End-of-Life Care for Older People in Acute and Long-Stay Care Settings in Ireland

Joint Statement
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Hospice Friendly Hospitals Programme
Irish Hospice Foundation
32 Nassau Street
Dublin 2
www.hospicefriendlyhospitals.net

National Council on Ageing and Older People
11th Floor
Hawkins House
Hawkins Street
Dublin 2
www.ncaop.ie

Statement prepared for
the National Council on Ageing and Older People
and the Irish Hospice Foundation
by Mr Bob Carroll.
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1. Introduction

In 2001, the Report of the National Advisory Committee on Palliative Care (NACPC) stressed that all clinical and support work for those who are dying should be informed by what is termed 'a palliative care approach', focusing on excellent communication and a concern with quality of life for both patient and family.

There was also a growing awareness among those caring for people dying in hospitals of the need for improvement in the provision of end-of-life care outside of specialist palliative care settings. This led to the launch of a pilot project in 2004 called Care for People Dying in Hospitals by the Irish Hospice Foundation (IHF) in Our Lady of Lourdes Hospital in Drogheda and the subsequent establishment of the Hospice Friendly Hospitals Programme (HfH) throughout the country.

Meanwhile, conscious of the paucity of information on older people's quality of life in Ireland, the National Council on Ageing and Older People (NCAOP) had embarked on a programme of research into the quality of life of different groups of older people, including those living in long-stay settings and those with a disability. Given that more than three in every four people who die in Ireland are over the age of 65 and given that 'we don't have good data on how people die (as opposed to what they die of), but (that) there is a strong impression that many die badly' [as noted in an editorial in the British Medical Journal (2003)], the NCAOP and the IHF agreed to commission and jointly publish a study, End-of-Life Care for Older People in Acute and Long-Stay Care Settings in Ireland, which was undertaken by O'Shea et al. (2008).

The Study, as we will refer to it throughout this Statement, made six recommendations:

- for the testing of new models and approaches that bring about greater fusion between end-of-life care and gerontological care within all long-stay settings in Ireland;

- for practice development to ensure that end-of-life care for older people is integrated into the everyday life of acute hospitals and long-stay facilities;

- for greater consultation with older people to establish needs and preferences with respect to end-of-life care;

- for an improvement in the physical environment where people die, particularly with respect to the availability of single rooms and facilities for families and friends;

- for policy reform to ensure that end-of-life care is recognised as an important public health issue, separate to palliative care but inclusive of many of its key elements;

- for greater cultural awareness and understanding of death and dying, including consideration of the current disparity of esteem between younger and older deaths within the health and social care system.
The NCAOP and the IHF jointly organised a seminar on 17 April 2008 to mark the publication of the Study and to consider the implications of its findings:

- for Irish society;
- for policy on older people and end-of-life care;
- for the promotion of the best end-of-life care for older people in acute and long-stay care settings.

Following consideration of the Study and its findings, together with the issues raised at the seminar, the NCAOP and IHF in partnership have set out in this paper their recommendations on the development of high quality end-of-life care for older people in acute and long-stay care settings in Ireland. The Statement is addressed to policy-makers, to service planners and providers, and to all those whose concern it is to develop and promote a more humane and person-centred model of end-of-life care for older people in this country.
2. A New Model for Care at the End-of-Life

The Study provides a new model for care at the end-of-life which goes beyond specialist palliative care provision for cancer patients to embrace a compassionate and holistic approach that supports older people who are living with, or dying from, progressive, chronic and life-threatening conditions. This approach is holistic and comprehensive, and allows a longer lead time to death. It also takes into account the potential uncertainty surrounding dying and death, including the possibility that some people follow more complex and non-linear pathways to death.

As a model for service planning and provision, the focus is on maximising the quality of life of older people at the end of their lives and on attending to all their needs: physical, psychological, social and spiritual. End-of-life care is not dominated by people's conditions or their cure, but rather by the wider spectrum of needs of persons facing the end of their lives.

Every person's end-of-life trajectory is different, and needs differ in intensity and quality over time. End-of-life care must therefore adapt to differing and changing needs, and cannot be limited to certain settings or services. As the Study indicates, ‘the neat separation of end-of-life into a defined period when palliative care services can be mobilised and administered is not possible’ (O'Shea et al., 2008: 178). Nor is it possible to neatly distinguish between, or separate, gerontological care and end-of-life care. End-of-life care must inform all services in settings where older people die. The NCAOP and the IHF therefore support the recommendation of the authors of the Study that new models and approaches which bring about a greater fusion between end-of-life and gerontological care within all long-stay settings in Ireland should be tested (O'Shea et al., 2008: 21).

