help (Table 8.6); this being particularly evident in the case both of needing a loan of money (65%) and needing to be put up for an indefinite period (40%).

Consideration of level of support across the different crisis situations, reveals that 46 per cent of carers receive a very high level of support in that they have someone to call on in the case of each one of the difficulties investigated (Table A8.22). A further 27 per cent may be considered to have a high level of support having someone to depend on in 4 of the 5 crisis situations described. However, there is a group of carers (12%) who have a low level of support, there being only one situation where they can call on someone for help.

EMOTIONAL SUPPORT PROVIDED THROUGH INFORMAL NETWORK

With respect to the emotional or psychological support provided by family, friends and neighbours, the following dimensions were investigated: the degree of similarity of values and ideals between the carer and members of the support network, the extent of concern and trust existing between them and the amount of interaction desired by the carer.

Table 8.6: Person who helps in different crisis situations

Problem	Person To Whom Carer Would Turn											
	Spouse		Parent		Brother/ Sister		Other Relative		Friend/ Neighbour		Other	
	N	%	N	%	N	%	N	%	N	%	N	%
Needing the Loan of a Car	40	27.6	2	1.4	20	13.8	19	13.1	26	17.6	2	1.4
Needing Loan of Sizeable Amount of Money	21	11.3	3	1.6	19	10.2	9	4.8	7	3.8	7	3.8
Needing to be Put Up for an Indefinite Period	3	2.8	4	3.7	25	23.4	13	12.1	13	12.1	6	5.6
Needing Someone to Mind Children for A Few Days	4	5.1	5	6.3	26	32.9	9	11.4	19	24.1	0	0.0
Needing to be Collected at the Airport Late at Night	41	27.5	2	1.3	40	26.8	22	14.8	23	15.4	3	2.0
											18	12.1
												149

Spouses emerge as the most important source of emotional support followed by friends and neighbours. For example, where sharing of values and ideas is concerned, it is spouses who are most likely to have similar ideals (50%) and philosophies (53%), who share interests (49%) and who enjoy the same kinds of books, music (44%) and entertainment (52%) as the carer (Table A8.23). Most carers (78%) may be regarded as having a very high level of support with respect to sharing of values and interests in that they have someone with whom they share in all the situations explored (Table 8.7). There are, however, some carers (6%) who have no support at all in this area.

As with value-sharing, the person for whom the carer is most likely to feel concern is a spouse: more carers worry about spouses (38%) and remember spouses' birthdays (46%) than they do in relation to any other relatives or friends. Brothers and sisters are the most frequently nominated with respect to aspects of concern involving visits when sick (23%) or giving lifts (22%) (Table A8.24). The majority of carers (60%) are able to identify someone for whom they feel concern in each of 4 areas investigated, which suggests a very high level of support.

By comparison with aspects of emotional support related to value-sharing and concern, the level of support in relation to trust is much lower among the carers studied. Less than half (46%) could nominate someone they trust in all of 4 situations explored while 9 per cent had nobody to support them in any of the situations investigated (Table 8.7). It is noteworthy that 18 per cent of carers have nobody to share with if upset, 15 per cent have no-one to talk to about confidential matters, 24 per cent have no-one to trust with a psychological problem and 55 per cent would not trust anybody to talk about a sexual problem (Table A8.25). Where the carer does have someone to trust, the person most frequently mentioned is a spouse (33%) followed by friends and neighbours (13%) and brothers and sisters (11%).

The majority of carers (66%) appear to have a high level of support with respect to desired interaction (Table 8.7) although approximately a quarter of the carers indicate that there is nobody whom they would like to see more often or spend more time with (Table A8.26).

OVERALL EXTENT OF SUPPORT PROVIDED THROUGH INFORMAL SOCIAL NETWORK

The level of practical support provided by family, friends and neighbours has been described above as being very high, high, medium or low

Table 8.7: Overall level of emotional support in various areas

Area of support	Level of Support										Total
	Very High		High		Medium		Low		No Support		
	N	%	N	%	N	%	N	%	N	%	
Value-Sharing	123	77.8	13	8.2	12	7.6	1	0.6	9	5.7	158
Concern	112	59.3	47	24.9	14	7.4	10	5.3	6	3.2	189
Trust	76	45.5	49	29.3	16	9.6	11	6.6	15	9.0	167
Desired Interaction	0	0.0	121	65.8	32	17.4	16	8.7	15	8.2	184
Non-respondents excluded											

according to whether or not the carer has someone to count on in relation to a number of common problems and in relation to a number of more serious practical difficulties. Emotional support has been described in similar terms according to whether or not the person has someone to count on in relation to a number of different situations involving trust, concern, value-sharing and desired interaction. For the purposes of the present study, the overall extent of support available to the carer through her/his informal social network is determined by examining the degree of help which the carer receives across each of the practical and emotional areas described. Whether or not the carer's circle of friends has changed with becoming a carer is also included in the determination of overall extent of informal support (22% have decreased and 78% have increased or not changed their circle of friends). The great majority of carers (87%) may be regarded as receiving a very high overall level of support in that in one or more of the 7 areas explored they are receiving this degree of assistance. A further 12 per cent may be said to enjoy a high overall level of emotional support. Just one person may be considered to have low support, overall, from family, friends and neighbours (Table 8.8). It should be noted, however, that according to this global measure, a carer may be regarded as having a very high overall level of support but yet may be experiencing this level of help in just one of the 7 areas investigated and may even be lacking support in some areas.

Table 8.8: Overall extent of informal support

Level of Support	Number	Percentage
Very High Level	174	87.0
High Level	23	11.5
Medium Level	2	1.0
Low Level	1	0.5
Total (N)	200	

SUMMARY

Social Contact: Family

Family members play an important role in the carer's social support network: overall 65 per cent of carers may be regarded as having high levels of contact with others in their immediate family. Of all immediate family members, adult children visit most frequently. Among carers with children (40%) almost three-quarters (73%) have at least a weekly visit

from one child or more. Most carers (81%) have brothers or sisters in their social network but these particular family members visit less frequently than do children with weekly visits occurring among 37 per cent of the carers. A smaller number of carers (28%) have grandchildren but, among those who do, the level of contact is typically high with visits occurring at least weekly among 69 per cent. Parents (14%) or parents-in-law (12%) figure infrequently in the support networks of the carers. Among all family members the extent of contact with the carer is very much influenced by geographical distance: those who visit rarely are most likely to be living over 50 miles away while those who visit most frequently live within 15 miles of the carer.

Social Contact: Friends and Neighbours

Apart from immediate family, many carers (56%) enjoy a high level of contact with relatives and friends having a visit from at least one person once a week or more. It is noteworthy, however, that among over a third of the carers (35%) calls from a relative or friend occur once a month or less. Neighbours, too, are an important source of contact among many carers (56%) but there are also carers who see those living close by only infrequently (21%) or never (8%).

Overall Social Contact

Taking account of all the different people in the carer's social network it appears that 53 per cent of the carers have a very high overall level of social contact in the sense that they receive a visit from at least one person a number of times each week. Among a further third the level of social contact may be regarded as being high with at least one person calling every week. Some carers (9%), however, have a visit from someone just once a month or less.

Visiting patterns have mostly remained unchanged since the carer began looking after the elderly person. Where changes have taken place, visits are more likely to have increased rather than decreased; this being particularly so in the case of relatives outside of immediate family and friends, with 35 per cent of this group now visiting more frequently than they had been used to doing.

Access to Telephone

Many carers seem to have little access to means of contact with others. Less than half (46%) have a telephone in the house and among those

without one 27 per cent have to travel distances of between a quarter of a mile to 2 miles to make a call. Among almost a third of carers (32%) there is no car in the household and public transport is often found to be very poor (25%) or poor (23%).

Help with Caregiving: Practical Support

While most carers (85%) may have at least one person calling to the home each week, such visits do not necessarily relieve the demands of caregiving. Indeed, almost half of the carers (48%) receive no practical help with caregiving from family, friends or neighbours outside the home. Where help is given, the main tasks most likely to be carried out are shopping and supervising the elderly person while the carer is out. Help with more difficult tasks such as washing or dressing the elderly person is rarely or never given. Friends and neighbours are the most likely to give help with caregiving followed by brothers and sisters and then children. Most carers (80%) feel they could call on someone in their social network if they needed help with common problems such as needing a lift, needing to borrow something or needing to ask advice or to talk to someone. However, there are many who have no one to turn to for help where more serious difficulties are involved such as needing the loan of a sizeable amount of money (65%) or needing a place to stay for some time (40%).

Help with Caregiving: Emotional Support

Where emotional support is concerned, most carers (86%) have someone — usually a spouse — with whom they share interests, ideals, values and preferences in entertainment. A lesser number of carers (59%) have someone with whom they share concern as expressed in visiting when ill or remembering birthdays. A striking finding is that less than half of the carers (46%) could nominate someone they trust in all of 4 situations explored and some (9%) had nobody to support them in any of the situations involving trust investigated.

Overall Level of Support

Consideration of the degree of help which the carer receives across different practical and emotional areas suggests that, overall, most carers have a very high (87%) or high (12%) level of support from family,

friends and neighbours. This overall measure, however, categorises a carer as having high support if s/he receives this level of help in any one of a number of different areas investigated and s/he may well be lacking help in some particular areas.

The overall picture which emerges is that while frequency of contact with social network members is high, practical help in carrying out the day-to-day tasks of caregiving is not widely available to carers.

CHAPTER NINE

Carers and Statutory and Voluntary Support Networks

Introduction

Family, friends and neighbours can be an important source of support to carers in coping with the stresses and demands of caregiving. A genuine community of caring implies, however, that any help given by family, friends and neighbours is backed-up by the provision of formal support from statutory bodies in the form of services. The carer's informal social support network may provide practical and emotional help but carers also need professional expertise and assistance which such sources cannot provide. What service support do the carers of the present study receive? What are the carers' perceptions of these services?: and what impact do they have on the experience of caregiving? This chapter outlines the extent and frequency of provision of services and examines their effectiveness and usefulness.

SERVICES AVAILABLE TO THE CARER

Domiciliary Services

While domiciliary care may cover several types of service, two of these services, namely the home-help service and the meals-on-wheels service, are investigated here. These two services are a potential source of significant support to the carer since the domestic tasks which they carry out are those which the carer normally has to perform. By relieving the carers of these routine tasks they could be freed either to spend time with the elderly person in a more leisurely way or to devote time to their own lives. Despite their obvious relevance to the day-to-day demands on carers, the provision of domiciliary services is practically non-existent for the carers in the present study. In the 6 months prior to interview, just 2 elderly persons had the home-help service and one person had

received the meals-on-wheels service. According to the 3 carers involved, these services do make the job of caregiving easier.

Medical and Related Services

The only formal service widely available to the elderly and their carers is that of the G.P.. Eighty per cent of the elderly had had the services of their G.P. in the 6 months prior to interview. Visits from the G.P. typically were less than once a fortnight (81%). Carers with experience of the G.P. service find it satisfactory: most believe that visits are frequent enough (91%) and long enough (87%). With few exceptions, the elderly people (87%) accept the help of their G.P.'s quite readily and, from the carer's point of view (85%), their visits make caring easier.

Public health nurses who, potentially, could provide much support to carers, in practice play a far less important role than do G.P.'s. In the 6 months prior to interview, less than half of the elderly (47%) had had a visit from a public health nurse and, among these, visits were typically less than once a fortnight (63%). The significance of the support which this service could provide is evident from the finding that 96 per cent of those carers who had experience of the service found that visits from the public health nurse greatly relieved the burden of caregiving. Where the service is provided, it is viewed by most carers concerned (85%) as being satisfactory: visits are typically viewed as being frequent enough (71%) and long enough (79%).

Only a small group of the elderly (11%) had received the services of a chiropodist. Where such a service is provided it appears to be very satisfactory: visits are seen by all carers concerned as being long enough and are regarded as occurring frequently enough by most (91%). The elderly people accept the chiropodist's help quite willingly (96%) and her/his visits make caregiving easier for practically all carers (96%).

Just one elderly person had received the services of a social worker or occupational therapist in the 6 months prior to interview. The visits, in this case, were less often than once a fortnight, and were unsatisfactory in the view of the carer with visits being neither often enough or long enough. Again, only in isolated instances had an elderly person received a visit from health board or local authority personnel. Visits in both cases were seen as a help by the carer in question.

Services of Private or Voluntary Bodies

Compared to other services, a large number of carers (67%) have had visits from members of the clergy. Typically (80%), visits are less than

once a fortnight but in the view of the majority who experienced them they are frequent enough (86%) and long enough (89%) to be satisfactory. The support given by clergy is clear from the fact that, for most (80%), their visits from clergy help ease the life of the carer.

Support groups, by providing opportunities for sharing of experiences and information and for ventilation of feelings and frustrations, would seem to have an important role in alleviating some of the stresses of caregiving. Despite the potential of support groups, in the present study just one carer is involved with such a group.

Three carers receive the help of a private nurse or private household help. In one of the cases, the help is provided weekly while in the other cases help is given less than once a fortnight. All 3 carers concerned are satisfied with the frequency and duration of visits from these services and find that their help makes their lives easier.

Overall Level of Provision of Services

One measure of the level of formal service support available to carers may be derived from the overall number of service-providers who visit the household including personnel from domiciliary services and medical and related services, health board and local authority personnel and personnel of private or voluntary bodies. For the purposes of the present study, provision of at least 10 of the 12 services discussed in detail above is taken to represent a very high level of formal support. Provision of 7 to 9 services represents a high level of support and provision of 4 to 6 represents a medium level. Where less than 4 services are provided the carer is considered to have a low level of support. When level of support is determined in this fashion, it emerges that most carers (80%) receive a low level of formal support and for some (11%) there is no help whatsoever from any service-provider (Table 9.1).

Table 9.1: Level of formal support: Number of service* received

Level of Support	Number	Percentage
Very High Level: 10 to 12 Services	—	—
High Level: 7 to 9 Services	—	—
Medium Level: 4 to 6 Services	16	8.8
Low Level: Less than 4 Services	145	80.1
No Support: No Service	20	11.0
Total (N)	181	

Non-respondents excluded.

Receipt of Help Requested from Social Services

Generally, only small numbers of carers have requested specific kinds of help from the social services (Table 9.2). For example, just 5 have asked for assistance with laundry despite the high proportion of the elderly who are incontinent of urine (24%) or faeces (209c). The request most frequently made is for mobility aids (23%) and commodes (21%). With one exception, in the majority of cases where the carer does request help, that help is provided (Table 9.2). This is particularly true where the request involves some material object such as a commode (90%) or bed-rest (94%) or mobility aid (96%) rather than a personal service such as nursing help (84%) or assistance with laundry (80%). It is noteworthy, however, that of the 10 carers requesting home-help, only 3 actually received that service.

Table 9.2: Receipt of different kinds of help requested from social services (Q.72)

Type of Help	Requested Help				Received Help*	
	Yes		No		Yes	
	N	%	N	%	N	%
Home Help	10	5.0	190	95.0	3	30.0
Nursing Help	25	12.5	175	87.5	21	84.0
Mobility Aids	45	22.6	154	77.4	43	95.6
Commode	41	20.6	158	79.4	37	90.2
Bed Rest/Bed Chair	17	8.5	182	91.5	16	94.1
Assistance With Laundry	5	2.5	195	97.5	4	80.0

* Percentages based on those who had requested help
Non-respondents excluded

RECEIPT OF ADVICE FROM DIFFERENT SOURCES

Eighty-four per cent of the elderly persons being cared-for at home suffer some physical disability or other. This would seem to indicate a need among carers for advice on how to provide proper care and for medical support in providing that care. In addition to physical disabilities, approximately 15 per cent of the elderly persons are suffering symptoms of dementia such as memory loss, confusion, angry outbursts and sleep disruption. At least a further 24 per cent are suffering these symptoms occasionally. Carers need to know about the symptoms of dementia,

about the progress of the disease and about the best means of dealing with the elderly person's behaviour. It would seem then that the carers require professional advice and support to enable them to provide the best possible care for the elderly people they look after.

Provision of Advice by Service Personnel

The findings of the present study show that the only source of advice anyway widely available to carers is that of the G.P. (61%). Just half of the carers have had advice from public health nurses — professionals who potentially have a very important role in this area. Less than 20 per cent of carers receive advice in caring for the elderly from specialists such as opticians (14%), physiotherapists (16%) or chiropodists (17%). The social worker might be expected to be an important source of advice yet only a very small group of carers (5%) have received advice from this quarter (Table 9.3).

Advice from G.P.'s is generally considered by the carers who have received it to be 'very helpful' (56%) or 'helpful' (28%) (Table 9.3). Advice from public health nurses, though not as highly regarded as that of the G.P., is also usually considered by those who have experienced it to be 'very helpful' (41%) or 'helpful' (37%). However, some (13%) find the nurse's advice to be of little (9%) or no help (4%).

In comparison to G.P.'s and public health nurses, the advice received from specialist services such as opticians, physiotherapists and chiropodists is less highly regarded by the minority of carers who have actually experienced it. Advice from these sources typically is rated as 'helpful' rather than 'very helpful'. In the case both of opticians and physiotherapists there are substantial percentages for whom the advice is of little or no help (30% and 23% for opticians and physiotherapists respectively).

Receipt and Usefulness of Advice from Sources Other than Service Personnel

Apart from the different service personnel, some carers receive advice from relatives (42%) and friends (37%); advice which is almost always seen as being helpful (80%). A smaller number (21%) turn to books or television or radio for advice. While the information obtained from these sources is helpful for some (56%), for a substantial percentage (15%) it is of little or no help.

Table 9.3: Receipt and usefulness of advice from different service-personnel (Q.31)

Service Personnel	Usefulness of Advice											
	Very Helpful		Helpful		Satisfactory		Not Very Helpful		Of No Help		Total	
	N	%	N	%	N	%	N	%	N	%	N	%
G.P.	68	55.7	34	27.9	11	9.0	6	4.9	3	2.5	122	
Public Health Nurse	41	41.0	37	37.0	9	9.0	9	9.0	4	4.0	100	
Private Nurse	0	0.0	3	60.0	1	20.0	0	0.0	1	20.0	5	
Optician	8	29.7	10	37.0	1	3.7	6	22.2	2	7.4	27	
Ear Specialists	2	22.2	2	22.2	1	11.1	3	33.3	1	11.1	9	
Physiotherapist	2	6.5	17	54.8	5	16.1	5	16.1	2	6.5	31	
Chiropodist	12	35.3	11	32.4	8	23.5	2	5.9	1	2.9	34	
Occupational Therapist	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	
Social Worker	1	11.1	2	22.2	3	33.3	1	11.1	2	22.2	9	
Support Group	1	33.3	0	0.0	1	33.3	0	0.0	1	33.3	3	

Based on those who received advice.

Overall Level of Provision of Advice

The overall level of provision of advice from different sources including health professionals, support groups, friends and the media, may be taken as a second measure of the level of formal support available to carers. For the purposes of the present study, provision of advice from at least 12 of 14 different potentially useful sources is taken to represent a very high level of support. These sources are as follows: G.P., public health or private nurse, optician, ear specialist, physiotherapist, chiroprapist, occupational therapist, social worker, relatives, friends or neighbours, books, television or radio, support groups. Advice from 8 to 11 of these sources represents a high level and 4 to 7 represents a medium level of support. Where advice is received from less than 4 sources the carer is considered to have a low level of support. When level of support is determined in this fashion, it emerges that for almost half (45%) of the carers the level of support is low and for over a quarter (27%) there is no support at all in the form of provision of advice (Table 9.4).

Table 9.4: Level of formal support: Provision of advice

Level of Support	Number	Percentage
Very High Level: 12 to 14 Sources	—	—
High Level: 8 to 11 Sources	1	0.9
Medium Level: 4 to 7 Sources	27	23.9
Low Level: Less Than 4 Sources	54	47.8
No Support: No Source	31	27.4
Total (N)	113	

Non-respondents excluded

Carers' Perceptions of Provision of Advice

Given the low level of support in terms of provision of advice revealed above, it is not surprising that 56 per cent of carers indicate that their need for advice and information is not being addressed. Among those who feel that their need for advice is not being met, the vast majority (86%) believe that providing this service is the responsibility of the health boards (Table 9.5).

Table 9.5: Who should cater for need for advice/information (Q.117)

Service Provider	Number	Percentage
Government Grants	7	6.3
Health Boards	96	85.7
Support Groups	3	2.7
Voluntary Groups	4	3.6
Other	2	1.7
Total (N)	112	

Non-respondents and those for whom question is not applicable excluded

OVERALL LEVEL OF FORMAL SUPPORT

When provision of services and receipt of advice are taken together as an indicator of overall level of formal support, it appears that formal assistance to carers is typically minimal. Twenty-three per cent may be said to have a medium level of support . receiving the help of 4 services and getting advice from 4 sources, but for the majority (69%) formal support is low (Table 9.6). Eight per cent of carers receive no formal support at all.

Table 9.6: Overall level of formal support

Level of Support	Number	Percentage
High Level	1	0.5
Medium Level	42	22.6
Low Level	128	68.8
No Support	15	8.1
Total (N)	186	

Non-respondents excluded

CARERS' EXPERIENCES OF SERVICES

Apart from the practical effectiveness of the different services provided, the attitude of the personnel carrying through the services and their supportiveness and caring might be expected to influence the lives of the carers. As indicated above, apart from the G.P., the public health nurse and members of the clergy, most services are reaching only a tiny percentage of carers. With respect to the 3 services reaching more than a minority, the personnel involved are experienced by most carers as being supportive and caring (Table 9.7). This is particularly true in the case of G.P.'s and clergy where over half the carers who have experienced their services give them the highest rating of 'very supportive and caring' with a further third regarding them as 'supportive and caring'. The G.P., in fact, was nominated by 74 per cent of carers as being the key person who provides help with the job of caregiving. Public health nurses are not quite as highly regarded: carers who have received their services are more likely to regard them as 'supportive and caring' (47%) rather than giving them the highest rating (40%) and less than a quarter (23%) nominated them as providing the most useful service to caregivers.

Given the small amount of assistance provided both in terms of practical help and in terms of advice, it is not surprising that many carers (43%)

Table 9.7: Attitude of various service personnel to carer's situation (Q.73a)

Professional	Attitude					Total (N)
	Very Supportive and (Daring	Supportive and Caring	Unsupportive and Uncaring	Very Unsupportive and Uncaring		
G.P.	104	55.9	62	33.3	15	186
Public Health Nurse	49	39.8	58	47.2	11	123
Home Help	1	25.0	2	50.0	1	4
Social Worker/Occupational Therapist	2	40.0	3	60.0	0	5
Health Board	2	8.0	14	56.0	7	25
Local Authority	0	0.0	8	72.7	3	11
Meals-on-wheels	0	0.0	1	100.0	0	1
Support Group	3	75.0	0	0.0	0	4
Priest/Clergyman	72	52.9	47	34.6	14	136
Chiropodist	10	26.3	22	57.9	4	38
Private Nurse	1	33.3	1	33.3	1	3
Private Household Help	0	0.0	1	50.0	1	2

Non-respondents and those with no experience of the service in question are excluded

find the level of formal service support unsatisfactory for one reason or another (Table 9.8).

Table 9.8: Carers' perceptions of services (Q.74)

Perception	Number	Percentage
Co-Ordination of Services Unsatisfactory	26	24.8
Services Bad	10	9.5
None/Very Few Services Available	5	4.8
Good Experience of Services	32	30.4
Services Co-Ordinated	26	24.8
Services Fair/O.K.	4	3.8
No Services Requested	2	1.9
Total (N)	105	

Non-respondents or carers for whom question is not applicable are excluded

SUMMARY

Services Available to the Carer

While some degree of practical and emotional support is being received by carers through informal sources, little or no help is being given by formal service providers. Domiciliary services such as home-help and meals-on-wheels, which would provide the caregiver with some practical assistance, are virtually non-existent, being received by just 3 of the elderly. The only service which is widely available to the elderly and their carers is that of the G. P. (80%). This service is viewed as satisfactory by most carers and is regarded as greatly relieving the burden of caregiving. The G.P. is seen as being supportive and caring (89%) and in fact is nominated by 74 per cent of carers as being the key person who provides help with the job of caregiving. The only other service anyway widely used by carers is that of the public health nurse, but the fact that less than half (47%) of the carers have this service suggests that this potential source of support and help is very much under-exploited. Those carers who have had visits from a public health nurse find the service satisfactory (85%) and almost without exception (96%) see these visits as easing the burden of caregiving. The services of a chiropodist have been received only by a small group (11%) and in only isolated instances have there been visits from an occupational therapist, social worker or health board or local authority personnel. Likewise just one carer is involved in a support group.

The overall level of service-provision is low among the great majority of carers (80%): these carers receiving less than 4 of 12 potentially useful

services including doctors, public health nurses, social workers and health board and local authority personnel.

Small numbers of carers have requested specific kinds of help from the social services but where they have done so the majority have had their request granted. It is striking, however, that of 10 carers requesting home-help only 3 have actually received this service.

Receiving Advice

The provision of advice would seem to be an important aspect of support for carers who are looking after elderly people who typically have some physical disability (84%) and many of whom suffer symptoms of dementia constantly (15%) or occasionally (24%). However, the overall level of provision of advice is low among almost half of the carers (48%); these people receiving advice from less than 4 of 14 potentially useful sources. It is noteworthy that over a quarter of carers (27%) receive no advice whatsoever. Where carers receive any advice from professionals, most usually it is the G.P. who does so (61%) followed by the public health nurse (50%). Less than 20 per cent receive advice from specialists such as opticians, physiotherapists or chiropodists. Only 5 per cent have had advice from a social worker. Not surprisingly, over half of the carers (56%) indicate that their need for advice and information is not being addressed.

Overall Level of Formal Support

When provision of services and receipt of advice are taken together as an indicator of overall level of formal support, it emerges that the majority of carers (69%) receive a low level of formal support and a further 8 per cent receive no formal support of any degree. Given the small amount of assistance provided both in terms of practical help and in terms of advice, it is not surprising that many carers (43%) find the level of formal service provision unsatisfactory.

CHAPTER TEN

The Costs of Caring

While for many carers there may be emotional rewards in caregiving which outweigh the difficulties and disadvantages involved, there is no doubt that caring can often exact a heavy cost for the carer. Of course, those who care for the elderly do not form a homogeneous group and their experiences of caring are influenced by the level of care demanded, by their own attitudes and temperament and those of the elderly person, by their particular circumstances and the help and support available to them. However, it has been shown many times that looking after an elderly person can affect the physical and emotional health of the carer. It may affect the carer's social and family life and it may have serious financial consequences. What impact does caring have on the lives of the carers of the present study? The purpose of this chapter is to explore the costs of caring in different areas of the carer's life: social, emotional, physical, family and financial.

FINANCIAL COSTS OF CARING

One of the most basic costs of caring, yet one which is frequently overlooked, is the financial cost to the carer. Financial cost may be incurred essentially in two ways. First, the carer may feel obliged or may have no choice but to give up paid employment in order to provide the necessary care. Secondly, there may be extra expense involved in providing for the special needs of the elderly person; expenses such as extra heating costs, providing special diets and managing incontinence. Such expenses can put enormous pressure on carers particularly where no State assistance is available and where there is low income. Moreover, financial burden is often linked to other kinds of strain. For example, if a carer is experiencing financial strain then it becomes impossible for her/him to pay for such services as home-help or respite care which could alleviate other pressures in the carer's life.

Restriction of Employment Opportunities

In the present study, although 77 per cent of the carers are within the normal working age-range, only a minority (16%) are in paid employment with male carers (45%) more likely than female carers (10%) to work outside the home (see Chapter Five). The impact of caring in relation to work is reflected in the fact that, among women, while marriage and child-rearing are the prime reasons for giving up paid employment (72%), the second most important reason for leaving work is to take up the role of caregiver (17%). Among the male carers who are no longer in paid employment, 38 per cent have given up work specifically in order to become carers. A further indication of restriction of employment opportunities is the fact that 28 per cent of the carers say they would like to be in paid employment if they did not have to provide care. In addition, among the small number of carers who do work, caring has had an impact in that 43 per cent have been forced to take time off because of demands of caring. Because of such demands, some of those who work (16%) believe that caring restricts them in terms of career development.

Extra Expense Involved in Caring

Apart from its effects on the carer's employment situation, there are some indications in the present study that caring is also financially costly in terms of extra expenses incurred. For example, 17 per cent have had to have adaptations to the home to accommodate the elderly person but in only 5 per cent of cases was State assistance given to cover the costs. Again, almost one in 5 of the elderly persons (19%) are not financially independent which means that they have to be supported by their carers.

The findings show, however, that whether or not caring is experienced as having an adverse financial impact is influenced by the carers' own personal perceptions of the costs of caring and by the extent to which they receive financial assistance from different sources. Thus, while there are indications of restriction of employment opportunities and of extra expense, just 10 per cent of the carers of the present study say they experience caring as a financial burden.

Caring for an elderly person who is a spouse or parent is less likely to be experienced as financially burdensome than is care of other relatives or friends (Table A10.1). Those carers who are least likely to find caring a financial burden are single people (Table A 10.2): perhaps because they do not have dependent spouses or children for whom they would

also have to care. Only a very small minority of carers (6%) receive financial help from relatives but where such help is given carers rarely experience financial burden (Table A10.3). Most of the elderly people themselves (93%) do, in fact, contribute towards the cost of caring. That these contributions can have a significant impact is implied in the fact that in only 8 per cent of cases where they do occur, is the elderly person perceived as a financial burden compared to 46 per cent of cases where they do not occur (Table A 10.4).

SOCIAL COSTS OF CARING

Because of physical immobility or ill-health or confusion, many of the elderly cared-for at home cannot be left alone for any significant length of time. Accordingly, carers often find themselves being housebound except for short, essential outings. In the light of such circumstances it is not surprising that caring has often been found to have a major impact with respect to free time for oneself, opportunities to socialise with friends, opportunities to take holidays, to have leisure pursuits and to run one's own home.

Participation in Social Activities

In the present study, 59 per cent of the carers find the demands of caregiving restrictive of their social lives to a greater (20%) or lesser extent (39%) (Table 10.1).

Table 10.1: Whether caring places constraints on social life (Q.88)

Response	Number	Percentage
A Lot	40	20.0
Some	77	38.5
Hardly Any	39	19.5
None	44	22.0
Total (N)	200	

Consideration of overall patterns of participation in social activities reveals that most carers rarely or never get involved in clubs or societies (84%) or go to evening classes (90%) or to the cinema (79%) or to a play or a show (69%). A small percentage (15%) do go out for a drink or a meal each week with a further 15 per cent doing so once a month (Table 10.2).

Table 10.2: Rate of participation in social activities (Q.90a)

Rate of Participation	Social Activity							
	Evening Classes		Cinema		Play/Show/ Concert		Going for a Meal/Drink	
	N	%	N	%	N	%	N	%
At least once per week	5	2.5	2	1.0	1	0.5	30	15.0
At least once a month	1	0.5	3	1.5	5	2.5	30	15.0
Less than 12 times per year	1	0.5	7	3.5	9	4.5	12	6.0
Rarely	13	6.5	30	15.0	48	24.0	56	28.0
Never	180	90.0	158	79.0	137	68.5	72	36.0
Total (N)	200		200		200		200	

While in the majority of cases participation in social activities has remained unchanged with becoming a carer, the social costs of caring are evident from the fact that over a third (37%) now go out for a meal or a drink less frequently than they had been used to while others go less frequently to a show or concert (24%) or to a film (18%) (Table 10.3).

Table 10.3: Changes in participation in social activities (Q.90b)

Change in Participation	Social Activity							
	Evening Classes		Cinema		Play/Show/ Concert		Going for a Meal/Drink	
	N	%	N	%	N	%	N	%
Increased	2	1.2	2	1.2	1	0.6	3	1.6
Decreased	15	8.7	31	17.9	42	23.6	70	37.4
Same	155	90.1	140	80.9	135	75.8	114	61.0
Total (N)	172		173		178		187	

Non-respondents excluded

Pastimes of Carers

The most popular pastimes among the carers all take place within the home. Most (82%) watch television daily and many (57%) read a book or newspaper or magazine every day (Table 10.4). By contrast, just 18 per cent go walking daily. Only a very small group (3%) are ever involved

in sports (Table A10.5) but this may be due to ageing as much as to caregiving. The impact of caring on involvement in pastimes is most evident in relation to outdoor activities with 28 per cent of carers now going for a walk less frequently than they had been used to before becoming caregivers. However, 15 per cent also read less because of caring and 8 per cent watch television less often. On the other hand, the frequency of watching television has increased for 16 per cent of the carers studied (Table A10.6).

Table 10.4: Rate of participation in different pastimes (Q.90a)

Rate of Participation	Pastime					
	Watching TV/Video		Reading		Walking	
	N	%	N	%	N	%
Daily	164	82.0	114	57.0	35	17.9
3 or more times per week	15	7.5	27	13.5	26	13.3
Once or twice per week	4	2.0	34	17.0	17	8.7
1 — 3 times per month	0	0.0	2	1.0	19	9.7
11 times or less per year	0	0.0	2	1.0	6	3.1
Rarely	9	4.5	13	6.5	51	26.0
Never	6	3.0	8	4.0	42	21.4
Does not apply	2	1.0	0	0.0	0	0.0
Total (N)	200		200		196	

Non-respondents excluded

The only kind of outing which carers engage in with any regularity involves shopping. Seventy-six per cent visit the shops or the post office at least once weekly, with 24 per cent doing so on a daily basis (Table A10.7). It is of note that carers are almost as likely to shop more often (14%) as less often (18%) since taking on the job of caregiver.

Visits with Friends and Relations

The one area of social life where there is a relatively high level of participation among carers involves socialising with friends and relations. Fifty per cent of the carers receive weekly visits from friends and relations, with a further 19 per cent having visitors a few times each month. A smaller percentage of carers themselves go out to visit friends and relations each week (24%) or at least a number of times each month (17%). Many (30%), however, rarely or never have opportunities to socialise (Table 10.5).

Table 10.5: Frequency of visits with friends/relations (Q.90a)

Frequency	Visits to Friends/Relations		Visits from Friends/Relations	
	N	%	N	%
At least once per week	48	24.0	99	49.7
More than once per month	33	16.5	38	19.2
Once per month	38	19.0	28	14.1
Less than 12 times per year	21	10.5	12	6.0
Rarely	48	24.0	17	8.5
Never	12	6.0	5	2.5
Total (N)	200		199	

Non-respondent excluded

Caring has had a significant impact on visiting patterns in that 51 per cent of carers visit others less often now than they had been used to. On the other hand, visits from others to the carer have become more frequent in 30 per cent of cases (Table A10.8). In this context, it is noteworthy that among those carers where the elderly person has been institutionalized or is deceased (18%), the one aspect of social life which has changed significantly is visiting patterns: 59 per cent of the carers in question visit friends and relations more frequently now than when they had been looking after the elderly person (Table A 10.9).

Restriction of Free Time

The low rate of participation in social life among carers is not surprising in view of the fact that, apart from a small group (11%), most are confined to the house during the day for some number of hours. Over half (53%) are confined to the house for between 5 and 10 hours and almost a quarter (24%) are confined for periods longer than this (Table A10.10). Some carers (16%) do not have even one night in the week for themselves. In this respect, men seem to be somewhat less constrained than women. Women carers, typically, have one (29%) or 2 nights (22%) free, with 13 per cent being unrestricted in any way. Men, however, usually have 2 (28%) or 3 (14%) nights for themselves and 28 per cent are usually unrestricted in this regard (Table 10.6). When carers do get out, 57 per cent are always limited to time, with a further 22 per cent being sometimes limited.

Table 10.6: Number of nights male and female carers are free to go out (Q.94)

Response	Male		Female		Total	
	N	%	N	%	N	%
0	6	16.7	25	15.2	31	15.5
1	3	8.3	47	28.7	50	25.0
2	10	27.8	36	22.0	46	23.0
3	5	13.9	19	11.6	24	12.0
4	1	2.8	8	4.9	9	4.5
5	0	0.0	4	2.4	4	2.0
6	0	0.0	1	0.6	1	0.5
7	10	27.8	21	12.8	31	15.5
Don't Know	1	2.7	3	1.8	4	2.0
Total (N)	36		164		200	

In many cases (59%), an important factor related to the restriction of the carer's free-time is the fact that the elderly persons being cared-for cannot look after themselves in the carer's absence. Many of the carers (58%) of these elderly people do not have somebody else in the household who could take-over while they are out. Among those carers who have to find a substitute outside the home when they want to go out, almost half (48%) experience difficulty in getting someone to look after the elderly person and this is so whether it's day time (48%) or night time (35%) that is involved (Table A10.11). Not surprisingly, then, 65 per cent of those carers who need to find a substitute carer when going out find that caring is restrictive of their social lives. It is also true, however, that many carers (51%) of elderly people who can look after themselves find that their social lives are constrained by caring (Table A10.12).

When carers do go out socially, caring still has an impact on them in that 39 per cent find that they can never relax and forget about their caring responsibilities while 18 per cent manage to do so only at times. A common worry is that the elderly person will fall ill in the carer's absence (66%). Carers also worry that the elderly person will slip or fall (60%) or that a fire will break out (56%). In addition to their own worries, many carers have the added restriction that the elderly people themselves also worry about what will happen in the carer's absence. Many carers believe that when they are out the elderly person worries about fire (35%), about becoming ill (49%) or about falling (47%).

Social life is restricted for some carers by demands made by the elderly person: demands to know where the carer is going (78%) or demands

that the carer be home at a fixed time (53%) or even demands that the carer stay at home and not go out at all (47%) (Table A10.13).

COSTS TO RELATIONSHIPS

In addition to financial and social costs, a further cost of caring highlighted by research is the adverse affect which caring can have on the carer's relationships with others: not only with the elderly person being cared-for but also with family and friends. As has been described above, caring can radically affect social contact and thus put a halt — even if only temporarily — to many friendships the carer might have. However, research shows that it is often within the carer's family that some of the most severe conflict and tension arises. Children of carers may resent dependent grandparents through, for example, not being able to bring friends home. Spouses and families of carers may often feel neglected. Carers themselves often feel caught between the demands of different roles and can find themselves acting as mediator between the elderly person and their family. Also, resentments can arise when carers believe that other family members are not doing as much as they could or should to help the carer.

With respect to the costs of caring on the personal relationships of the carers of the present study, it is relationships with children which are most frequently adversely affected (21%) (Table A10.14). The fact that many carers (47%) say they have less time for their children because of caring demands may be partly responsible for this effect. Next to children, marital relationships are most affected by caring (16%). By comparison with spouse and children relationships, involvements with brothers and sisters (9%) or parents (6%) less often deteriorate through caregiving strains and demands. Most carers report little or no negative change in relationships with relatives outside of immediate family (4%) or with friends and neighbours (4%).