As the Study reports, almost 30,000 people die each year in Ireland, of whom just over three-quarters, 22,500, are aged 65 or older. Two-fifths of these older deaths (9,000 approximately) occur in acute hospital settings, with roughly the same number dying in public (5,625) and private (3,375) long-stay facilities. The remainder, approximately 4,000 older people, die at home (O'Shea et al., 2008: 29). Within the respondent population of this study, 60 per cent of recorded deaths were in long-stay facilities and 40 per cent in acute hospitals.

The NCAOP and IHF strongly recommend that all institutional care services, acute and long-stay, review their provisions for older people with life-threatening conditions to ensure that the services they provide are sufficient to meet the physical, social, psychological and spiritual needs of these older people and to maximise their quality of life at the end of life. They further support the Study’s recommendation that measures be taken to ensure that end-of-life care for older people is integrated into the everyday life and work of all acute hospitals and long-stay facilities (O'Shea et al., 2008: 21).
3. Quality of Life at the End-of-Life

The provision of good end-of-life care should be driven primarily by the concern to enhance the quality of life of those at the end of their lives, not just the clinical duty to ensure high quality specialised medical and palliative care, though these are clearly very important to the quality of life of many older people at the end of their lives. Therefore the philosophy and principles of hospice and palliative care should be evident in all facilities caring for older people.

Quality of life is a complex, multi-dimensional concept, difficult to define and measure, but as important nonetheless to the welfare of vulnerable older people as to other groups in society. Whatever the definition, it will encompass both subjective and objective components.

Quality of life at the end of life shares some of the features of quality of life in older age and quality of life of older people with a disability. For example, retaining one's personal identity and sense of self, as well as maximising connectedness with others and personal autonomy have been identified as important determinants of quality of life for these groups of vulnerable older people (Murphy et al., 2006; Murphy et al., 2007). But quality of life of older people at the end of their lives also incorporates determinants specific to this stage of life.

A systematic review of end-of-life care literature (Mularski et al., 2007), to which the Study refers (O'Shea et al., 2008: 41-42), identifies the following domains as important for quality of life at the end of life.

- **Life completion**: this is concerned with the person's sense that they have achieved what they want to achieve. It includes being able to help others, saying important things to loved ones, having a sense of meaning, being at peace, and having time with family.

- **The person's relationships with the healthcare system**: this includes a sense of control about treatment decisions, knowing where to get information, participating in care decisions, knowing what to expect about the illness, and being treated as a person.

- **Preparation/anticipatory concerns**: this includes worry about being a burden, about whether one's family is prepared for the future, fear of dying, financial strain and regrets about life.

- **Symptom impact**: this domain has been identified as central in most studies of end-of-life care. Control of symptoms is crucial in promoting the comfort of the patient and ensuring that their quality of life is as good as possible approaching death. Typical symptoms include pain, fatigue and nausea and patients have reported how these interfere with enjoyment of life and concerns about the future.

- **Connectedness and affective social support**: this assesses whether the person has a confidant to share their deepest thoughts and how much and how frequently they spend time with family/friends.
In light of the diversity of these quality of life domains and in keeping with a further recommendation of the Study (O'Shea et al., 2008: 21), the NCAOP and the IHF recommend greater consultation with older people by health and social care service planners and providers in order to establish their needs and preferences with regard to end-of-life care in a timely fashion.

The National Quality Standards for Residential Care Settings for Older People in Ireland (2008), recently published by the Health Information and Quality Authority, hold out significant hope that the quality of life of older people in public, private and voluntary long-stay care will be a primary concern of residential care service providers in the future, including as they do five standards addressing key quality of life issues in residential care settings (nos. 17-21, Section 4: Quality of Life). A further standard is devoted to end-of-life care (no. 16, Section 3: Health and Social Care Needs). The NCAOP and the IHF strongly support the introduction of the Standards and urge the Minister for Health and Children to introduce the statutory regulations required to underpin the Standards without delay.