The greater incidence of negative effects on close family relationships compared to other relations may be due, at least in part, to the fact that carers are more likely to be sharing a home with the former persons. Many carers (42%) say they get short-tempered and snappy which may make living with them difficult and some (24%) have arguments among family members over the carer's role. Moreover, in those cases where the elderly person has moved in with the carer, 20 per cent of the families involved find the presence of an extra adult difficult to handle. It should be noted, however, that despite the existence of negative effects of

caring on family relationships, in the vast majority of cases carers find their families to be supportive of them in their caregiving role (89%). Moreover, 89 per cent find that they can openly express their feelings about caring to family members.

COSTS TO PHYSICAL AND EMOTIONAL WELL-BEING

As described earlier, some of the carers of the present study (24%) suffer poor health themselves. Almost a third of the carers (30%) believe that their health has suffered because of the demands of caring. Of those who feel their health has suffered, almost half now rate themselves as having fair or poor health (Table A10.15). Moreover, among this group of carers 68 per cent suffer some on-going health problem, a percentage which is double that among those who see their health as being unaffected by caring (Table A10.16). Likewise with respect to emotional well-being. 6 of the 7 carers taking medication for a 'nervous condition' feel that caring has had a deleterious effect on their health.

Experience of Strain

As a summary measure of the impact of caring, carers completed the 'Caregivers' Strain Index' which investigates experience of strain in the areas of physical and emotional well-being, family relationships, financial circumstances, free-time and personal and social life. The findings on this index indicate that emotional strain is most evident among carers. Many (66%) find the changes in the elderly person upsetting and 30 per cent find problems such as incontinence or memory loss difficult to cope with. Over half (57%) of the carers report having felt completely overwhelmed at times because of worry or concern about the elderly person (Table 10.7). Some (25%) indicate that caring has involved major emotional adjustments.

Table 10.7: Whether carer experiences different kinds of emotional strain (Q.47)

Response	Kind of Strain							
	Having to Make Emotional Adjustments		Behaviour of Elderly Person Upsetting		Changes in Elderly Person Upsetting		Feelings of Being Overwhelmed	
	N	%	N	%	N	%	N	%
Yes	25	12.5	41	20.5	105	52.5	52	26.0
Sometimes	25	12.5	19	9.5	27	13.5	62	31.0
No	150	75.0	140	70.0	68	34.0	86	43.0
Total (N)	200		200		200		200	

The majority of carers (72%) feel strain in their social lives because of being confined through caregiving demands. Carers' personal lives are also affected in many ways. For example, 32 per cent find caring inconvenient in different ways. Many (43%) find they have had to make changes in their personal plans, while a lesser number (14%) have had to make work adjustments. Close on half of the carers have to cope with the fact that there are other demands on their time from, for example, other family members (46%). Similarly, 45 per cent have had to make difficult adjustments to family life because, for example, of disruption of routine or lack of privacy (Table A10.17). For the purposes of the present study, level of strain is considered to be very high if the carer experiences strain in 11 or more of the 13 separate areas investigated in the Caregivers' Strain Index. The level of strain is regarded as being high if the carer feels strained in 7 to 10 of the areas and medium if the carer experiences strain in 4 to 6 areas. The level of strain is considered to be low where the carer feels strained in relation to 1, 2 or 3 of the areas investigated. Using these criteria it emerges that 11 per cent of the carers experience very high levels of strain and a further 22 per cent feel highly strained. For some (33%) the level of strain is low and 10 per cent appear to suffer no strain whatsoever according to this particular index.

SUMMARY

The Costs of Caring: Financial Costs

The impact of caring on the carer may be expressed in terms of costs in different aspects of the carer's life including financial circumstances, social life, personal relationships and physical and emotional well-being. With respect to financial costs there are indications in the present study both of restriction of employment opportunities and of extra expense incurred through caring. Although 77 per cent of the carers are of normal working age only a minority (16%) are actually in paid employment. Seventeen per cent of the women and 38 per cent of the men have given up work specifically to become carers. Over a quarter (28%) would like to be in paid employment if they did not have to provide care. Among the small group who do work, many (43%) have been forced to take time off and the demands of caring are seen by 16 per cent as being restrictive of career development. Apart from restriction of employment opportunities, carers have had extra expense such as making adaptations

to their homes (17%) but without any State assistance in most cases to cover the costs. The elderly people themselves do in most cases (93%) contribute to the cost of caring but financial help from relatives is rare (6%).

The Costs of Caring: Social Aspects

In relation to their social lives, many carers are confined to the home for long periods during the day . between 5 and 10 hours (53%) or more (24%). Some carers (16%) do not have even one night in the week which is free for themselves. When carers do go out they are often limited to time (79%) and find it difficult to let go of caring responsibilities (57%). For over half of the carers (59%) the problem is that the elderly person cannot be left alone and there is often difficulty in finding someone who will act as a substitute carer. Given such restrictions, it is not surprising that 59 per cent of carers find caregiving has an adverse impact on their social lives. Carers rarely or never get involved in social activities such as evening classes, going to the cinema or a play or show. While a small number (15%) do go for a meal or a drink each week, 37 per cent do this less frequently now than they had been used to. The most popular pastimes among the carers all take place within the home; watching television being the most frequent leisure pursuit (82%). The only kind of outing which carers engage in with any regularity is shopping (76%). Visits to friends have decreased among 51 per cent of the carers. However, friends do call regularly to many of the carers (69%) and in fact visits from friends have increased in some cases (30%).

The Costs of Caring: Personal Relationships

Caring has consequences too for the carer's personal relationships. Children are most frequently adversely affected (21%) but marital relationships also sometimes suffer negative effects (16%). Many carers (42%) say they get short-tempered and snappy and arguments sometimes occur among family members over the carer's role (24%). Carers do, however, find that their families generally are supportive of them in their caregiving role (89%).

The Costs of Caring: Health and Strain

Almost a third of carers believe that their health has suffered because of caring demands and stresses. Among this group, 68 per cent suffer

some on-going health problem and current state of health is typically perceived as being fair or poor. One-third of carers experience high levels of strain in their lives generally. Emotional strain is particularly evident, but carers also experience strain in their social lives and in their personal lives.

CHAPTER ELEVEN

Needs of Carers

A central consideration in the home-care of the elderly is the ability of the carers to maintain their own lives apart from caring. The problem both for the carers themselves and for policy-makers and service-providers is how to reconcile the provision of care with the maintenance of the carer's well-being in relation to physical, social, emotional and financial aspects of life. So that carers are not providing care to the detriment of their own well-being, their needs must be recognised and addressed. How do the carers under study manage their own lives?; what are their needs as caregivers?; and are these needs being met? This chapter explores the varying needs of carers arising from different aspects of caring: needs arising from the amount and kind of care required because of the elderly person's disabilities and infirmities: needs arising from limitations in the carer's own capacity to do the job; and needs stemming from attempting to do a demanding job in an unsupportive environment. Special needs which may arise where the elderly person has died or has been institutionalised are also explored.

NEEDS ARISING FROM THE NATURE OF THE CARE REQUIRED

Need for Practical Help and Advice

As described earlier, 24 per cent of the elderly cared-for at home are highly dependent on their carers in relation to the management of personal care tasks. A large number suffer problems with incontinence (24%) or soiling (20%). Seventeen per cent are housebound and 14 per cent are bedridden. In addition to their physical care, many carers are looking after elderly people who are exhibiting symptoms of dementia and who accordingly are highly dependent, in psychological terms, on

their carers (21%). Given the nature of the care required of the carers, practical help and advice and support would seem to be primary' needs. The findings indicate, however, that such needs are not being met.

The great majority of the carers bear the burden alone of looking after the personal care of the elderly person, of assisting her/him with toileting and physical mobility and of coping with incontinence. In those cases (52%) where assistance from others outside the home is provided, it is typically confined to shopping or supervising the elderly person. Practical help from statutory or voluntary services, such as home-help or meals-on-wheels, is practically non-existent.

The carer's need for advice and counselling on how to cope with the physical and mental infirmities of those in their care is another need which is largely unmet. Just over a third of carers (36%) believe that their need for advice and information is being addressed. G.P.'s are seen as providing a satisfactory service but advice and support from such potentially useful professionals as public health nurses and social workers is very much lacking. Carers who want more advice and information typically (86%) believe that its provision is the responsibility of the health boards.

Need for Respite

Since 20 per cent of carers are providing 24-hour care and a further 30 per cent are providing care constantly throughout the day, a respite from caring is an obvious need. However, most carers (82%) had not had a holiday in the year prior to interview. Of those who did have a holiday, for most (64%) it was of short duration being between 3 and 7 days (Table A11.1). Where carers did have a respite, typically it was brothers or sisters (42%) or adult children (28%) who took over the caring role rather than that the elderly person was placed in short-term care (4 persons) (Table A11.2). According to the carers, short-term relief care is, in fact, available locally only to a small minority (9%) and a large number (45%) point out that the need for this kind of service is not being met. Carers typically (74%) see the provision of this service as the responsibility of the health boards (Table A11.3). It is noteworthy that when questioned about availability of short-term care, 42 per cent of carers stated that they did not know what was provided in their area. This underlines the need for advice and information which might be provided by, for example, a social worker. It is also striking that among the 18 carers who do have access to relief care, just 5 have availed of

the service. The need for counselling and advice in this area is suggested by the fact that while many carers believe that short-term care in general is important and valuable (Table A11.4) less than half (44%) feel that it would be useful to them personally.

The reason for the contradictory attitudes of carers to short-term care may be due, at least partly, to their beliefs about how the elderly person would react to such a suggestion. Eighteen per cent believe that the elderly person would be very angry or unhappy about short-term care while a further 51 per cent think the elderly person would prefer not to have to go into care even if only in the short term (Table 11.1).

Table 11.1: Beliefs about elderly person's reaction to short-term relief care (Q.114)

Reaction	Number	Percentage
Elderly Person Would Like/Would Not Mind	25	13.4
Elderly Person Would Do It to Give Carer a Break	12	6.5
Elderly Person Would Think Carer Was Trying to Get Rid of Him/Her	2	1.1
Elderly Person Would Prefer Not to Go Into Short-term Care	94	50.5
Elderly Person Would Be Very Angry/Very Unhappy	33	17.7
Do Not Know What Elderly Person's Reaction Would Be	20	10.8
Total (N)	186	

Non-respondents excluded

NEEDS ARISING FROM CARER'S PERSONAL CIRCUMSTANCES

Needs Related to Carer's Age and Health

The fact that many of the carers are themselves elderly suggests that if they are to maintain their physical well-being in the face of such a physically demanding role, they require practical help from both informal and formal sources. However, as indicated above, such help is not available to many carers. In addition to their age, the carers' own ratings of their health clearly indicate a need for medical care of the caregivers themselves. This is one of the few areas where the majority of carers (74%) believe their needs are being met. Most carers (68%) too are satisfied that their needs in relation to emotional well-being are catered

for. This is indeed surprising considering the substantial percentage of carers who report feeling overwhelmed by worry and concern (57%) or who find themselves having to make difficult emotional adjustments (25%) or who find the elderly person's deteriorating state disturbing (66%). Counselling and support groups would seem to have an important role here but only one carer has had such help. In this respect, information and advice again appear to be lacking as many carers are not aware of how support groups might help and less than a third (31%) say they would definitely find such a group helpful. Carers, for the most part (55%), believe that it is the responsibility of the health boards to set up such groups (Table A 11.4).

Needs Related to Duration of Care

One potential source of breakdown among carers is fatigue due to the length of time they have had to care for the elderly person. In the present study, the general picture which emerges is that caring is a long-term commitment. Where such long-term care is involved, it seems likely that there might be instances where prolonged strain indicates that others should take over the caregiving responsibilities through the provision of institutional care. This may be particularly pertinent in the case of elderly carers and where the carers themselves are suffering from ill-health. Just over half of the carers (51%) have access to a public nursing home in their locality. Again, among 51 per cent there is a private nursing home in the area but the vast majority of the carers in question (90%) could not afford to avail of its services. Most carers (62%) would not even consider long-term care as an option, primarily because they believe the elderly person would 'hate it' or be 'very unhappy' with the idea (61%) (Table A11.5). Here again, advice and counselling may be necessary to help the carer accept when the point has come when home-care is no longer feasible. The lack of information to carers is also underscored by the fact that 15 per cent do not know what long-term care facilities are available locally.

NEEDS ARISING FROM ENVIRONMENTAL SOCIAL CIRCUMSTANCES

Needs Related to Carer's Home

Aspects of the carer's home which are unsuitable to a disabled or infirm elderly person add considerably to the stresses of caregiving. If carers

are to give proper care then it is very important that their homes be structured in the most convenient way. This may necessitate structural or other alterations. Among a substantial number of the carers of the present study there are aspects of the home which cause difficulties in caregiving. Problems with stairs (30%) or dampness (24.9%) are the most usual difficulties. A sizeable group (18%) find their homes too small for the purposes of caregiving and 16 per cent lack basic amenities such as toilet or shower (Table 11.2).

Table 11.2: Conditions of house which make caring difficult (Q.48)

Conditions of House	Whether Caring is Difficult				Total (N)
	Yes		No		
	N	%	N	%	
Steps/Stairs	59	29.5	141	70.5	200
Heating/Damp/Condensation	47	23.5	153	76.5	200
Too Large	9	4.5	191	95.5	200
Too Small	35	17.5	165	82.5	200
Too Isolated	18	9.0	182	91.0	200
Outside Access Difficult	18	9.0	182	91.0	200
Lack of Toilets/Showers	31	15.5	169	84.5	200
Lack of Commode	7	3.5	193	96.5	200
Lack of Washing Machine	24	12.0	176	88.0	200
Lack of Other Aids/Adaptations	17	7.5	183	92.5	200
Other	5	5.0	95	95.0	100

Needs Related to Financial Circumstances

Shortage of money can greatly add to the physical and emotional strains of caring. In the present study, over a third of carers (35%) do in fact report experiencing financial strain. This, indeed, is not surprising since only 16 per cent of the carers are in paid employment and almost one-fifth of the elderly persons being cared-for are not financially independent. Moreover, there are 64 households which are totally dependent on State benefits or allowances in order to survive (see Chapter Five). Under these circumstances, financial help and advice would seem to be an important need of carers. However, as described earlier, only 4 per cent of the carers are in receipt of the 'Prescribed Relative Allowance' which is the only financial help specifically available for caregiving. With respect to advice on financial entitlements, over half the carers (54%) indicate that this is a need which is not being met. Where carers indicate that advice on entitlements should be provided, the vast majority (90%) see this as being the responsibility of the health boards (Table A11.6). Most carers (59%) point out that they would find this kind of advice helpful.

Needs Related to Carer's Social Life

It is clearly important for their psychological well-being that the carers be able to maintain their own social lives, that they manage to continue their own interests and that they keep contact with their friends. As an indication of the extent to which this need is not being met 71 per cent of the carers studied indicate that they feel confined by the demands of caregiving. Many (38%) experience loneliness (Table 11.3); the most difficult times being special holidays (36%) and evening time (25%) (Table A11.7).

Table 11.3: Frequency of experience of loneliness (CL59a)

Frequency	Number	Percentage
Never	112	56.0
Rarely	12	6.0
Sometimes	55	27.5
Frequently	18	9.0
Most of the Time	3	1.5
Total (N)	200	

Some (22%) have lost contact with friends (Table A11.8) and over half (58%) report that their social life is directly restricted through caregiving. Considering the reports of loneliness, the constriction of social circle and restriction of social activities, it is not surprising that 29 per cent of carers feel that their need for a social life is not being met. Of those who indicate that this is a need which should be catered for, the majority (69%) see this as the responsibility of family, friends and relatives (Table A11.9).

NEEDS ARISING THROUGH DEATH OR INSTITUTIONALISATION OF THE ELDERLY PERSON

In the present study, 35 carers have had to deal not only with the taxing job of caring but also have had to come to terms with the death or institutionalisation of the elderly person. For most (80%), this event had occurred within the year prior to interview. Having to adapt to a new life and loss of a familiar role brings its own challenge and raises its own particular needs. Carers may need help, counselling and support in dealing with the situation. This is particularly true where the carer's

physical and emotional well-being have already been undermined through long-term caring for the elderly person.

Many carers do, in fact, report that their lives have been changed to a greater (34%) or lesser degree (25%) through the death or institutionalisation of the elderly person. The majority of those who have experienced a change in role experience difficulty in adapting to a new way of life (64%) (Table 11.4).

Table 11.4: Degree of difficulty in adapting to a new way of life (Q.131)

Degree of Difficulty	Number	Percentage
Very Difficult	11	33.3
Difficult	10	30.3
Not Too Difficult	8	24.2
Easy	1	3.0
Very Easy	3	9.1
Total (N)	33	

Non-respondents and those for whom the question is not applicable excluded

The feelings of grief and loneliness suffered by almost all carers suggest that help may be needed in coming to terms with their loss (Table 11.5). Despite the fact that the person being cared-for was elderly, many also experience a sense of shock when death or institutionalisation occurs (73%). Counselling may be particularly valuable for those carers whose reaction is tinged with anger (15%) or remorse (21%).

Table 11.5: Carer's response to death/institutionalisation of elderly person (a 127)

Response	Yes		No		Don't Know		Total N
	N	%	N	%	N	%	
Shock	24	72.7	7	21.2	2	6.1	33
Grief	31	93.9	2	6.1	0	0.0	33
Remorse	7	21.2	25	75.8	1	3.0	33
Guilt	1	3.0	31	93.9	1	3.0	33
Relief	12	36.4	20	60.6	1	3.0	33
Loneliness	32	97.0	1	3.0	0	0.0	33
Anger	5	15.2	28	84.8	0	0.0	33

Non-respondents excluded

SUMMARY

Needs Unmet

The needs of carers must be taken into account and catered for if they are to continue to provide care without undermining their own physical

and psychological well-being. However, the general picture which emerges in the present study is one of needs being unmet.

Provide Care Alone

Given the nature and extent of care which the elderly people require, the carers clearly need practical help with caregiving tasks. The great majority of the carers, however, bear the burden alone of providing care. Where help is given from others outside the home it is usually confined to shopping or supervising the elderly person with help rarely or never being given with the more difficult tasks of caring. Practical help through voluntary or statutory services is virtually non-existent. The carer's need for advice and information on how to provide the most appropriate care for elderly people who are often ill, infirm or suffering symptoms of dementia, is another need which is largely unmet. Apart from the G.P. who appears to provide a satisfactory service in this area, the carers have little access to other potentially useful sources of advice such as the public health nurse or social worker.

No Respite Care

Since a substantial number of carers are providing 24-hour care (20%) or constant daily care (30%), respite from caring is an obvious need. However, most carers (82%) have not had a holiday in the past year. Since short-term relief care is available only to a small minority (9%) it is not surprising that 45 per cent of carers point out that this is a need which has yet to be addressed. Many (42%) are unaware of what short-term services are actually available which further underlines the need for advice and information.

Availability of Long-Term Care Outside the Home

The availability of the option of long-term institutional care would seem an important need for those carers who, despite ill-health and age, have been providing care for many years. Just over half of the carers (51%) have access to a public nursing home in their area. For others (51%) there is a private nursing home in the locality but the vast majority (90%) of the carers in question could not afford to use its services.

Little Social Life

The importance of social life in maintaining the carer's well-being is obvious. Yet, 29 per cent of carers report that this need is not being met. Most (71%), feel confined by caring and many feel loneliness (28%) and experience loss of contact with friends (22%). Over half (58%) report that their social life is directly restricted through caregiving. Most see the responsibility for addressing this need as resting with family, friends and relatives.

Needs Arising from Environmental and Social Circumstances

The carers also have needs arising from their environmental and social circumstances. Thus, for example, the home of the carer is unsuitable for caring purposes because of stairs (30%) or dampness (24%) or because it lacks such basic necessities as toilet or shower (16%). Over a third of carers (35%) find themselves under financial strain but only 4 per cent are receiving any allowance specifically for the work involved in caring. More than half of the carers (54%) feel their need for advice on financial entitlements is not being met. Of these, the vast majority (90%) believe the provision of such advice is the responsibility of the Health Board.

Needs in Relation to Physical and Emotional Health

The one area where the majority of carers believe their needs are being met is in relation to their physical (74%) and emotional (68%) health. Satisfaction in relation to emotional needs might seem surprising given the evidence of emotional strain among carers and the fact that no support is available to them in terms of counselling or support groups.

Impact of Institutionalisation and Bereavement

The re-adjustments which carers indicate are required where the elderly person is institutionalised or has died and the feelings of grief, loneliness and shock which are experienced suggest that carers who find themselves in this situation may well need support, advice and counselling.

CHAPTER TWELVE

The Carer's View of Caregiving

Introduction

The carer's own attitudes and individual response to the role of caregiver are very important in determining what impact caring will have in terms of feelings of burden. From an outsider's perspective a particular carer may be carrying out a very onerous task in unsupportive circumstances and yet that carer may find positive things about the caring role that outweigh the negative aspects and may find her/his life satisfactory. On the other hand, another carer may be looking after an elderly person who appears to be comparatively easy to care for and yet may find the role very burdensome because of frustration of personal freedom and opportunity. Among other influences, the relationship between the carer and the elderly person is likely to affect the carer's personal response to the objective circumstances of caregiving. How do the carers of the present study view the role of caregiver?; how satisfied are they with their lives?; what do they see as the good and bad aspects of caring? This chapter explores the carer's personal experiences of caring in the context of the kind of relationship that exists between the carer and the elderly person being looked after.

QUALITY OF THE RELATIONSHIP BETWEEN CARER AND ELDERLY PERSON

In the present study, the great majority of carers are looking after elderly people with whom they have a high quality relationship. Most feel that the relationship between themselves and the elderly person is very good (58%) or good (31%) (Table 12.1). With few exceptions, the carers get along well with the persons in their care (93%), feel very close to them (86%), and feel that they understood each other well (88%).

Table 12.1: Quality of relationship between carer and elderly person (Q. 118)

Quality of Relationship	Number	Percentage
Very Good	101	57.7
Good	55	31.4
Fair/Tolerable	17	9.7
Poor	1	0.6
Very Poor	1	0.6
Total (N)	175	

Non-respondents and carers for whom question is non-applicable are excluded

While the majority of carers (76%) do not feel that the elderly person makes requests which are perceived as being over and above what s/he needs, nevertheless almost a quarter (24%) experience the elderly person as overly demanding or manipulative. Moreover, according to half, the elderly person will accept help only from the carer and acts as if the carer were the only one whom s/he could depend on. However, on the whole, carers feel appreciated by the elderly people for whom they care (76%) and the feeling of contributing to the well-being of the elderly person is a source of satisfaction for most. Given that the reported relationship between the carer and the elderly person is "good" and "close" in most cases, it is not surprising that just 15 per cent wish for a better relationship.

An indication of the carer's experience of burden may be derived by considering the number of different aspects of the relationship between carer and elderly person in which caring has had a negative impact. These aspects — which have been discussed individually above — are as follows: unreasonable requests by the elderly person; dependency of the elderly person; feelings of contributing to well-being of the elderly person; desire for better relationship; lack of appreciation on the part of the elderly person; feelings of being manipulated; being made to feel indispensable. In the present study, a carer is regarded as experiencing a very high level of burden in her/his relationship with the elderly person if s/he considers that caring has had a negative impact in at least 6 of the 7 aspects described. A negative impact in 4 or 5 aspects reflects a high level of burden. Burden is considered to be low if just one or 2 aspects have suffered. Based on these guidelines, it appears that two-thirds of carers experience little (59%) or no burden (7%) in their relationships with the elderly person (Table 12.2). Where burden is experienced it is more likely to be at a medium rather than high level.

Table 12.2: Level of burden: Relationship with elderly person

Level of Burden	Number	Percentage
Very High Level: negative effect on 6 or 7 aspects	1	0.5
High Level: negative effect on 4 or 5 aspects	19	9.9
Medium Level: negative effect on 3 aspects	45	23.4
Low Level: negative effect on 1 or 2 aspects	114	59.4
No Burden: no negative effect	13	6.8
Total (N)	192	

Non-respondents excluded

NATURE OF INTERACTION BETWEEN CARER AND ELDERLY PERSON

The majority of carers (84%) feel pleased about their interaction with the elderly person and find the caring relationship a rewarding experience (76%). Part of this pleased feeling may be due to the fact that, with few exceptions, carers feel useful in the interaction (91%) (Table 12.3).

Naturally, there are also some uncomfortable feelings associated with caregiving; the one most frequently reported being a feeling of strain which is an element of the interaction with the elderly person among almost a quarter (24%) of carers. Some carers experience feelings of nervousness or depression (18%) while others feel anger (13%), resentment (13%) or guilt (12%) (Table 12.3).

Table 12.3: Carer's feelings about interaction with elderly person (Q.125)

Feeling	Response				Total (N)
	Yes		No		
	N	%	N	%	
Feel Angry	26	13.1	173	86.9	199
Feel Nervous/Depressed	36	18.2	162	81.8	198
Feel Resentful	26	13.1	173	86.9	199
Feel Pleased	167	84.3	31	15.7	198
Feel Strained	48	24.2	150	75.8	198
Feel Guilty	23	11.6	175	88.4	198
Feel Useful	180	91.4	17	8.6	197

Non-respondents excluded

Overall, the nature of the interaction between the carer and the elderly person suggests that in relation to this particular aspect of caring the experience of burden is not very widespread. For the purposes of the present study, a carer is considered to experience a very high level of burden if s/he indicates that interaction with the elderly person has suffered in at least 6 of the 7 aspects discussed above. At the other end of the scale, level of burden is regarded as being low if caring has a negative impact in just one aspect of the interaction. Using this measure, it emerges that in relation to their interactions with the elderly person most carers (62%) do not feel burdened at all and for a further 16 per cent the level of burden is low (Table 12.4).

Table 12.4: Level of burden: Interaction with elderly person

Level of Burden	Number	Percentage
Very High Level: negative effect on 6 or 7 areas	7	3.6
High Level: negative effect on 4 or 5 areas	16	8.2
Medium Level: negative effect on 2 or 3 areas	20	10.3
Low Level: negative effect in one area	32	16.4
No Burden: no negative effect	120	61.5
Total (N)	195	

Non-respondents excluded

Experience of Strain in the Carer's Personal Life

Despite the existence of a good and close relationship between the carer and the elderly person, strains can still arise due to 'side-effects' of caring such as restriction on social life or conflicting family interests.

Over a third of carers (34%) do in fact experience strains in their relationship with the elderly person. Among those circumstances which cause strain, the most frequently noted is that carers do not have enough time for themselves (48%). Again, almost half of the carers (47%) find that caring restricts their social life. Another frequent complaint is that the carer feels that the present situation does not allow enough privacy (44%). Deterioration of health because of the caring role, though less frequent than other complaints, is still reported by close on a third of carers (30%). Some carers (16%) feel restricted in that they feel uncomfortable about the elderly person when friends visit (Table 12.5).

Table 12.5: Perceived restrictions of caring relationship on carer's life (Q.125)

Restriction	Response				Total (N)
	Yes		No		
	N	%	N	%	
Not Having Enough Time For Self	96	48.2	103	51.8	199
Deterioration of Health	59	29.8	139	70.2	198
Not Enough Privacy	87	43.9	111	56.1	198
Restriction of Social Life	93	47.0	105	53.0	198
Feeling Uncomfortable Before Visiting Friends	31	15.7	166	84.3	197

Non-respondents excluded

A source of strain for many carers (45%) is having to juggle the demands of caring for the elderly person with looking after family and other responsibilities. However, the majority of carers (79%) do not feel that the elderly person adversely affects their relationships with other family members or friends.

Consideration of the carers' experience of strain across the different areas discussed above provides another indication of the carer's level of burden. A carer is considered to experience a very high level of burden if s/he experiences a negative impact of caring in at least 8 of the 9 aspects of personal life investigated. A negative impact of caring in 6 or 7 aspects reflects a high level of burden while a negative impact in 3 to 5 aspects reflects a medium level. The level of burden is regarded as low if the carer sees only 1 or 2 aspects as suffering because of caring. Using these criteria, almost a quarter of carers experience very high (11%) or high (12%) levels of burden in their personal lives (Table 12.6).

Table 12.6: Level of burden: strains in personal life

Level of Burden	Number	Percentage
Very High Level: Negative Effect on 8 or 9 Areas	20	10.7
High Level: Negative Effect on 6 or 7 Areas	23	12.3
Medium Level: Negative Effect on 3 to 5 Areas	39	20.9
Low Level: Negative Effect on 1 or 2 Areas	44	23.5
No Burden: No Negative Effect	61	32.6
Total (N)	187	

Non-respondents excluded

Experience of Worries

The extent to which the carer experiences worries about different aspects of the caregiving relationship may be taken as a further indication of the burden of caregiving. In this regard, it appears that for 27 per cent of carers caregiving imposes a high level of burden in that they experience worry in at least 3 of the 4 following areas: not doing enough for the elderly person; not having done enough for the elderly person in the past; fears for what the future holds; worry about the elderly person ageing. The ageing process gives rise to the most common worry: most carers (89%) are anxious about their elderly charges' physical health while worry about their state of mind, though less common, is still experienced by two-thirds of the carers. Carers also worry about the future of the elderly person (52%) and about her/his financial position (31%). Almost one in 5 worries that s/he will not have enough money to support the elderly person in addition to all the other expenses incurred. In addition, a large percentage (39%) would like to be able to provide more money than presently able to give in order to support the elderly person.

Effects of Nature of Care on Quality of Relationship

The quality of the relationship between the carer and the elderly person is not significantly related to the extent of care which the carers see themselves as providing: very similar percentages of those providing 24-hour care (63%), constant day-care (60%) and occasional care (55%) report having a very good relationship with the elderly person (Table A12.1). The two people who report a poor or very poor relationship are in fact providing just occasional care. The relationship between carer and elderly person does, however, seem to be connected with the perceived amount of care provided. While just over half of those giving a lot (57%) or a little care (55%) report having a very good relationship with the elderly person, 87 per cent of those giving 'occasional' care see their relationship as being very good. Moreover, neither of the 2 carers who describe their relationship with the elderly person as being poor or very poor see themselves as providing just occasional care (Table A12.2). The level of dependency of the elderly persons also affects the quality of the relationship between them and their carers. The percentage of carers who regard their relationship with their charges as being 'very good' increases directly with decreasing level of dependency from 46 per

cent of those with a very high level of dependency to 79 per cent of those who are not dependent at all (Table A12.3).

SATISFACTION WITH THE ROLE OF CAREGIVER

The majority (63%) of the carers, in the present study, had made a specific decision to become caregivers. The decision for most would appear to have been a positive one in that 72 per cent are either very satisfied (17%) or satisfied (55%) with their lives at present. A small group (11%) are dissatisfied, while 17 per cent describe themselves as 'neutral'

The extent to which the carers feel satisfied with their lives is related to the quality of the relationship between them and the elderly people they look after. Eighty-two per cent of those carers who are very satisfied with their lives compared to 28 per cent who are dissatisfied, report having a very good relationship with the elderly person (Table A12.4). At the other end of the scale, none of those who are very satisfied report anything less than a good relationship with the elderly person whereas 28 per cent of those who are dissatisfied describe their relationship as fair or tolerable.

As might be expected, there is also a highly significant connection between the carers' life satisfaction and the amount of care which they see themselves as providing. Just 11 per cent of those who provide a lot of care report being very satisfied with life; by contrast 22 per cent of those providing a little care are very satisfied and, even more strikingly, 60 per cent of those providing occasional care are very satisfied. With respect to those who are dissatisfied with life, none of those providing occasional care feel anything less than satisfied whereas 9 per cent of those providing a little care and 12 per cent of those providing a lot of care report feeling dissatisfied (Table A12.5).

Carers' life satisfaction is also very much influenced by the extent of care which they have to provide. Thus, only 11 per cent of those giving 24-hour care, compared to 18 per cent of those giving constant day-care and 25 per cent of those giving occasional care, report being very satisfied with life. On the other hand, the percentage of those being dissatisfied is greater among those providing 24-hour care (16%) than it is among those giving day-care only (12%) or occasional care (8%) (Table A12.6).

The carers, typically, understood exactly what caring entailed when they took on the role (20%) or at least had a fairly accurate idea (51%). For many, caring has turned out to be no better or worse than anticipated

(53%) and for a small percentage (7%) it has been even better than expected. However, over a third of carers (39%) find caring worse than had been expected. In this context, information and advice would appear to be important as the majority (56%) of those for whom caring turned out to be worse than expected had had no idea of what was entailed when they took on the job.

At this stage, over half of the carers (52%) profess not to mind looking after the elderly person. Many (38%) are actually 'very happy' to be doing the job. Just 10 carers describe themselves as 'reluctant' caregivers while 7 are actively 'unhappy' with the role. Among those not currently in the caregiving role because of the death or institutionalisation of the elderly person, all, with one exception, report that they are happy to have provided care. The great majority (79%) indicate that they would do so again should someone else become dependent on them.

Perceived Positive Aspects of Caring

When asked what, if any, were the positive aspects of caring, over three-quarters (78%) of the carers could identify something about the role which was good for them personally. The most frequently noted positive aspect of caring is the knowledge that the elderly person is being well looked after (18%) (Table 12.7). Another commonly reported good thing is the feeling of being appreciated (15%). For some (14%), the satisfaction of fulfilling one's duty or responsibility is the best thing about caring. Others (12%) note the companionship and loving involved in the caring relationship.

Table 12.7: Perceived positive aspects of caring (Q.122a)

Positive Aspects	Number	Percentage
None	40	20.0
Companionship/Loving Relationship	23	11.5
Knowing Elderly Person Is Well Looked After	36	18.0
It's Natural, My Responsibility/Duty	27	13.5
Good for Me Personally	16	8.0
Being Appreciated	29	14.5
Opportunity to Repay Elderly Person	10	5.0
Keeping Elderly Person out of Institution	6	3.0
Don't Know	5	2.5
Other	8	4.0
Total (N)	200	

For some, caring has had a practical pay-off in that the elderly person intends to leave the house or land to the carer (21%) or the elderly person looks after the carer's children (11%) (Table A12.7). Caring has also been of personal benefit to some (15%). In general comments on caring, one carer talks about "benefit from the older people's advice and example" and another notes that "it is very good for children to have a granny with them and she can teach them a lot".

Perceived Negative Aspects of Caring

While there may be good things about caring, it is also true that for most carers (74%), caring also has its negative aspects. The most common complaint about caregiving is that it is confining and restricting of the carer's life (23%) (Table 12.8). For some, the worst aspect of caring is seeing the elderly person suffer (15%). Others note the strain of caring (8%) and trying to meet the demands of the elderly person (6%) as being the most negative aspects.

Table 12.8: Perceived negative aspects of caring (Q.123)

Type of Help	Number	Percentage
None	51	25.5
Strain of Caring	16	8.0
Seeing Elderly Person Suffer/Worry	30	15.0
Lack of Support/Comfort	4	2.0
Confined/Restricted	46	23.0
Trying to Please Elderly Person's Demands	11	5.5
Don't Know	7	3.5
Upset Relations/Marriage	7	3.5
Other	28	14.0
Total (N)	200	

CARER'S GENERAL COMMENTS ON CARING

The carers' general comments on their experiences of caring for an elderly person provide an insight into the difficulties which arise in caregiving and serve to highlight and underscore the issues which have emerged in previous chapters.

Financial Issues

The issue which appears to be of most concern to carers is connected with financial matters. Financial issues account for 22 per cent of all the

comments made and constitute the single largest category of statements. Basically, carers believe that there should be more financial recompense for the labour involved in caring. The following quotations illustrate the carer's viewpoint:

"If my husband was in an institution it would cost the state a lot of money so why can't they give me some allowance for looking after him at home".

"I feel it's an awful shame that carers don't get an allowance for caring for the elderly. It seems to be expected that old people stay with their relatives and this is saving the state a lot of money".

"The social services could do more financially and otherwise for the elderly. My husband is unemployed and I feel I should get a regular payment to ease the financial strain".

"I feel I should get more than 11/16S & 2£1/16S'2600 because I'm saving the Health Board a lot of money".

"It would be wonderful if people caring for old people got a small payment each week, just a little token to encourage sons and daughters to look after their parents at home, where they are happy".

Issue of Services Available to Carers

Of almost equal importance to financial matters is the question of services available to carers. Twenty per cent of all comments are connected with this issue, only one of which is favourable. Some of the comments are concerned with the lack of help as illustrated in the following quotations:

"I feel very worried about the lack of help given to carers".

"I have been a carer for 21 years and have never had any outside help. My whole life has been devoted to caring and while I love my mother I am very tired of caring"".

The lack of practical assistance in the form of home-help is also noted:

"Home-help is non-existent in country areas".

"I feel I should get home-help for my grand-aunt because if I went off she would not be able to live on her own".

Some comments express a need for contact with professionals who would advise and support them in caring:

"I would have liked to have a physiotherapist visit and treat my husband at home".

"The chiroprapist should call once a month".

"There should be people to call out and visit, for example, social workers".

The lack of aids which would ease the task of caring and the difficulty involved in getting services to provide such aids is the subject of several comments:

"I have no water on tap. toilet or bathroom. I am most anxious to have these but there is no help coming from the County Council or Health Board".

"After all the trouble I had to go to get the commode and bed-rest, I swore I would never ask for anything again — it was all too humiliating".

" Aids of different kinds are very difficult to get".

"I had to badger the public health nurse for disposable sheets just 3 days before the elderly person died and did not get them at all".

"When I applied for the 'phone, the fact that I had an elderly person with me was not considered — I had to wait a very long time".

The issue of the inadequacy of the service provided by the public health nurse in itself accounts for 6 per cent of all the comments of the carers. The carers' viewpoint is illustrated in the following quotations:

"I know there are cut-backs in the health service but it is a fright that I can only have the public health nurse once a month and I find it very hard to get used to the urine bag and catheter".

"I think the public health nurse could have shown more interest in the situation".

"Public health nursing is very poor in the country".

"I can't understand why the district nurse does not call regularly".

In just one instance was the public health nurse praised:

"I would like to say that the public health nurses are great and should get more credit for the work they do".

Issue of Need for Support

The issue of support, particularly from family members, comprises 12 per cent of all the statements made by carers. Typically, the comments are concerned with the lack of such support. The desire for more social contact is revealed in the following quotations:

"It would be nice if somebody called now and then to see how we are getting on".

"It's very hard for me to manage being so far from family and people I know".