Encouraging progress is being made on mainstreaming hospice principles in hospital practice across the country through the HfH Programme. The Programme prioritises four areas in particular: Integrated Care; Communications; Design and Dignity; and Patient Autonomy. While it focuses on all those dying in hospitals, the change of culture around dying, death and bereavement which this Programme is bringing about has great potential for improving the quality of life of older people who die in hospitals, as well as their families. The NCAOP and the IHF recommend that every support be given by hospital management and health authorities to ensure the continued development and roll out of the HfH Programme to all acute and non-acute hospitals in the country. This process should include:

- the implementation of the comprehensive patient-focused standards currently being developed by the Programme in relation to dying, death and bereavement;
- the development of standing committees on dying, death and bereavement within and across hospitals and long-stay care settings to address all end-of-life issues in a comprehensive and integrated way;
- the development of a role of End-of-Life Services Coordinator in larger facilities;
- the inclusion of end-of-life care in all hospital service plans;
- participation in the audit and evaluation system for end-of life care currently being developed by the Programme.

The extension of the HfH Programme to privately owned nursing homes and hospitals should also be discussed with the appropriate sector representatives.
4. Design and Dignity

One of the significant barriers to delivering quality end-of-life care is the physical and sensory environment in acute hospitals, psychiatric hospitals and voluntary hospitals/homes. Hard questions must be asked about how we plan the physical environment in facilities where significant numbers of people are known to die:

- Why do some facilities not provide the physical environment needed to allow their residents to live and to die in dignity, for example with only thin curtains separating the living from the dying, those eating from those using a commode, etc?
- Why are so many older people allowed to die in busy wards against a background of noise from other patients, televisions, etc. (Keegan et al., 1999)?
- Why are appropriate facilities not provided for the dying and amenities for those who accompany the dying in their last hours?

The results of a 2007 study conducted in twenty hospitals by TRIBAL on behalf of the IHF entitled Design & Dignity Baseline Review confirm the validity of these questions. The report acknowledges the considerable efforts being made to overcome the limitations and constraints of the physical environment within some older buildings and it also identified some examples of good design practice.

The NCAOP and the IHF agree with the authors of the Study that there is a need for an improvement in the physical environment where people die, particularly with respect to the availability of single rooms and facilities for families and friends visiting the dying. They recommend that ‘care of the dying’ be included in mission statements or statements of purpose of all healthcare institutions where people die and that ‘end-of-life care and organisation’ should feature in all hospital and nursing home service plans.

They recommend that basic information on whether people die in wards or single rooms, and the end-of-life services they receive, be routinely and systematically collected, to promote greater visibility of end-of-life care and comparability in how it is provided. Such information should be gathered through the audit and evaluation system for end-of-life care currently being developed through the HFH Programme (see Section 3).

They further recommend that those responsible for the design or redesign of healthcare facilities include provision for end-of-life care in accordance with best national and international practice. They advocate the early establishment of effective governance and development structures to guide this challenging change process. In addition, they recommend that the Design & Dignity Guidelines for Physical Environments of Hospitals Supporting End-of-Life Care developed by the HFH Programme should be used to guide the design of all new build and refurbishment projects for acute hospitals and residential facilities. In this regard, the NCAOP and the IHF particularly commend the introduction of the Teaghlach/Household model of residential care for older people in Ireland, which aims to reconfigure care from the current hospital model to a more home-like one.
5. Desired Outcomes of End-of-Life Care

The Study provides valuable information on respondents' understanding of end-of-life care. They distinguished it from other kinds of care as follows, 'the quality of care in the last six months of life'; 'care that is provided when death is expected' and 'not terminal care' (O'Shea et al., 2008: 120).

The Study identifies common keywords used to define end-of-life care, including 'holistic care', 'maintaining dignity', 'pain relief', 'symptom control' and 'open communication'. Allowing patients to 'live until they die', by providing a peaceful, comfortable environment with suitably trained staff, is central to this type of care. In addition to caring for patients, catering for the needs of families and friends is also perceived to be important. Meeting both their and the patients' 'physical, spiritual and psychological needs' was one of the most common phrases referred to when defining end-of-life care (O'Shea et al., 2008: 120-121). Good end-of-life care outcomes which should be expected include: pain relief; symptom control; maximising health and functional status; facilitating connectedness with family and friends; psychological well-being; spiritual well-being; control over decision-making; and a comfortable death.