The lack of support from other family members is the subject of several comments as in the following examples:

"I wish my other sister who lives with us would do more. She's very reluctant to do anything to help out".

"My two brothers and their wives just don't want to know anything about my situation".

"I feel everything has been left to me and I feel very resentful of this".

The positive impact of family support on the carer's life is underlined in the following comment:

"I have a lot of family living beside us and they are a great help and comfort".

Issue of Relationship with the Elderly Person

Apart from the issues of finance and support systems which between them account for 62 per cent of all the statements made, the next most numerous category of comment (8%) is connected with the relationship between the carer and the elderly person. With one exception, it is the difficulties in the relationship rather than the positive aspects that are commented on. Some of these difficulties are illustrated in the following comments:

"I feel that caring for my mother would be easier if I had a better relationship with her".

"He was a bit aggressive in the beginning. No doubt he has a lot to contend with".

"My mother is a very negative and stubborn person. Sometimes I feel mentally exhausted. I feel very sad about the strain in my relationship with my mother".

The following comment, on the other hand, reveals how rewarding caring can be when the relationship between the carer and elderly person is good:

"Being so close to someone is great and I had a wonderful relationship with her. Someone told me my life had been wasted. I couldn't disagree more. I feel privileged to have looked after her".

Need for Respite from Caring

The need for a respite from caring is underlined in several of the carer's comments (7%). The concern is reflected in the following quotations:

"I would like to be able to have my husband looked after now and again so I could have a rest and change".

"I would love if the elderly person would go away once a year to give me a rest but it is pointless even discussing it with him".

"It's a pity they've done away with these short breaks — they would have been ideal for me".

"I would like to see an organised group who would maybe come to the house and just look after my mother — just talk to her so that I could have a whole morning or afternoon off— free for myself.

The value of such respite services is indicated in the following comment:

"My mother goes to a day-care centre 3 days a week and she loves it. She plays bingo and has a chat with people".

Need for Information

The difficulty of obtaining information is a concern among 5 per cent of carers. The following quotations illustrate the concern:

"Information is not readily available — one has to dig and go from one place to another to find it".

"it is hard to find out if one is entitled to anything".

Worry about the Future

The comments of 5 of the carers indicate that worry about the future is the primary concern:

"I worry a lot about what happens in the future".

"The elderly person has heart problems and has great difficulty in walking. I can manage at present but I'm dubious about the future".

"I can cope at present — whatever the future holds, God only knows".

SUMMARY

Quality of Relationship Between Carer and Elderly Person

In the present study most of the carers are looking after elderly people with whom they have a good (89%) and close relationship (86%). The carers and their elderly charges get along well together (93%) and understand each other (88%). Carers, for the most part, feel pleased with (84%) and useful (91%) in their interaction with the elderly person and few (15%) would wish for a better relationship. Given the good relationship which typically exists between the carer and the elderly person, it is not surprising to find that most find caring rewarding (76%) and feel appreciated in their role (76%). There are also, however, some uncomfortable feelings involved in caregiving. Some carers (24%) feel strain in their interaction with the elderly person while others experience nervousness or depression (18%), anger (13%), resentment (13%) and guilt (12%). Among those circumstances which cause strain in the relationship between the carer and the elderly person, the most frequently noted include restriction of time for oneself (48%), restriction of social life (47%) and privacy (44%) and deterioration of health (30%). Some carers find the elderly person overly demanding (24%) or manipulative (24%).

Nature of Interaction Between Carer and the Elderly Person

A sizeable percentage of carers (45%) experience strain in their relationship with the elderly person because of having to fulfill the demands of multiple roles. Worry is also common among carers: worry about the future of the elderly person (52%), about her/his health (89%) and financial position (31%). The quality of the relationship between the carer and the elderly person is not significantly associated with the extent of care which the carer perceived themselves as providing but is connected with the amount of care required and the level of dependency of the elderly person.

Satisfaction with Caregiving

Typically, the carers are satisfied with their lives (72%). The carer's life satisfaction is significantly connected with the quality of the relationship with the elderly person and with the perceived amount and extent of care provided. Most find that there are positive aspects to caring (78%); the most frequently noted being the knowledge that the elderly person is being well cared-for (18%), the feeling of being appreciated (15%) and the satisfaction of fulfilling one's duty (14%). Many report practical and personal benefits from caring. There are, however, also negative aspects to caring, the most common complaint being confinement and restriction of one's own life (23%).

Needs Not Being Addressed

In their general comments on their lives as caregivers, one of the most striking aspects is the extent to which their needs are not being addressed. For example, carers are concerned about the lack of financial recompense for their labours. The inadequacy of services is also very evident from their comments on the lack of practical help, the lack of caring aids, the lack of contact and the difficulty of obtaining information.

Better Support Structures Required

Carers' comments also underline the need for better support structures and the importance of obtaining the help and co-operation of other family members so that the carer is not carrying a solitary burden. Support in the form of provision of respite services seems a particularly urgent need.

CHAPTER THIRTEEN

The Life of the Carer: Conclusions and Issues

Introduction

Until recently, the significance and value of the work of those who care for the elderly at home has barely been acknowledged by policy-makers and planners. However, the nature of present population trends and current emphasis on community care mean that those who provide home-care for the elderly can no longer be ignored. For example, in Britain today, more women are caring for elderly or disabled relatives than are caring for children under 16 years of age. A similar pattern is evident in Ireland as families get smaller and the number of elderly people in the population rises.

Earlier chapters of this report have explored the different stages in the process of caring for an elderly person at home. The nature of the care given, the costs which caring can exact and the impact it can have on different aspects of the carer's life have been investigated. The support which carers receive both from informal and formal sources has been outlined. The purpose of this final chapter is to draw a general picture of what life is like as a carer and to highlight the key issues which emerge from the study. While it is clear from the results of the study that neither the carers nor those for whom they care form a homogeneous group, it is, nevertheless, possible to detect some common elements, experiences and issues in their lives. A central issue in home-care of the elderly — both for the carers themselves and also for policy-makers and service-providers — is how to provide the care required while at the same time maintaining the carer's own personal life apart from caring. This chapter outlines the kinds of interventions necessary to enable the carer to maintain the elderly person in the community with high quality of life in a way that ensures that the carer's own quality of life is also maintained. These guidelines for interventions are presented in the context of the key needs arising at different stages of the process of caring.

PROFILE OF THE LIFE OF THE CARER

When the elderly person gets to the stage of needing care who becomes the carer?; who makes the choice?; what decides the final choice?; how is the carer's life likely to turn-out? Based on the results presented in previous chapters, a profile of the typical kind of life one might expect as a carer is presented below.

Who Cares?

Becoming a carer is fairly haphazard. When the elderly person needs care the person who becomes the carer is much more likely to be female than male and is likely to be already sharing a home with the elderly person. A combination of factors are involved but illness of the elderly person or the threat of institutionalisation are important. A sense of duty and responsibility provides further motivation. When becoming a carer the person in question may not fully understand what is involved and sometimes the job may turn out to be worse than expected. The person who becomes carer is likely to be middle-aged but may well be elderly and may not be in very good health. The carer is most likely to find her/himself looking after a parent or, if not a parent, then a spouse. The carer is unlikely to work outside the home and may have to give up work specifically to provide care. The person who becomes carer is facing a long-term commitment likely to be of at least 5 years.

Who Gets the Care?

The person the carer looks after is more likely to be female than male and will be in her/his 80's or 90's. The elderly person will have some physical health problem; most likely disease of the joints. The elderly person may be independent in some respects but is likely to need help in managing personal care tasks of washing and bathing, dressing and toileting. The elderly person will depend on the carer to prepare food and cook meals. At the later stages, at least, of caring the elderly person may very well have problems with incontinence and soiling and may be showing symptoms of dementia.

What Type of Care?

What is involved in caring on a daily basis will depend on the elderly person's level of functional ability and on her/his mental state and

physical health. It is likely, however, that the carer will have to help the elderly person get out of bed and will have to help her/him to get washed. The carer may also have to dress the elderly person and perhaps help with toileting.

The carer will almost certainly have to prepare meals for the elderly person and will have to supervise and administer medication. The elderly person may need help day and night and, if not 24-hour care, is likely to need constant day care. The amount of care which will have to be given is likely to be 'a lot', or at least 'a little' rather than occasional. The carer will spend at least 4-7 hours each day looking after the elderly person; care will be spread throughout the day rather than being confined to a particular period; and it is unlikely that there will be any time for a rest. The responsibility for looking after the elderly person will fall mainly on the shoulders of the carer and there will be little or no back-up help within the home. The carer can expect to feel constantly tired.

What Kind of Support Do Carers Receive?

If the carer has children living away from home s/he is likely to have frequent visits from them. Brothers and sisters and parents — where alive — will have less regular contact with the carer. Friends and neighbours are likely to call frequently. While there may be frequent contact with family and friends the carer will receive little practical help from others outside the home. If s/he does receive practical help it is most likely to be confined to shopping and 'keeping an eye on' the elderly person when the carer is out. The carer will not get help with more intimate and difficult tasks such as washing, dressing or toileting. Friends and neighbours will help out more than others. The carer is likely to have someone to depend on when common problems arise but may find support lacking if a more serious situation develops. The carer — particularly if s/he has a spouse — will probably have someone with whom to share interests, ideals and values and may have someone with whom s/he shares mutual concern but may very well not have someone s/he can trust with deeper personal issues. Support from formal services will be greatly lacking. The carer will get neither the practical help nor the advice and information s/he needs and there will be no financial support for caring. The G.P., however, will be of great help; calling regularly and giving advice and moral support as well as medical help.

Costs of Caring?

Caring may well affect the carer's health and may cause financial strain.

It will almost certainly restrict the carer's social life. The carer will have little time for her/himself during the day and may have difficulty getting a night off. When the carer does get out s/he is likely to be restricted in time and to find that s/he cannot relax but is worried about the elderly person at home. Visits to friends will occur less often although friends may call to the carer more frequently. The carer will not participate much in social activities and pastimes are likely to be home-based such as watching television. The carer may well find caring a physical strain and it may be emotionally upsetting to see the elderly person grow old and change from her/his former self. At times, the carer may feel overwhelmed by it all. If the carer has children s/he may find her/himself not having enough time with them and the marital relationship too may suffer to some extent. Family members will, however, be supportive of the carer and will provide an environment where s/he can safely and freely express feelings.

Relationship with the Elderly Person

The carer and the elderly person will share a good and close relationship and will get on well together. There will also, however, be strains. The carer is likely to experience constriction of social life, lack of time for her/himself and lack of privacy. The carer may be trying to balance the demands of different roles and may be concerned about financial matters. The carer is likely also to be worried about the health and general future of the elderly person.

Level of Satisfaction — The Quality of Life

The carer will more than likely be satisfied with her/his life but this will depend on the quality of the relationship with the elderly person, on the elderly person's level of dependency and on the amount and extent of care required. One of the most negative aspects of caring will probably be the constriction of one's private life. The personal needs of the carer will not be addressed. There will, however, also be positive aspects to caring: the carer will have the comfort of seeing the elderly person well looked after and will have the satisfaction of having done one's duty. The carer is likely also to be much appreciated by the elderly person and to feel useful and valuable in the caregiving role.

WHAT IS HOME-CARE WORTH?

The descriptions in earlier chapters of the tasks involved in caring, the restrictions it imposes and the costs it exacts, clearly indicate the amount of time, labour and commitment that is involved in the care of the elderly at home. As is evident from the study, there is no doubt that carers provide an invaluable service not only to their elderly charges but also to the community and to the State. However, despite the enormous value of their contribution the services of carers go largely unrecognised. One way of appreciating the worth of home-care is to look at it in economic terms and to reckon what it would cost to pay for the carer's time and labour. Putting a price in financial terms on the service of carers highlights its value using different criteria. It is impossible, of course, to put a price on the central value of home-care, which is that it enables the elderly people to live out their lives in their home environment and provides them with a quality of life in their final years that could not be attained with other forms of care.

Putting a Price on Home-Care

If carers were to be paid for the kind of care they provide what would it cost? In attempting to give an estimate of the price of home-care, three factors need to be taken into account: the overall level of dependency of the elderly person, the amount of time devoted to caring and the degree of expertise involved. The elderly person's level of dependency may be very high, high, medium or low. The amount of time given to caring may vary from the situation where the carer is on 24-hour call, to where care is constant throughout the day, to where care is provided just occasionally. The level of expertise required may involve professional care (for example, nurse or occupational therapist) or personal care (such as bathing) or domestic care (such as cleaning or cooking).

Taking into account these three components of cost, a notional scale of labour costs may be devised on the basis that professional care would cost £7.00 per hour, personal care £3.70 per hour and domestic care £2.00 per hour. The question then arises: what would it cost the state to provide care for an elderly person if the carer were not available to provide the necessary care? Based on 1984 rates — the latest figures available — the estimated weekly cost to a health board of maintaining

an elderly person in different kinds of long-stay care facilities is as follows¹.

District Long-Stay Hospitals	£267.67
Health Board Long-Stay Geriatric	£159.00
Health Board Welfare Home	£ 85.00
Allowance to Private Nursing Home or Centre	£40.25
(Maximum allowance on 1/7/84)	

These figures give some idea of what it would cost the State to look after the elderly person if the carers were not there to undertake this work. It should be emphasised however, that institutional or nursing home care — however excellent — is nevertheless group care, is public care and takes the elderly person out of her/his environment. The quality of the care that can be provided in the elderly person's home is very different. In home-care there is a one-to-one relationship between the elderly person and her/his caregiver and the person being looked-after remains within the family and in the community with which s/he is familiar. Moreover, the figures do not reflect the fact that in caregiving carers not only give their time and labour but also pay a price in terms of their social, emotional and personal lives — a price which is impossible to estimate in financial terms. Given the value of the service which carers provide, it is clearly very important that their work should be recognised and supported.

PLANNING A COMPREHENSIVE RANGE OF SERVICES FOR CARERS

Earlier chapters of this report have painted a picture of the life of the carer. The picture which has been presented has highlighted issues which arise at different stages of the caring process and has identified the primary needs of carers — needs which currently are largely unmet. The primary needs of carers revolve around:

- practical help in caregiving.
- relief or respite care.
- financial support.
- psychosocial support.
- advice and information.

¹ Latest estimates available.

Source: Dail Debates. Vol. 353, No. 9, Col. 1761, 13th Nov, 1934.

At least some of the services which would meet the needs of the carers are already in existence; services such as home-helps, public health nurses, chiroprodists and so on. However, the results of the study clearly show that whatever services are already there are not reaching those who urgently need them — the carers. We need to know why the services that are available are not being used; why the provision appears to be haphazard. Carers give their time, labour and commitment to caring and enable elderly people to remain in the community setting with a high quality of life in their later years. The analysis presented above of the financial value of home-care gives one measure of their value to the community not taking into account how critical their role is to the elderly person. *The central question, then, is what kind of support is needed and what services are required to maximise the potential of home-care of the elderly?*

Main Recommendation

In order to maximise the potential of home-care of the elderly it is recommended that an integrated plan be developed which would allow the establishment of a comprehensive range of services for carers. Up-to-now, the focus has primarily been on the elderly people; the focus of this recommended plan is specifically on the carers and on their needs. The essential elements of the plan are:

—identification of the needs of the carer at different stages of the caring process:

- making the decision to become a carer
- preparing to be a carer
- day-to-day working out of the caring role
- reviewing of caring process
- termination of caring role

—detailing of the action which needs to be taken to address the needs identified

—consideration of who should carry out the required action — whether statutory bodies; voluntary organisations; family, friends, and neighbours or some combination of the three.

An Integrated Care Programme Linking Formal and Informal Support

According to the recommended plan, statutory bodies, voluntary groups

and family, friends and neighbours would work hand-in-hand to enable carers to look after their elderly charges at home while maintaining the quality of their own lives. Accordingly, a vital aspect is the *integration* of informal sources of help with formal services. Different emphasis will be placed on formal and informal sources of support at different stages of the caring process and in relation to different needs. What is required is *co-ordination* of all the different sources of assistance so that carers have ready access to help, information and advice.

Guidelines For a Comprehensive Support Structure For Carers

Following from the plan outlined above, guidelines for the development of a comprehensive support structure for carers are presented in the following sections. These guidelines are presented in the context of the different stages of the caring process. The issues identified from the results of the study are first presented followed by suggestions for necessary action and indications as to who should carry out the required action.

MAKING THE DECISION TO BECOME A CARER

Issues to be Addressed

While the majority of carers in the present study indicated that they had made a specific decision to care, the decision was not made in any kind of systematic manner. Decisions about who becomes the carer need to be made in a considered fashion. This would enable carers to arrive at the best solution for both the carer and the elderly person. The potential carer would be in a better position to make a real decision about taking on the role and may feel more in control of the situation. The decision has to take account of the needs both of the potential carer and of the elderly person and must be based on investigation of all possible choices and alternatives. However, it must be recognised that sometimes alternatives do not appear to exist.

What Action is Required and by Whom?

At this first stage of the caring process family members play the most

important role in supporting the carer. What is needed at this stage is discussion among all family members, including the elderly person, about the extent and kind of care required. Family members need to get together to investigate as many choices and alternatives as possible — for example, the carer moves to the elderly person's home or vice-versa, day-care only, full-time care, shared caring between family members and so on. Alternatives need to be evaluated taking account both of the needs of the potential carer and of the elderly person. One or more persons in the family then choose to take on the role having evaluated the advantages and disadvantages involved. After a period of time the decision will need to be reviewed and a new decision made if necessary. Caring for the elderly is a continuous process, needs change and these changes have to be considered.

While family members have the key role at this stage, statutory services also have a function in terms of advice and information-giving. People such as the G.P. or social worker could assist in discussions on the choices and alternatives that are available. Likewise, the advice of the G.P. or a consultant geriatrician would be very important in determining the care needs of the elderly person.

PREPARING TO BE A CARER

Issues to be Addressed

As indicated in the results of the study, carers sometimes take on the task of caregiving without having much understanding of what the job involves and, for many, caring turns out to be worse than expected. In order to be able to give the best possible care the potential carer needs to be given advice, information and training so that s/he may be properly prepared for the tasks involved. The study also shows that the full responsibility of caring usually falls on the shoulders of the carer and that, once having taken on the job, s/he receives little back-up assistance. Accordingly, if frustration and stress are to be avoided, organisation is important; the carer needs to decide on the limits of the care s/he can provide so that plans can be made for support and practical help from others.

What Action is Required and by Whom?

In enabling carers to prepare themselves for the caregiving role, action

is required not only from the carers themselves but also from voluntary groups, from family, friends and neighbours and most particularly from statutory services. At this stage the carers need a professional service which will assess the care needs of the elderly person so that care is based on comprehensive medical and physical information and so that the emotional, social, intellectual and spiritual needs of the elderly person may be identified. Both statutory bodies and voluntary groups have a role to play in providing the carer with knowledge of the ageing process and of what changes might be expected in the physical, medical and psychological aspects of the elderly person's life. Personnel of formal services need to give the carer information, advice and training on how to deal with and anticipate the typical problems which arise in the care of elderly persons and information and advice on how to deal with difficult behaviour which, for example, may stem from dementia. Such information and training could be provided either at an individual level or at family sessions or at group meetings. It is not enough that information and training services be made available but the whole information-giving process and the uptake and delivery of information, advice and support services must be thoroughly examined. Advice and information attains worth according to the carer's ability to understand and act on it and timing is very important. Accordingly, an important aspect of the support required of statutory services at this stage of the caring process is ensuring that the carer has ready access to information s/he understands, at the time when s/he needs it, through the G.P., public health nurse or social worker. It is important to decide who is to be the 'Gate-keeper' of services. It is recommended that this person is the G.P. who already plays an important role in supporting the carers. The G.P. could put the carer in touch with those who can best help in relation to practical needs, medical needs, psychosocial needs and general preventive needs. Family and friends can help out at this stage by letting the carer know what support and assistance they are willing to give. The carers themselves have to collect information they need and they have to figure out the costs involved and make financial arrangements. They also have to plan on how other responsibilities in their lives are going to be met.