The report identifies significant barriers to the achievement of these outcomes, including:

- lack of adequate funding to provide optimal care;
- lack of trained staff and variable, sometimes poor, staffing levels;
- lack of continuity among caregivers and an associated lack of communication between care staff in primary care settings, long-stay care settings and acute hospitals;
- in some private and voluntary facilities, lack of established links with external specialist service providers;
- limited availability of palliative care services for non-cancer patients in acute hospitals;
- limited availability of hospice beds necessitating transferral of some patients to acute hospitals to continue their care;
- inappropriate care provision, for example an over-emphasis on cure and aggressive treatments at the expense of symptom alleviation, or an over-emphasis on routine at the expense of the creation of a home-like atmosphere;
- poor physical resources for pain and symptom management;
- limited availability of single room accommodation and a consequent lack of privacy, especially in the period approaching death in some facilities;
- lack of accommodation of people's cultural beliefs;
- lack of emotional and psychological support;
lack of clarity over who should provide spiritual care;

poor communication from medical staff to patients, limiting an ‘open awareness’ of the proximity of death and the possibility of having some sense of control over the process;

inadequate staff training in the use of specialist equipment and in the holistic care of older people at the end of their lives.

The National Quality Standards for Residential Care Settings for Older People in Ireland (HIQA, 2008) now require that all residential care settings for older people ensure that each resident ‘continues to receive care at the end of his/her life which meets his/her physical, emotional, social and spiritual needs and respects his/her dignity and autonomy’ (no. 16, Section 3: Health and Social Care Needs). The criteria stipulated by HIQA to meet this standard will address some of the barriers to good end-of-life care in long-stay care settings listed above.

The NCAOP and the IHF recommend that the same end-of-life care standard be applied in all healthcare facilities, including acute hospitals, and furthermore that the same criteria by which implementation of the standard is judged be adopted.
6. Framework for Good End-of-Life Care

The Study provides a useful model for understanding older people’s experiences at the end-of-life and a framework for calibrating end-of-life care service responses based on the complexity of their needs, rather than on their medical diagnosis alone. It suggests that ‘all older people in hospitals (acute and community) and in nursing homes will require good quality “fundamental” care, such as attention to their comfort, dignity, safety and respect for their wishes. As their needs become greater and their levels of distress become more difficult to address, some may require “enhanced”, “advanced” and ultimately “complex” care. Complex care may involve specialists in palliative care, but it might equally involve experts in psychological or spiritual well-being, if that is where the need exists’ (O'Shea et al., 2008: 173).

In the interests of effective service development, the NCAOP and the IHF recommend that the HSE and Nursing Homes Ireland support the preparation and circulation of a national Framework for Quality End-of-Life Care of Older People to assist all facilities, particularly long-stay care facilities, in the planning and delivery of end-of-life care for older people. The NCAOP and the IHF would be pleased to assist in this process, as appropriate.
7. Matching End-of-Life Care Needs and Services: The Roles of Assessment and Information Provision

The Study raises questions about end-of-life care that challenge our conceptualisation of hospital care and long-stay care for older people. End-of-life care is part of a continuum of care, which begins with neo-natal care and includes preventative, curative, rehabilitative, maintenance of biopsychosocial function, and palliative care. This continuum responds to the health and social care needs of the individual throughout the life-cycle. It does not represent a fixed time sequence or a number of discrete settings, where certain care services are practised and provided on an exclusive basis.

In view of latent, and sometimes overt, ageism, it is particularly important to question our understanding of what health and social care services are available to older people, and where and how they are delivered. If, for example, for clinical reasons, an older person is being cared for in an acute hospital, does he/she have access to the end-of-life care services appropriate to his/her needs?

So too, in long-stay residential care, do older people have access to preventative, curative, rehabilitative and palliative care services in accordance with need? Do those at the end of their lives have access to services in keeping with their physical, psychological, social and spiritual needs?

These questions assume particular importance and relevance in the context of Towards 2016: The Ten-Year Social Partnership Agreement (Government of Ireland, 2006) and the proposed introduction of A Fair Deal: The Nursing Home Care Support Scheme later this year. Setting out the principles to underpin the development of an infrastructure of long-term care services for older people, Towards 2016 begins with the principle that ‘all relevant public services should be designed and delivered in an integrated manner around the needs of the care recipient based on a standardised needs assessment’.

In keeping with this, the Guide to A Fair Deal (DoHC, 2006) indicates that ‘you or a family member/guardian can apply to the HSE for an assessment of care needs’. Clearly, it will be essential that the design of care needs assessments should be such as to maximise the opportunity of matching service provision with each individual's biopsychosocial and spiritual needs in a long-stay care setting.

The NCAOP and the IHF recommend that the standardised needs assessment to be introduced be capable of assessing each person's physical, mental health, psychological, social and spiritual needs and preferences to ensure that those requiring long-stay and end-of-life care will have the best possibility of receiving the service that matches their needs.

A Fair Deal will confer equality of entitlement to nursing home support among all older people who volunteer to join the scheme, who are assessed as requiring long-stay in-patient care and who contribute to the scheme. It is assumed that by ‘nursing home support’ is meant the services required to meet assessed need.

The Guide to A Fair Deal states, ‘You can … choose care in any approved nursing home or in a public facility’. It goes on to state that this choice would be subject to availability, and ‘also, in some cases your choice of nursing home may be limited by the capacity of
different homes to cater for your needs'. Readily accessible information on availability of residential care services and on the service capacity of different facilities, including information on capacity to provide high quality end-of-life care, will therefore be important to service users and their families.

The Study states that 'the current law on decision-making at the end-of-life is based on principles of autonomy and self-determination. But if these principles do not hold during all the time of their care, beginning at admission, it is difficult to give them meaning at the end stage of dying and death. The first challenge therefore is to involve older people directly in all matters related to their care. This means more information and enhanced communication among providers of care, families and patients. Many studies have shown that patients want much more information than doctors believe they do' (O'Shea et al., 2008: 182).

The matter of openness in information provision was recently considered by the Forum for Older People, established by the Consumer Affairs Division of the HSE in response to the Leas Cross scandal. The Forum agreed a proposal for the development of an online database of residential care services to assist older people and their families in considering their options and making the best choice when faced with the need to look for long-term care.

The NCAOP and the IHF support this proposal and recommend that the database and associated print materials should provide comparative information on end-of-life care services available in long-stay facilities throughout the country, using the levels of end-of-life care and service provision proposed in the Study (fundamental, enhanced, advanced and complex). As advocated in the Study, and in keeping with the discussion on legal and ethical considerations (see Section 11), they recommend that the database should also provide information on other matters of assistance in end-of-life decision-making including: advance care planning; living wills; consent; communication; bereavement and loss; pastoral care and spirituality.

In addition, the NCAOP and the IHF recommend that those providing residential care facilities for older people indicate in their residents' brochures whether they provide end-of-life care services and what those services are.
8. Staffing

The National Quality Standards for Residential Care Settings for Older People in Ireland (HIQA, 2008) require that ‘there are appropriately skilled and qualified staff sufficient to ensure that services are delivered in accordance with the standards and the needs of the residents’ (no. 23, Section 5: Staffing). The standard further stipulates that ‘staffing numbers and skill mix of qualified/unqualified staff are at all times appropriate to the assessed needs of the residents’. This is critically important given the worrying finding of the Study that staff shortages sometimes prevented the provision of person-centred care and that ‘staff did not always have the time to give dedicated personal care to patients who were dying’ (O’Shea et al., 2008: 187).

The NCAOP and the IHF therefore recommend that when facilities and inspection teams are computing the appropriate staff numbers and the skill mix required by a facility, they take into account the special service requirements of those assessed as having end-of-life care needs. This is particularly important given the unexplained differences in staff levels reported in the Study for different types of facility. Conscious that one of the key statements of the HfH Programme is that ‘no one should die alone, frightened and in pain’, the NCAOP and the IHF strongly recommend that staffing should be organised and rostered so as to provide all necessary clinical care and personal support required by a dying patient.

The Study’s analysis of service resources and workforce requirements implied by its framework for good end-of-life care will be most helpful in this regard, particularly if it is incorporated in a national Framework for Quality End-of-Life Care for Older People, as recommended in Section 6.

The NCAOP and the IHF recommend that health authorities provide greater public support for, and recognition of, end-of-life pastoral care services and that the funding and provision of these services are improved to ensure that appropriately qualified personnel are available as required to those who need their services, and that dedicated private areas and sanctuary spaces are also provided to meet pastoral care needs. The NCAOP and IHF also recommend that every facility providing end-of-life care services identify a pastoral care champion to promote the development of pastoral care services as an integral part of its operations. They further recommend exploring the feasibility of developing volunteer services in hospitals, perhaps linked to pastoral care services, to support dying patients/residents and their families, and assist in meeting the wide range of needs that occur at the end-of-life.
9. Education, Training and Practice Development

The Study provides valuable quantitative data on levels of relevant qualifications, experience and training of staff engaged in end-of-life care of older people (O’Shea et al., 2008: 110-111). It concludes that, while the majority of facilities do realise the importance of knowledge in the provision of good end-of-life care for older people, the level of formal education and training programmes available may not be able to meet current needs (O’Shea et al., 2008: 124-125). Lack of trained staff was a key issue and barrier to delivering good quality care for all facilities, the report states (O’Shea et al., 2008: 127).