DAY-TO-DAY CARRYING-OUT OF THE CARING ROLE

Issues to be Addressed

The descriptions given by the carers of the study of the day-to-day

working out of the caring role suggest that for many the caring burden is very great: there are those, for example, who provide 24-hour care, some are caring for people who have problems of incontinence and soiling while other are dealing with difficult behaviour related to dementia. The results show that carers receive little help in day-to-day caregiving and that their task imposes strain in many aspects of their lives. It is clear from the results that not only do carers have needs arising from the kind of care which they provide but they also have needs arising from the necessity of looking after themselves in giving that care. The fact that the carer's satisfaction with caregiving is very much influenced by the quality of the relationship with the elderly person implies that the maintenance of a mutually satisfactory relationship between them is a very important need in the day-to-day life of the carer.

What Action is Required and by Whom?

In enabling the carers to carry out the day-to-day tasks of caregiving in a way that maintains a high quality of life both for themselves and their elderly charges, all three elements of a community of caring have an important role to play — statutory services, voluntary groups and family, friends and neighbours.

Practical Help Required

At this stage of the caring process a primary requirement of statutory bodies is the provision of back-up practical help to the carer. This back-up help may take a variety of forms, for example, home-help, meals-on-wheels or laundry service. In Britain, a system has been developed in some areas whereby Care Attendants are trained and paid to take over, when the need arises, some of the practical tasks normally carried out by the carer. The provision of aids such as walking frames, incontinence pads, bath rails and so on is also important in the practical support of the carers. In the day-to-day care of the elderly, carers require the provision of back-up medical assistance in the form of regular contact with the G.P. and the public health nurse and, if necessary, community psychiatric nurse. The provision of back-up rehabilitation services — such as occupational therapist, chiropodist or physiotherapist — is also required. A further important service required of statutory bodies is the provision of counselling and emotional support in coping with day-to-day caring.

Respite Services

A very important requirement of statutory bodies, at this stage, is the provision of short-term respite services. Different forms of respite service need to be developed to suit the varying needs of the carers and the elderly people being looked after. Some of these services may be home-based such as the 'sitting services' or care attendant schemes which have been developed in Britain. Other respite services may involve relief care away from home. In this context the provision of day-care centres is central to a service for both the carer and the elderly person involved. There are also other possibilities for relief care which will suit the needs of some carers: social clubs, day hospitals, short-term in-patient hospital services and intermittent relief admission.

Financial Support

Apart from practical help and respite services, a further issue highlighted by the results of the study — and which currently is not being addressed — is the need for financial support to cover the costs of extra expenses incurred in caring and to recompense the carer for the work s/he does. The Prescribed Relative Allowance excludes married women who, as the study shows, are the main carers of the elderly. Its provisions not only lack uniformity but are inadequate to meet the financial needs of carers. This provision is outdated and needs to be replaced with a comprehensive allowance that recognises the role of the carer in the provision of care.

Help from Family and Community Members

In addition to services provided by statutory bodies, family, friends and neighbours and voluntary groups play an essential role in supporting the carer in day-to-day caregiving. An obvious aspect of the support required of these groups is the provision of practical help in the personal and domestic care of the elderly person. Perhaps less obvious, but also important, is the provision of emotional support. Voluntary bodies which set up support groups for carers may be particularly valuable here by providing opportunities for sharing of experiences and for ventilation of the many feelings arising from caring; in particular uncomfortable feelings such as anger, frustration, resentment, sadness and guilt. Family, friends and neighbours can also provide important support by providing opportunities for respite from caring so that the carer can continue to

maintain a satisfactory social life. Voluntary groups could also provide sitting or minding services or care attendant schemes to enable the carer have a break from caregiving. More long-term opportunities for respite have been developed by voluntary groups in Britain. These respite schemes include week-end live-in companions to relieve the carer and 'fostering' schemes whereby the host family will take the elderly person into their own home for 2-3 weeks.

Setting Limits

Carers themselves have to learn to set limits on the amount of care they provide. They have to learn to ask for the help they need from whatever source — statutory services, voluntary groups or informal sources. They need to develop means of relieving stress in their lives and they need to learn satisfactory and effective means of communication with those in their care.

REVIEW STAGE OF THE CARING PROCESS

Issues to be Addressed

It sometimes happens that carers take on caregiving at a time of crisis and then find themselves in that role on a long-term basis though it may be very difficult for them to continue giving care. The findings of the present study indicate that caring is often a long-term commitment. The findings also show that many carers suffer health problems, that they give care at great cost to their social lives and that their financial circumstances are often strained. Such findings highlight the importance of continual review of how caring affects the carer's life. Clearly, both the carers and their elderly charges will be better for it if caregiving is organised in such a way that at least some of the carers' needs are also met. The needs both of the elderly person and of the carer will, of course, change over time and accordingly, periodic reviews are necessary so that changing needs can be identified, acknowledged and dealt with.

What Action is Required and by Whom?: Assessment and Co-ordination

In supporting the carer in reviewing the long-term outcomes and effects

of caregiving the main emphasis is likely to be on family and community members but statutory services also have a role to play at this stage. Perhaps one of the more important actions required of formal sources is to ensure that appropriate medical services are available to maintain in the long-term the physical well-being both of the carer and the elderly person. Part of this provision would be to ensure that long-term respite care is available where required: for example, residential homes, nursing homes, special units in hospitals. Possibilities for respite other than institutional care should also be explored such as the respite programme developed in the United States where elderly people who are not highly dependent are placed for a period of time in a specially designed apartment.

Informal Support

Informal sources of help also have a part to play in helping the carers keep physically well by ensuring that they get regular breaks from caregiving which allow time for rest and relaxation. Family, friends and voluntary groups can help the carers maintain their emotional well-being by providing opportunities, both for the carers and the people they look after, for talking about their experiences and for expressing the different feelings — both comfortable and uncomfortable — arising in the caring relationship. They can help the carer maintain a satisfactory social life by providing company and social contact and by taking over caregiving from time to time. They also have a role in supporting the carers in relation to their intellectual and spiritual well-being by providing opportunities for sharing of interests and views and for discussion of issues important in the carers' lives.

TERMINATION OF CARING ROLE

Issues to be Addressed

Carers of the present study who are no longer providing care, either because of the death or institutionalisation of the elderly person, describe the difficult role adjustment which such an event gives rise to and talk about the grief and loneliness which they experience. Whatever reason leads to the cessation of caregiving, the carer goes through a process of bereavement. The carers themselves and those who support them —

whether informally or formally — need to have an understanding of the different stages of the bereavement process. Only in this way will the carers get the help they need to work through the different reactions and feelings associated with different stages.

What Action is Required and by Whom?

In dealing with the ending of their caregiving role, statutory bodies can support the carers by ensuring that any professionals involved understand the bereavement process and can give counsel and support in dealing with such feelings as loss, grief, sadness, anger, loneliness, and guilt. They can also help by providing counselling and advice so that the carer may accept when the time has come where home-care is no longer feasible. Financial support also plays a very important part at this stage when the carer may lose certain sources of income and may have great difficulty in getting back into the labour market. Family and community members and voluntary groups can be a very valuable source of support to carers at this stage by comforting them and helping them to adjust to their loss.

KEY ISSUES FOR A COMMUNITY OF CARING

A community of caring implies that the carer does not find her/himself caring for the elderly person in isolation but rather is involved in a partnership of care with formal service providers, with family, friends and neighbours and with voluntary groups. A central element in a community of caring is the provision of services from formal, informal and voluntary sources which will address the different needs of the carer and the elderly person at each stage of the caring process. It is suggested that a Carers' Charter be drawn up which recognises and acknowledges the value of the role of the carer and which sets out the support required to enable the carer to continue looking after the elderly person in a way that ensures a high quality of life for them both.

Carers' Charter

- need for recognition both by public authorities and by family and community members of the enormous contribution of the carers and of the central role which they play in community care of the elderly.

- need for practical help in carrying out the tasks of caregiving.
- need for back-up services to the carer in providing medical, personal and domestic care.
- need for financial support and recompense for carers.
- need for involvement of all family members.
- need for emotional and moral support.
- need for information, advice and training.
- need for counselling.
- need for planning.
- need for assessment.
- need for integration and co-ordination of services.
- need for liaison between formal, informal and voluntary sources of assistance.
- need for awareness of services and easy access to information.

Agenda for Policy

The importance of initiating a comprehensive policy response centred around the needs of carers and those for whom they care is evident. In undertaking this initiative the unique demographic developments up to and beyond the year 2000 should be considered. The ageing of the Irish population has major implications for both families and social policy. Our response is to place emphasis on 'community care' as a way of meeting the needs of an increasing number of frail and dependent elderly persons. In the case of carers of the elderly, the reality is that 'community care' is largely care by families, and most often this means care by women. In practice the carers receive little practical support and are under considerable strain. There is a need for a co-ordinated, integrated approach incorporating the areas of health, social welfare, housing and social policy. Furthermore, there is a need for long-term planning. Short-term considerations dominated by budgetary constraints are not the answer. Substantial costs may be saved in the longer term, as many of the pressing issues in this area depend on our ability to develop policies and structures which will address these issues on the ground over a 10 to 15 year period. Our policies are constrained because we are not thinking and planning ahead for a society that will be radically different in structure than it is at present. We end this report with a series of questions. The answers to these questions will go some way towards creating a community of caring which supports carers and utilises and maximises the potential of the community. The implementation of the

answers will create an environment and an infrastructure where carers, their families, voluntary and statutory bodies work together each contributing to care in the community.

Questions for Policy-Making*

- Health Services

How can the services of G.P.'s, public health nurses and other health service professionals be used effectively to meet the needs of the carers and those for whom they care?

How can the carers' need for information, advice and training on how to provide care for an elderly person be met?

How can the support of rehabilitation services such as occupational therapist, chiropodist or physiotherapist, be made more widely available to carers?

What counselling and support services are required to enable the carers manage the stresses and demands of day-to-day caring and the bereavement and loss of role that follows from death or institutionalisation of the elderly person?

What are the implications for community health services of the current emphasis on faster return to the community of hospital patients?

- Personal Social Services

How can practical help in the form of domiciliary services be made widely available to carers?

What are the different kinds of respite service that are required to meet the varying needs of carers and how might these services be established in co-operation with family, community and voluntary bodies?

What practical aids and adaptations do carers require and how are these to be provided?

What structures are required to ensure that carers have ready access to any information and advice they need?

* Modified from Henwood M. and Wicks, M. *The Forgotten Army: Family Care and Elderly People*. Family Policy Studies Centre, 1984.

- **Social Welfare**
 What priority should be given to the extension of the Prescribed Relative Allowance to *all carers*?
 What adjustments have to be made to the social welfare system to ensure that the needs of elderly people requiring care can be met without imposing intolerable financial strain on their carers?
- **Taxation**
 Should the taxation system recognise the financial costs incurred by those providing home-care of the elderly?
- **Employment**
 What support is required to ease the problems of carers who are combining caregiving with employment outside the home?
- **Housing**
 What balance is required in allocating resources between special needs housing for the elderly and schemes for improvement of the existing homes of the elderly?
 What are the implications for housing policies of care of the elderly in their own homes?

CONCLUSION

This study, which is the first detailed account of home-care of the elderly in Ireland, has presented an analysis of the different stages of the caring process and has documented the life-experiences of carers. The study has identified key needs and has presented guidelines for action required of family, community members and voluntary and statutory bodies in supporting those who look after elderly people at home. By demonstrating the extent of caring, by exploring the nature of the caring process and by identifying the areas most in need of attention the study provides the groundwork for future policy-making.

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Appendix One

Additional Tables Related to Chapters Four to Twelve

Table A4.1: Age off elderly person (Q.2)

Age Group:	Male		Female		Total	
	N	%	N	%	N	%
65 — 70	11	13.4	10	8.5	21	10.5
71 — 75	16	19.5	18	15.3	34	17.0
76 — 80	17	20.7	18	15.3	35	17.5
81—85	13	15.9	37	31.4	50	25.0
86 — 90	16	19.5	20	16.9	36	18.0
91 — 95	8	9.8	12	10.2	20	10.0
Over 95	1	1.2	3	2.5	4	2.0
Total (N)	82		118		200	

Table A4.2: Previous employment status of elderly person (Q.3b)

Employment Status	Number	Percentage
Self-Employed	7	3.5
Employee	75	37.5
Farmer	48	24.0
Housewife	59	29.5
Don't Know	1	0.5
Did Not Work	10	5.0
Total (N)	200	

Table A4.3: Size of farm of elderly person (Q.3b)

Size of Farm	Number	Percentage
More than 200 Acres	1	2.1
100—199 Acres	2	4.2
50 — 99 Acres	15	31.3
30 — 49 Acres	12	25.0
Less than 30 Acres	15	31.3
Size Unknown	3	6.3
Total (N)	48	

Table A4.4: Previous occupation of elderly person (Q.3a)

Occupation	Number	Percentage
Higher Professional and Higher Managerial	1	1.2
Lower Professional and Lower Managerial	9	11.0
Other Non-Manual	11	13.4
Skilled Manual	19	23.2
Semi-Skilled Manual	17	20.7
Unskilled	24	29.3
Unknown	1	1.2
Total (N)	82	

Table A4.5: Duration of physical disability of elderly person (Q.24)

Number of Years	Number	Percentage
1	11	6.5
2	11	6.5
3	18	10.7
4	16	9.5
5	17	10.1
6	13	7.7
7	6	3.6
8	8	4.7
10	23	13.6
11	4	2.4
12	7	4.1
14	3	1.8
15	7	4.1
16	1	0.6
20	10	5.9
24	1	0.6
25	4	2.4
26	1	0.6
30	4	2.4
40	2	1.2
63	2	1.2
Total (N)	169*	

* Based on those who suffer a disability

Table A4.6: Persons who help with personal care of the elderly person

Person Who Helps	Washing and Bathing				Shaving and Hair-Care				Cutting Toe-Nails			
	First Helper		Second Helper		First Helper		Second Helper		First Helper		Second Helper	
	N	%	N	%	N	%	N	%	N	%	N	%
No-One	6	3.8	94	59.9	4	4.8	57	67.9	2	1.1	112	60.2
Carer	120	76.4	2	1.3	69	82.1	0	0.0	139	74.7	4	2.2
Spouse	7	4.5	9	5.7	8	9.5	4	4.8	8	4.3	8	4.3
Other Household Member	1	0.6	23	14.6	1	1.2	14	16.7	3	1.6	24	12.9
Other Relative	9	5.7	12	7.6	1	1.2	4	4.8	8	4.3	15	8.1
Public Health Nurse	14	8.9	9	5.7	1	1.2	2	2.4	9	4.8	14	7.5
Friend/Neighbour	0	0.0	5	3.2	0	0.0	2	2.4	2	2.1	3	1.6
Other	0	0.0	3	1.9	0	0.0	1	1.2	15	8.1	6	3.2
Total (N)	157		157		84		84		186		186	

Non-respondents and those not requiring help are excluded

Table A4.7: Persons who help with different aspects of dressing

Person Who Helps	Shoes and Stockings				Buttons and Zips				Other Aspects of Dressing			
	First Helper		Second Helper		First Helper		Second Helper		First Helper		Second Helper	
	N	%	N	%	N	%	N	%	N	%	N	%
No-One	4	3.1	84	64.6	2	1.8	78	69.7	2	2.0	67	68.4
Carer	119	92.2	3	2.3	102	91.1	3	2.7	92	93.9	1	1.0
Spouse	2	1.6	7	5.4	2	1.8	8	7.1	2	2.0	4	4.1
Other Household Member	3	2.3	27	20.8	6	5.4	15	13.4	2	2.0	19	19.4
Other Relative	1	0.8	6	4.6	0	0.0	5	4.5	0	0.0	4	4.1
Public Health Nurse	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
Friend/Neighbour	0	0.0	2	1.5	0	0.0	2	1.8	0	0.0	2	2.0
Other	0	0.0	1	0.8	0	0.0	1	0.9	0	0.0	1	1.0
Total (N)	129		130		112		112		98		98	

Non-respondents and those not requiring help are excluded

Table A4.8: Person* who help with feeding and cooking

Person Who Helps	Feeding				Cooking Meals			
	First Helper		Second Helper		First Helper		Second Helper	
	N	%	N	%	N	%	N	%
No-One	1	2.3	32	74.4	5	2.8	141	77.9
Carer	42	97.7	0	0.0	171	94.5	0	0.0
Spouse	0	0.0	0	0.0	1	0.6	3	1.7
Other Household Member	0	0.0	6	14.0	2	1.1	25	13.8
Other Relative	0	0.0	3	6.9	1	0.6	11	6.1
Public Health Nurse	0	0.0	0	0.0	0	0.0	0	0.0
Friend/Neighbour	0	0.0	1	2.3	1	0.6	1	0.6
Other	0	0.0	1	2.3	0	0.0	0	0.0
Total (N)	43		43		181		181	

Non-respondents and those not requiring help excluded

Table A4.9: Persons who help with mobility

Person Who Helps	Getting out of Bed				Climbing Stairs				Walking			
	First Helper		Second Helper		First Helper		Second Helper		First Helper		Second Helper	
	N	%	N	%	N	%	N	%	N	%	N	%
No-One	4	4.8	53	63.9	8	6.6	82	67.8	13	11.7	74	66.7
Carer	77	92.8	2	2.4	111	91.7	0	0.0	94	84.7	2	1.8
Spouse	2	2.4	9	10.8	1	0.8	11	9.1	1	0.9	11	9.9
Other Household Member	0	0.0	11	13.3	0	0.0	17	14.0	2	1.8	18	16.2
Other Relative	0	0.0	3	3.6	0	0.0	10	8.3	0	0.0	4	3.6
Public Health Nurse	0	0.0	1	1.2	0	0.0	0	0.0	0	0.0	0	0.0
Friend/Neighbour	0	0.0	2	2.4	0	0.0	1	0.8	0	0.0	1	0.9
Other	0	0.0	2	2.4	1	0.8	0	0.0	1	0.9	1	0.9
Total (N)	83		83		121		121		111		111	

Non-respondents and those not requiring help excluded

Table A4.10: Ability of elderly person in getting to and using toilet (Q.25a)

Degree of Ability	Number	Percentage
Without Difficulty	118	59.6
With Difficulty	32	16.2
Only with Help	25	12.6
Not at All	23	11.6
Total (N)	198	
Non-respondents excluded		

Table A4.1.1: Duration of symptoms of dementia

Number of Years	Memory Loss		Depression		Angry Outbursts		Sleeplessness		Confusion		Wandering		Failure to Recognise Family	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
1	22	25.0	13	12.0	14	18.4	15	17.4	18	23.7	6	16.7	7	21.9
2	16	18.0	14	13.0	12	15.8	13	15.1	18	23.7	10	27.8	10	31.3
3	15	17.0	22	21.0	10	13.2	15	17.4	13	17.1	10	27.8	5	15.6
4	13	15.0	15	14.0	6	7.9	8	9.3	9	11.8	2	5.6	5	15.6
5	5	5.0	13	12.0	11	14.5	11	12.8	8	10.5	4	11.1	4	12.5
6	4	5.0	2	2.0	3	3.9	4	4.7	1	1.3	0	0.0	0	0.0
7	2	2.0	2	2.0	0	0.0	2	2.3	2	2.6	1	2.8	0	0.0
8	0	0.0	2	2.0	3	3.9	0	0.0	2	2.6	0	0.0	0	0.0
9	1	1.0	1	1.0	2	2.6	1	1.2	1	1.3	0	0.0	0	0.0
10	7	8.0	8	8.0	5	6.6	9	10.5	2	2.6	2	5.6	0	0.0
11	0	0.0	0	0.0	1	1.3	0	0.0	0	0.0	0	0.0	0	0.0
12	1	1.0	2	2.0	1	1.3	1	1.2	0	0.0	0	0.0	0	0.0
13	1	1.0	3	3.0	0	0.0	1	1.2	1	1.3	0	0.0	0	0.0
14	0	0.0	1	1.0	2	2.6	1	1.2	0	0.0	0	0.0	0	0.0
15	0	0.0	3	3.0	1	1.3	2	2.3	0	0.0	0	0.0	1	1.3
17	0	0.0	1	1.0	1	1.3	0	0.0	0	0.0	0	0.0	0	0.0
20	0	0.0	2	2.0	4	5.3	2	2.3	0	0.0	0	0.0	0	0.0
24	0	0.0	1	1.0	0	0.0	0	0.0	1	1.3	0	0.0	0	0.0
30	1	1.0	1	1.0	0	0.0	1	1.2	1	1.3	1	2.8	0	0.0
Total (N)	88		106		76		86		76		36		32	

Based on those who exhibit the symptom

Non-respondents excluded

Table A4.12: Relationship between house-boundness and extent of care required

Degree of House-Boundness	Needs 24-Hour Care	Constant Care by Day	Care Needed Occasionally
Bedridden Permanently	4	6	1
Bedridden Temporarily	8	6	3
Housebound Permanently	9	9	15
Able to Get Out Only With Help	16	26	39
Able to Get Out Unassisted	2	12	44
Total (N)	39	59	102

Table A4.13: Relationship between incontinence and extent of care required

Whether Incontinent	Needs 24-Hour Care	Constant Care by Day	Care Needed Occasionally
Yes	21	17	10
No	18	42	92
Total (N)	39	59	102

Table A4.14: Relationship between soiling and extent of care required

Whether Elderly Person Soils	Needs 24-Hour Care	Constant Care by Day	Care Needed Occasionally
Yes	18	15	6
No	21	44	96
Total (N)	39	59	102

Table A4.15: Relationship between amount of care and extent of care required

Amount of Care	Needs 24-Hour Care	Constant Care by Day	Care Needed Occasionally
A Lot	36	47	31
A Little	3	12	61
Occasional	0	0	10
Total (N)	39	59	102

Table A5.1: Age at finishing full-time education (Q.89)

Age	Number	Percentage
11	1	0.5
12	1	0.5
13	6	3.2
14	45	23.9
15	42	22.3
16	41	21.8
17	19	10.1
18	28	14.9
20	2	1.1
21	1	0.5
22	2	1.1
Total (N)	188	
Non-respondents excluded		

Table A5.2: Level of education of carers (Q.86)

Level of Education	Number	Percentage
Primary Certificate	90	45.5
Intermediate Certificate	35	17.7
Group Certificate	34	17.2
Leaving Certificate	30	15.2
University/NIHE	5	2.5
Other 3rd Level	1	0.5
Other	3	1.5
Total (N)	198	100.0

Table A5.3: Employment status of carer (Q.99)

Employment Status	Male		Female		Total	
	N	%	N	%	N	%
In Paid Employment	15	41.66	16	9.75	31	15.5
Not in Paid Employment	21	58.33	148	90.24	169	84.5
Total (N)	36		164		200	

Table A5.4: Size of farm (Q. 106)

Size of Farm	Number	Percentage
100-199 Acres	1	7.1
50-99 Acres	5	35.7
30-49 Acres	4	28.6
Less than 30 Acres	4	28.6
Total (N)	14	

Table A5.5: Number of years since carer was last in paid work (Q.10c)

Last Year of Employment	Number	Percentage
1930	1	0.8
1934	1	0.8
1937	1	0.8
1939	1	0.8
1941	1	0.8
1943	1	0.8
1945	2	1.7
1949	3	2.5
1950	4	3.3
1951	2	1.7
1952	1	0.8
1953	1	0.8
1955	2	1.7
1956	1	0.8
1958	1	0.8
1959	5	4.2
1960	2	1.7
1961	2	1.7
1962	3	2.5
1963	2	1.7
1964	3	2.5
1965	3	2.5
1966	4	3.3
1967	7	5.8
1968	3	2.5
1970	2	1.7
1971	2	1.7
1972	5	4.2
1973	2	1.7
1974	1	0.8
1975	2	1.7
1976	5	4.2
1977	3	2.5
1978	6	5.0
1979	3	2.5
1980	5	4.2
1981	5	4.2
1982	2	1.7
1983	6	5.0
1984	6	5.0
1985	4	3.3
1986	1	0.8
1987	3	2.5
Total (N)	120	

Non-respondents excluded

Table A5.6: Reasons for leaving employment (Q.10b)

Reason	Male		Female		Total	
	N	%	N	%	N	%
Redundancy	6	28.6	2	2.0	8	6.5
Retirement	4	19.0	3	2.9	7	5.7
Marriage	0	0.0	63	61.8	63	51.2
Child-Rearing	0	0.0	10	9.8	10	8.1
To Care for Elderly Person	8	38.1	17	16.7	25	20.3
Other	3	14.3	7	6.9	10	8.1
Total (N)	21		102		123	

Table A5.7: Amount received in pensions in household (Q.76)

Amount	Social Welfare Pension	Old Age Pension
	N	N
Undisclosed	1	8
£20-28	1	0
£29-40	2	9
£41-45	0	15
£46-50	4	61
£51-55	3	19
£56-60	0	4
£66-70	0	5
£71-75	0	1
£76-80	1	2
£81-85	0	2
£86-90	4	5
£91-95	2	18
£96-100	0	13
£101-105	0	1
£106-110	0	2
£131	1	0
£178	0	1
Total (N)	19	166

Table A5.10: Relationship between amount of income and experience of financial strain

Whether Financial Strain is Experienced	Amount Undisclosed	£12-40	£50-100	£102-150	£154-200	£210-250	£260-300	£350-400	£450	No Wage/Salary	Total N	%
Yes	6	3	5	3	4	1	1	0	0	19	42	21.0
Sometimes	4	2	4	4	6	0	2	0	0	7	29	14.6
No	22	4	17	14	20	7	2	3	1	38	128	64.3
Total (N)	32	9	26	21	30	8	5	3	1	64	199	
Non-respondent excluded												

Table A5.11: Relationship between overall weekly income and experience of financial burden

Response	£31-50	£53-100	£103-150	£157-200	£202-250	£252-303	£306-400	£490	Total N	%
Yes	4	13	11	7	3	0	8	0	42	21.0
Sometimes	2	5	7	3	7	2	2	0	29	14.5
No	14	29	22	18	15	15	8	2	128	64.0
No Response	1	0	0	0	0	0	0	0	1	0.5
Total (N)	21	47	40	28	25	17	11	2	200	

Table A5.12: Home ownership (Q.13)

Ownership	Number	Percentage
Owned Outright	143	72.2
Mortgage/Loan	27	13.6
Rented: Local Authority	10	5.1
Rented: Private	2	1.0
In Relative's Home	13	6.6
Other	3	1.5
Total (N)	198	

Non-respondents excluded.

Table A5.13: Number of people in household (Q.11a)

Number of People	Number	Percentage
2	63	31.7
3	43	21.6
4	18	9.0
5	19	9.6
6	19	9.6
7	22	11.1
8	6	3.0
9	5	2.5
10	4	2.0
Total (N)	199	

Non-respondents excluded.

Table A5.14: Number of visits to doctor in previous year (Q.44)

Number of Visits	Number	Percentage
1	35	24.3
2	29	20.1
3	9	6.3
4	18	12.5
5	6	4.2
6	10	6.9
7	1	0.7
8	4	2.8
9	2	1.4
10	4	2.8
12	22	15.3
17	1	0.7
24	2	1.4
26	1	0.7
Total (N)	144	

Based on those who had visited a doctor

Non-respondents excluded

Table A5.12: Home ownership (Q.13)

Ownership	Number	Percentage
Owned Outright	143	72.2
Mortgage/Loan	27	13.6
Rented: Local Authority	10	5.1
Rented: Private	2	1.0
In Relative's Home	13	6.6
Other	3	1.5
Total (N)	198	

Non-respondents excluded.

Table A5.13: Number of people in household (Q.11a)

Number of People	Number	Percentage
2	63	31.7
3	43	21.6
4	18	9.0
5	19	9.6
6	19	9.6
7	22	11.1
8	6	3.0
9	5	2.5
10	4	2.0
Total (N)	199	

Non-respondents excluded.

Table A5.14: Number of visits to doctor in previous year (Q.44)

Number of Visits	Number	Percentage
1	35	24.3
2	29	20.1
3	9	6.3
4	18	12.5
5	6	4.2
6	10	6.9
7	1	0.7
8	4	2.8
9	2	1.4
10	4	2.8
12	22	15.3
17	1	0.7
24	2	1.4
26	1	0.7
Total (N)	144	

Based on those who had visited a doctor

Non-respondents excluded

Table A8.1: Number of children living away from home (Q.49a)

Number of Children	Number	Percentage
1	17	21.3
2	21	26.3
3	15	18.8
4	9	11.3
5	9	11.3
6	3	3.8
7	2	2.5
8	1	1.3
9	2	2.5
10	1	1.3
Total (N)	80	

Based on carers with children living away from home.

Table A8.2: Age of children living away from home (Q.49c)

Child	<20	21-25	26-30	31-35	36-40	41-45	46-50	>50	Total
1st	5	14	18	11	20	4	6	1	79
2nd	3	12	11	12	12	5	4	1	60
3rd	3	8	12	9	2	4	3	1	42
4th	4	5	8	2	3	3	2	0	27
5th	2	7	3	2	1	3	0	0	18
6th	1	6	0	1	0	1	0	0	9
N	18	52	52	37	38	20	15	3	235
%	7.7	22.1	22.1	15.7	16.2	8.5	6.4	1.3	

Non-respondents excluded.

Table A8.3: Employment status of children living away from home (Q.49)

Child	Employment Status				
	Full-Time	Part-Time	Housewife	Not Working	Total
1st	55	6	13	7	81
2nd	42	5	13	3	63
3rd	27	2	8	5	42
4th	13	2	10	2	27
5th	8	1	8	1	18
6th	2	1	5	1	9
N	147	17	57	19	240
%	61.3	7.1	23.8	7.9	

Table A8.4: Relationship between proximity of children and frequency of visits

Frequency of Visits	Distance of Children from Carer in Miles				N
	<5 N	>5<15 N	>15<50 N	>50 N	
More than once per week	31	4	0	0	35
Weekly	9	10	4	1	24
2-3 times monthly	0	2	3	2	7
6-12 times yearly	0	1	1	9	11
Rarely	0	0	1	3	4
N	40	17	9	15	81
%	49.4	21.0	11.1	18.5	

Table A8.5: Relationship between sex of children and frequency of visits

Frequency of Visits	Sex of Child			Total N	%
	Male N	Female N			
More than once per week	26	9		35	43.2
Weekly	17	7		24	29.6
2-3 Times Monthly	3	4		7	8.6
6-12 Times Yearly	9	2		11	13.6
Rarely	3	1		4	4.9
N	58	23		81	
%	71.6	28.4			

Table A8.6: Satisfaction with number of visits from children (Q.49h)

Child	Degree of Satisfaction		
	Would Like More	Would Like Less	Satisfied
1st	10	2	69
2nd	8	1	53
3rd	4	1	36
4th	2	1	23
5th	2	0	16
6th	0	0	9
N	26	5	206
%	11.0	2.1	86.9

Non-respondents excluded.

Table A8.7: Nature of relationship with children living away from home (Q.49i)

Child	Nature of Relationship					Total
	Very Close And Friendly	Reasonably Good	Based On Duty/ Responsibility/	Contact By Letter Only	No Contact	
1st	74	3	2	2	0	81
2nd	55	4	2	1	0	62
3rd	38	2	1	0	0	41
4th	24	0	1	1	0	26
5th	17	0	0	1	0	18
6th	9	0	0	0	0	9
N	217	9	6	5	0	237
%	91.6	3.8	2.5	2.1	0.0	

Non-respondents excluded.

Table A8.8: Number of siblings living apart from carer (Q.51a)

Number of Siblings	Number	Percentage
1	43	26.5
2	31	19.1
3	33	20.4
4	14	8.6
5	16	9.9
6	10	6.2
7	5	3.1
8	2	1.2
9	4	2.5
10	3	1.9
11	1	0.6
Total (N)	162	

Table A3.9: Age of siblings (Q.51c)

Sibling	Age(3roup							
	<20	21-30	31-40	41-50	51-60	61-70	71-80	Total
1st	2	2	24	46	43	31	12	160
2nd	1	2	20	38	29	22	5	117
3rd	1	6	20	26	18	12	2	85
4th	0	3	12	14	14	8	0	51
5th	0	2	10	12	6	5	0	35
N	4	15	86	136	110	78	19	448
%	0.9	3.3	19.2	30.4	24.6	17.4	4.2	

Non-respondents excluded.

Table A8.10: Relationship between proximity of siblings and frequency of visits

Frequency of Visits	Distance of Siblings in Miles				N
	<5 N	>5<15 N	>15<50 N	>50 N	
More than once per week	28	0	0	0	28
Weekly	15	10	4	3	32
2-3 times monthly	12	7	5	2	26
6-12 times yearly	6	7	4	8	25
Rarely	2	3	6	36	47
Never	0	0	0	2	2
N	63	27	19	51	160
%	39.4	16.9	11.9	31.9	

Table A8.11: Nature of relationship between carer and brothers and sisters (Q.51h)

Sibling	Nature of Relationship					Total
	Very Close and Friendly	Reasonably Close	Based on Duty and Responsibility	Contact by Letter Only	No Contact at All	
1st	72	66	5	10	7	160
2nd	59	37	5	11	4	116
3rd	45	32	1	4	3	85
4th	25	17	2	4	3	51
5th	16	13	1	3	2	35
N	217	165	14	32	19	447
%	48.5	36.9	3.1	7.2	4.3	

Non-respondents excluded.

Table A8.12: Distance of parents/parents-in-law from carer's home (Q.52c)

Distance	Father	Mother	Mother-in-Law	Father-in-Law
Within 5 miles	6	6	9	6
More than 5; Less than 15	2	6	6	2
More than 15; Less than 50	1	2	0	1
More than 50	3	3	2	0
Total (N)	12	17	17	9

Table A8.13: Satisfaction with frequency of contact with parents/parents-in-law (Q.52f)

Degree of Satisfaction	Mother	Father	Mother-in-Law	Father-in-Law
Want More	7	2	1	0
Want Less	0	1	1	1
Want Same	10	8	15	8
Total (N)	17	11	17	9

Non-respondents excluded.

Table A8.14: Other relatives/friends with whom carer has contact (Q.53a)

Relation/Friend	Nature of Relation				Total
	Aunt/ Uncle	Niece/ Nephew	Cousin	Other Friend	
1st Mentioned	25	15	36	35	111
2nd Mentioned	14	12	12	23	51
3rd Mentioned	5	7	7	13	32
4th Mentioned	2	7	4	2	15
N	46	41	59	73	209
%	22.0	19.6	28.2	34.9	

Table A8.15: Age of friends/relatives of carers (Q.53b)

Age-Group In Years	Relative					Total	
	1st	2nd	3rd	4th		N	%
>10	2	1	0	0		3	1.4
11-20	4	6	4	3		17	7.9
21-30	5	3	4	1		13	6.0
31-40	22	14	8	3		47	21.9
41-50	24	14	6	5		49	22.8
51-60	23	14	3	0		40	18.6
61-70	15	4	3	1		23	10.7
71-80	9	5	3	1		18	8.4
81-90	4	0	0	0		4	1.9
>90	1	0	0	0		1	0.5
Total (N)	109	61	31	14		215	

Non-respondents excluded.

Table A8.16: Relationship between proximity of relatives/friends and frequency of visits

Frequency of Visits	Distance From Carer of Relatives/Friends in Miles				
	Within 5 Miles N	>5<15 N	>15 <50 N	>50 N	N
More than once per week	26	2	0	0	28
Weekly	27	6	1	0	34
2-3 times monthly	8	0	1	1	10
6-12 times yearly	7	7	3	5	22
Rarely	0	0	4	11	15
Never	0	0	0	2	2
N	68	15	9	19	111
%	61.3	13.5	8.1	17.1	

Table A8.17: Proximity of permanent neighbours (Q.66)

Proximity	Number	Percentage
Next Door	95	47.5
Across The Road	23	11.5
50-100 Yards Away	49	24.5
100 Yards to 0.25 Miles	24	12.0
0.25 Miles to 2 Miles	8	4.0
More Isolated	1	0.5
Total (N)	200	

Table A8.18: Relation of helper to carer (Q.55)

Helper	Parent	Parent-in-Law	Child	Sibling	Sibling-in-Law	Other Relative	Friend/Neighbour	Other	Total
1st	3	3	30	33	7	7	20	1	104
2nd	0	0	14	14	3	14	15	3	63
3rd	0	0	5	7	1	4	16	1	34
4th	0	0	0	0	0	2	4	0	6
5th	0	0	0	1	0	0	1	0	2
6th	0	0	0	0	0	0	1	0	1
N	3	3	49	55	11	27	57	5	210
%	1.4	1.4	23.3	26.2	5.2	12.9	27.1	2.4	

Table A8.19: Second activity which helper carries out (Q.55)

Kind of Help	Helper						Total	
	1st	2nd	3rd	4th	5th	6th	N	%
Shopping	4	3	1	0	1	0	9	5.2
Cooking	10	7	2	0	0	0	19	11.0
Laundry	6	2	1	0	0	0	9	5.2
Making Fires	5	4	0	0	0	0	9	5.2
Cutting Fuel	3	1	2	2	0	0	8	4.6
Bringing in Fuel	4	4	2	0	0	0	10	5.8
Gardening	4	3	1	1	0	0	9	5.2
Cleaning	8	3	2	1	0	0	14	8.1
Decoration	1	2	4	0	0	0	7	4.0
Household Repairs	5	3	3	0	0	0	11	6.4
Looking after Elderly Person	13	8	5	0	0	0	26	15.0
Bathing/Washing Elderly Person	5	1	0	0	1	0	7	4.0
Lifting/Helping Elderly Person	1	0	1	0	0	0	2	1.2
Dressing Elderly Person	2	2	0	0	0	0	4	2.3
Taking Elderly Person Out for a Walk	14	11	3	1	0	0	29	16.8
Total (N)	85	54	27	5	2	0	173	

Table A8.20: Duration of visits of helper (Q.55)

Duration	Helper						Total	
	1st	2nd	3rd	4th	5th	6th	N	%
1-2 Hours	45	34	22	5	9	1	109	55.6
3-4 Hours	35	21	6	1	0	0	63	32.1
5-6 Hours	9	1	3	0	0	0	13	6.6
8-12 Hours	2	2	1	0	0	0	5	2.6
Over 12 Hours	3	2	1	0	0	0	6	3.1
Total (N)	94	60	33	6	2	1	196	

Non-respondents excluded.

Table A8.21: Changes over time in help provided (Q.55)

Change	Helper						Total	
	1st	2nd	3rd	4th	5th	6th	N	%
Increased	61	47	25	6	2	1	142	67.9
Decreased	1	1	1	0	0	0	3	1.4
Remained the Same	40	14	7	0	0	0	61	29.2
Other	1	1	1	0	0	0	3	1.4
Total (N)	103	63	34	6	2	1	209	

Non-respondents excluded.

Table A8.22: Level of informal support with crisis situations

Level of Support	Number	Percentage
Very High Level	19	46.3
High Level	11	26.8
Medium Level	5	12.2
Low Level	5	12.2
No Support	1	2.4
Total (N)	41	

Non-respondents excluded.

Table A8.23: First most important person with whom carer shares values/interests (Q.65)

Value/Interest	Person With Whom Carer Shares												Total (N)		
	Spouse		Parent		Brother/ Sister		Other Relative		Friend/ Neighbour		Other			No-One	
	N	%	N	%	N	%	N	%	N	%	N	%		N	%
Similar ideals on the right way of life	100	50.0	4	2.0	28	14.0	10	5.0	32	16.0	1	0.5	25	12.5	200
Great Many Interests In Common	97	48.5	3	1.5	26	13.0	10	5.0	42	21.0	0	0.0	22	11.0	200
Share Same General Philosophy of Life	105	52.8	3	1.5	28	14.1	9	4.5	31	15.6	3	1.5	20	10.1	199
Enjoy Same Books/ Movies/Music	78	43.6	2	1.1	22	12.3	7	3.9	41	22.9	0	0.0	29	6.2	179
Enjoy Same Kind of Party	88	51.5	1	0.6	20	11.7	3	1.8	33	19.3	2	1.2	24	14.0	171

Non-respondents excluded.

Table A8.24: First person for whom carer feels concern (Q.65)

Kind of Concern	Person												Total (N)		
	Spouse		Parent		Brother/ Sister		Other Relative		Friend/ Neighbour		Other			No-One	
	N	%	N	%	N	%	N	%	N	%	N	%		N	%
Worry A Great Deal About Person	76	38.2	28	14.1	16	8.0	14	7.0	6	3.0	1	0.5	58	29.1	199
Visit Person When Sick	37	19.1	16	8.2	45	23.2	33	17.0	37	19.1	1	0.5	25	12.9	194
Send Christmas/Other Gifts	42	21.2	15	7.6	43	21.7	40	20.2	26	13.1	2	1.0	30	15.2	198
Remember Person's Birthday	90	45.5	15	7.6	28	14.1	22	11.1	14	7.1	2	1.0	27	13.6	198
Non-respondents and carers for whom question is non-applicable excluded.															

Non-respondents and carers for whom question is non-applicable excluded.

Table A8.2B: First person whom carer trusts (Q.65)

Element of Trust	Person												Total (N)		
	Spouse		Parent		Brother/ Sister		Other Relative		Friend/ Neighbour		Other			No-One	
	N	%	N	%	N	%	N	%	N	%	N	%		N	%
Would Talk About 'Put Down' Had Received	95	47.5	5	2.5	23	11.5	12	6.0	27	13.5	2	1.0	36	18.0	200
Would Share Information That Could Get Me Fired	97	48.7	6	3.0	32	16.1	14	7.0	18	9.0	3	1.5	29	14.6	199
Would Share Psychological Problems	63	31.8	2	1.0	23	11.6	12	6.1	32	16.2	19	9.6	47	23.7	198
Would Share Sexual Problems	43	24.3	1	0.6	6	3.4	1	0.6	20	11.3	8	4.5	98	55.4	177

Non-respondents or carers for whom the question is non-applicable are excluded.

Tabla A8.26: First parson whom carar dasiras interaction (Q.65)

Desired Interaction	Person												Total (N)		
	Spouse		Parent		Brother/ Sister		Other Relative		Friend/ Neighbour		Other			No-One	
	N	%	N	%	N	%	N	%	N	%	N	%		N	%
See him/her every day	59	30.6	8	4.1	33	17.1	26	13.5	42	21.8	1	0.5	24	12.4	193
Spend More Free Time With him/her	80	41.9	6	3.1	15	7.9	15	7.9	28	14.7	2	1.0	45	23.6	191
Would Like to see More Often	17	8.8	9	4.6	42	21.6	39	20.1	36	18.6	1	0.5	50	25.8	194

Table A10.1: Influence of relationship between carer and elderly person on experience of financial burden

Relationship of Carer to Elderly Person	Whether or not Financial Burden is Experienced				
	Yes		No		Total (N)
	N	%	N	%	
Spouse	2	4.3	45	95.7	47
Parent	8	8.8	83	91.2	91
Parent-in-law	3	7.9	35	92.1	38
Brother	1	50.0	1	50.0	2
Brother-in-law	1	100.0	0	0.0	1
Sister	1	33.3	2	66.7	3
Sister-in-law	1	50.0	1	50.0	2
Other Relative	1	10.0	9	90.0	10
Friend	2	33.3	4	66.7	6

Table A10.2: Influence of marital status on experience of financial burden

Marital Status of Carer	Whether or not Financial Burden is Experienced				
	Yes		No		Total (N)
	N	%	N	%	
Married	15	11.3	118	88.7	133
Widowed	2	14.3	12	85.7	14
Divorced/Separated	1	25.0	3	75.0	4
Deserted	0	0.0	2	100.0	2
Single	2	4.3	45	95.7	47

Table A10.3: Influence of receipt of financial aid from relatives on experience of financial burden

Whether Aid is Received From Relatives	Whether or not Financial Burden is Experienced				
	Yes		No		Total (N)
	N	%	N	%	
Yes	1	9.1	10	90.9	11
No	19	10.1	170	89.9	189

Table A10.4: Influence of elderly person's contribution on experience of financial burden

Whether Elderly Person Contributes to Costs	Whether Financial Burden is Experienced						Total (N)
	Yes		No		Don't Know		
	N	%	N	%	N	%	
Yes	14	7.5	171	91.9	1	0.5	186
No	6	46.2	7	53.8	0	0.0	13

Table A10.5: Participation in sports and other interests (Q.90a)

Rate of Participation	Activity			
	Sport		Knitting/Dressmaking/Craftwork	
	N	%	N	%
At least weekly	2	1.0	26	13.0
2-3 times per month	1	0.5	11	5.5
Once per month	1	0.5	7	3.5
Less than 12 times per year	1	0.5	11	5.5
Rarely	3	1.5	37	18.5
Never	192	96.0	108	54.0
Total (N)	200		200	

Table A10.6: Changes in involvement in different pastimes (Q.90b)

Change in Involvement	Pastime					
	Watching TV/Video		Reading		Walking	
	N	%	N	%	N	%
Increased	32	16.3	13	6.6	4	2.0
Decreased	15	7.7	30	15.3	53	27.8
Same	149	76.0	153	78.1	134	70.2
Total (N)	196		196		191	

Non-respondents excluded.

Table A10.7: Involvement in practical outings

Rate of Involvement	Outing					
	Shops/ Post-Office		Hairdresser		Library	
	N	%	N	%	N	%
Daily	48	24.0	1	0.5	1	0.5
3 times or more a week	36	18.0	3	1.5	0	0.0
1-2 times a week	67	33.5	3	1.5	1	0.5
1-3 times a month	36	18.0	21	10.6	18	9.1
11 times or less a year	2	1.0	58	29.3	5	2.5
Once a year	2	1.0	22	11.2	6	3.0
Rarely	4	2.0	61	30.8	32	16.2
Never	5	2.5	29	14.6	135	68.2
Total (N)	200		198		198	

Non-respondents excluded.

Table A10.8: Changes in visits with relations and friends since becoming a carer (Q.90c)

Change	Visits to Friends/ Relations		Visits from Friends/ Relations	
	N	%	N	%
Increased	8	4.1	59	29.9
Decreased	99	51.0	35	17.8
Same	87	44.9	103	52.3
Total (N)	194		197	

Non-respondents excluded.

Table A10.14: Effect of caring on different relationships*

ect	Relationship									
	Spouse		Children		Parent		Sibling		Other Relation	
	N	%	N	%	N	%	N	%	N	%
Positive	7	6.0	8	5.5	2	2.8	8	4.5	8	4.2
Negative	18	15.7	31	21.2	4	5.6	15	8.5	7	3.7
None	90	78.3	107	73.3	66	91.6	154	87.0	174	92.1
Total (N)	115		146		72		177		189	
									199	

* Percentages based only on those carers for whom the particular relationship is applicable.
Non-respondents excluded.

Table A10.15: Relationship between carer's belief that health has suffered and self-rating of health

Self-Rating of Health	Whether Health has Suffered			
	Agree		Disagree	
	N	%	N	%
Very Good/Excellent	2	3.4	36	25.9
Good	14	23.7	56	40.3
Average for Age	14	23.7	29	20.9
Fair	19	32.2	11	7.9
Poor	8	13.5	7	5.0
Very Poor	2	3.4	0	0.0
Total (N)	59		139	

Non-respondents excluded.

Table A10.16: Relationship between carer's belief that health has suffered and experience of health problem

Experience of Health Problem	Whether Health has Suffered			
	Agree		Disagree	
	N	%	N	%
Yes	30	50.8	37	26.6
Sometimes	10	16.9	7	5.0
No	19	32.2	95	68.3
Total (N)	59		139	

Non-respondents excluded.

Table A10.17: Whether carers experience different strains in their personal lives (Q.47)

	Response									
	Kind of Strain									
	Caring is Inconvenient		Changes made in Personal Plans		Work Adjustments		Other Demands on Time		Family Adjustments Necessary	
	N	%	N	%	N	%	N	%	N	%
Yes	47	23.5	75	37.5	15	7.5	75	37.5	67	33.5
Sometimes	17	8.5	10	5.0	12	6.0	16	8.0	23	11.5
No	136	68.0	115	57.5	173	86.5	109	54.5	110	55.0
Total (N)	200		200		200		200		200	

Table A11.1: Duration of carer's holiday (Q.109b)

Duration	Number	Percentage
3 Days or Less	3	8.3
4-7 Days	20	55.6
More than 1 Week: less than 2	9	25.0
Less than 3 Weeks	4	11.1
Total (N)	36	

Based on those who had a holiday.

Table A11.2: Person who looked after elderly person while carer on holiday (Q.109c)

Person	Number	Percentage
Spouse	2	5.6
Parent/Parent-in-law	2	5.6
Adult Child	10	27.8
Brother/Sister	15	41.7
Hospital/Short-term Care	4	11.1
Other Relative	1	2.8
Friend/Neighbour	1	2.8
Other	1	2.8
Total (N)	36	

Based on those who had a holiday.

Table A11.3: Who should provide respite/day-care service (Q.117)

Service-Provider	Number	Percentage
Family	3	2.6
Friends/Relatives	3	2.6
Government Grants	15	12.8
Health Boards	86	73.5
Support Groups	4	3.4
Voluntary Groups	6	5.1
Total (N)	117	

Non-respondents and those for whom question is non-applicable excluded.

Table A11.4: Carers' opinion off short-term relief care (Q.111)

Opinion	Number	Percentage
Would Love it	71	36.2
Good Idea but Not for Me	33	16.8
Good Idea	36	18.4
Would Feel Guilty About it	2	1.0
No Need for It	11	5.6
Good Idea but Elderly Person would Not Like It	10	5.1
Essential	2	1.0
Don't Know	12	6.1
Good if Elderly Person is Willing	19	9.7
Total (N)	196	

Non-respondent excluded.

Table A11.5: Beliefs about elderly person's reaction to institutional care (Q.114b)

Belief	Number	Percentage
Would not Mind	6	3.2
Would do It to Give Carer a Break	54	28.4
Would Agree to Go if Necessary	6	3.2
Would Hate It/Very Unhappy	114	60.0
Do Not Know	10	5.2
Total (N)	190	

Non-respondents and carers for whom question is not applicable are excluded.

Table A11.6: Who should cater for need for information on entitlements? (Q-117)

Service-Provider	Number	Percentage
Government	6	4.8
Health Boards	113	90.4
Support Groups	2	1.6
Voluntary Groups	3	2.4
Other	1	0.8
Total (N)	125	

Non-respondents and those for whom question is non-applicable excluded.

Table A11.7: Time when carer feels most lonely (Q.59b)

Time	Number	Percentage
Evenings	22	25.3
Weekends	8	9.3
Special Holidays	31	35.6
Winter	11	12.6
Anniversaries	4	4.6
Other	7	8.0
All the Time	1	1.1
No Specific Time	3	3.4
Total (N)	87	

Non-respondents and those for whom the question is not applicable excluded.

Table A11.8: Changes in carer's circle of friends/contacts (Q.58)

Changes	Number	Percentage
Increased	13	6.5
Decreased	44	22.1
Remained the Same	140	70.4
Other	2	1.0
Total (N)	199	

Non-respondent excluded.

Table A11.9: Who should cater to need for special life? (Q.117)

Person	Number	Percentage
Family	27	36.5
Friends/Relatives	24	32.4
Government	5	6.8
Health Boards	10	13.5
Support Groups	8	10.8
Total (N)	74	

Non-respondents and those whom the question is not applicable excluded.

Table A12.1: Association between extent of care and quality of relationship between carer and elderly person

Quality of Relationship	Perceived Extent of Care		
	Needs 24-Hour Care	Constant Care by Day	Care Needed Occasionally
	N	N	N
Very Good	20	30	51
Good	10	15	30
Fair/Tolerable	2	5	10
Poor	0	0	1
Very Poor	0	0	1
Total (N)	32	50	93
	18.3	28.6	53.1

Table A12.2: Association between perceived amount of care and quality of relationship between carer and elderly person

Quality of Relationship	Perceived Amount of Care		
	A Lot	A Little	Occasional
	N	N	N
Very Good	54	40	7
Good	31	23	1
Fair/Tolerable	8	9	0
Poor	1	0	0
Very Poor	0	1	0
Total (N)	94	73	8
(%)	53.7	41.7	4.6

Table A12.3: Association between overall level of dependency and quality of relationship between carer and elderly person

Quality of Relationship	Overall Level of Dependency				
	Very High	High	Medium	Low	No Dependency
	N	N	N	N	N
Very Good	1	16	36	25	11
Good	1	15	20	5	2
Fair/Tolerable		2	7	6	1
Poor		0	0	0	0
Very Poor		0	1	0	0
Total (N)	28	33	64	36	14
(%)	16.0	18.9	36.6	20.6	8.0

Table A12.4: Association between quality of relationship between carer and elderly person and degree of life satisfaction of carer

Quality of Relationship	Level of Satisfaction			
	Very Satisfied	Satisfied	Neutral	Dissatisfied
	N	N	N	N
Very Good	27	58	9	5
Good	6	30	11	8
Fair/Tolerable	0	6	6	5
Poor	0	1	0	0
Very Poor	0	0	0	0
Total (N)	33	96	26	18
(%)	19.1	55.5	15.0	10.4

Table A12.5: Connection between life satisfaction and perceived amount of care

Degree of Life Satisfaction	Perceived Amount of Care		
	A Lot N	A Little N	Occasional N
Very Satisfied	12	16	6
Satisfied	62	43	4
Neutral	25	8	0
Dissatisfied	14	7	0
Total (N)	113	74	10
(%)	57.4	37.6	5.1

Table A12.6: Connection between life satisfaction and perceived extent of care

Degree of Life Satisfaction	Perceived Extent of Care		
	Needs 24-Hour Care N	Constant Care by Day N	Care Needed Occasionally N
Very Satisfied	4	5	25
Satisfied	21	33	55
Neutral	7	13	13
Dissatisfied	6	7	8
Total (N)	38	58	101
(%)	19.3	29.4	51.3

Table A12.7: Whether caring has been a help in any way (Q.122b)

Type of Help	Number	Percentage
None	99	50.3
Good Personally	30	15.2
Elderly Person Looks After Children	21	10.7
Elderly Person will Leave House/Land	42	21.3
Has Been a Financial Arrangement	5	2.5
Total (N)	197	

Non-respondents excluded.

Appendix 2

Outline of Questionnaire design

1. Details about those for whom respondent is caring.
2. Facts about elderly person (needing most care).
3. Whether respondent is caring for any mentally and/or physically handicapped persons.
4. Focus on carer.
5. Carer's household.
6. Becoming a carer.
7. Physical health of elderly person.
8. Mental health.
9. Advice on caring.
10. Daily routine.
11. Carer's physical strength.
12. Carer's mental health.
13. Items about the house that may make caring difficult.
14. Support from carer's family and friends.
15. Services assisting carer.
16. Financial circumstances.
17. Caring: constraints on social life.
18. Caring: does it affect relationships?
19. Whether a break from caring was experienced.
20. Needs of carers not being met at present.
21. Relationship between carer and elderly person.
22. Best things about caring.
23. Worst things about caring.
24. Life satisfaction of carer.
25. Section for carers of deceased elderly people and where elderly person is in long-term care or no longer living with carer.
26. Any further comments of carer.

The Questionnaire Design and Questionnaire, together with a description of indices and measures used in the study, are available on request from the National Council for the Aged.

NATIONAL COUNCIL FOR THE AGED REPORTS:

1. Day Hospital Care, April 1982.
2. Retirement: A General Review, December 1982.
3. First Annual Report, December 1982.
4. Community Services for the Elderly, September 1983.
5. Retirement Age: Fixed or Flexible (Seminar Proceedings), October 1983.
6. The World of the Elderly: The Rural Experience, May 1984.
7. Incomes of the Elderly in Ireland: And an Analysis of the State's Contribution, May 1984.
8. Report on its Three Year Term of Office, June 1984.
9. Home from Home? Report on Boarding Out Schemes for Older People in Ireland, November 1985.
10. Housing of the Elderly in Ireland, December 1985.
11. Institutional Care of the Elderly in Ireland, December 1985.
12. This is Our World: Perspectives of Some Elderly People on Life in Suburban Dublin, September 1986.
13. Nursing Homes in the Republic of Ireland: A Study of the Private and Voluntary Sector, September 1986.
14. "It's Our Home": The Quality of Life in Private and Voluntary Nursing Homes, September 1986.
15. The Elderly in the Community: Transport and Access to Services in Rural Areas, September 1986.
16. Attitudes of Young People to Ageing and the Elderly, March 1987.
17. Choices in Community Care: Day Centres for the Elderly in the Eastern Health Board, September 1987.
18. Caring for the Elderly Part I. A Study of Carers at Home and in the Community, June 1988.
19. Caring for the Elderly Part II. The Caring Process: A Study of Carers in the Home, November 1988.

NATIONAL COUNCIL FOR THE AGED FACT SHEETS:

Fact Sheet 1 — Caring for the Elderly at Home.

Fact Sheet 2 — Carers: You Matter Too!

A price list for the above publications is available on request from the National Council for the Aged, Corrigan House, Fenian Street, Dublin 2. Please note that Reports 12, 13, 14, 17, 18 and 19, may be purchased through any bookseller or directly from:

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The front cover shows
the 'Tao' symbol for long life.
The symbol is signed by
the eighty five year old artist
Yen Chih.