The NCAOP and the IHF recommend that every support and encouragement be given to continuous professional development for those providing end-of-life care services and that current workforce development initiatives designed to improve quality of life for older people in acute and residential care are also supported and developed. Given the increasingly heterogenous cultural origins of service providers and patients/residents, it is imperative that much greater attention be given to the development of cultural awareness and understanding in all training programmes for those providing long-term and end-of-life care services.

They recommend that the curriculum of such initiatives be informed by research findings on the domains of quality of life for different groups of older people, and that end-of-life care be included as an integral part of all such training.

They further recommend that training programmes in the essentials of end-of-life care be provided for all clinical staff and healthcare assistants. A national audit of education, training and practice development programmes relevant to the promotion of quality of life and quality of care in long-term and end-of-life care for older people should also be conducted on behalf of those responsible for the planning and provision of this care.

As stated previously, the introduction of the National Quality Standards for Residential Care Settings for Older People in Ireland (HIQA, 2008) has the potential to significantly improve the quality of life of residents in long-stay care. The NCAOP and the IHF recommend that the HSE and Nursing Homes Ireland work together to ensure that long-stay care service providers are aware of and have access to:

- the legislation, regulations, clinical guidelines and codes of professional conduct referred to in the National Quality Standards;
- contact details of authorities and agencies referred to in the National Quality Standards, and information on their functions and the services they provide;
- up-to-date information on best practice in promoting quality of life for older people in residential care;
- up-to-date information on best end-of-life care practice with older people;
- comprehensive information on training, practice and career development opportunities relevant to staff in older people’s facilities, including training relating to care services and training to assist understanding of cultural and quality of life issues;
the findings of the audit and evaluation of end-of-life care, when conducted.

Connectedness, the ability to communicate with, and be understood by others is very important to the quality of life of most patients, including particularly residents in long-stay care and those at the end of their lives. Regulations, standards, guidelines or procedures will not, of themselves, ensure connectedness. Even the achievement of optimum staffing levels and certification will not do so. It is essential, therefore, that relationships of friendship and companionship with staff are not denied for communication or cultural reasons.

The NCAOP and the IHF consider that facilitating communication between staff and residents is a most important consideration which managers and persons-in-charge should prioritise when recruiting and inducting staff, and when selecting or evaluating education, training and practice development initiatives.

'Quality of caring', as distinct from 'quality of care', is particularly important at the end-of-life, not least because of the often intimate nature of the care provided, including bathing, dressing and toileting. 'In addressing clinical and functional concerns, the worker is often attuned to the emotional and spiritual needs of the resident …' (Stone et al., 2003; Glass, 1991).

'Quality of caring', as distinct from 'quality of care' emphasises the relationship between the carer and the care recipient. It requires the kind of leadership that recognises, values and rewards this relationship, and one which appreciates that, in the absence of relationships of friendship and trust between residents and staff, the provision of person-centred care and the realisation of a good quality of life for residents will be difficult to achieve.

The NCAOP and the IHF therefore recommend that persons-in-charge of all facilities where long-term and end-of-life care is provided regularly review with staff the communication needs of residents to ensure that all have time and opportunity to relate in an appropriate manner with at least one 'significant other', including a member of staff if desired, without impediment.
10. Policy Reform

Towards 2016: The Ten-Year Social Partnership Agreement (Government of Ireland, 2006) adopts a life-course framework to identify social challenges faced by citizens during their lives. It does not, however, advert to the last stage of the life-course and the challenges faced, predominantly by older people, at that time. The NCAOP and IHF strongly recommend that this be addressed in the current review of the Agreement to ensure that those at the very end of the life journey are recognised and properly provided for in the period to 2016. They agree the need for policy reform to ensure that end-of-life care for older people is recognised as an important public health issue, ‘separate to palliative care but inclusive of many of its key elements’ (O’Shea et al., 2008: 21).

The NCAOP and the IHF recommend that a new model of end-of-life care, in keeping with that described in Section 6 of this Statement, be supported by the Social Partners and incorporated into all future national healthcare and health-related policies and strategies, including as recommended by the Study:

- facilitating greater coordination of geriatric care and medicine with palliative care and medicine;
- allocating resources to developing end-of-life care as an embracing philosophy in acute, long-stay and home settings;
- ensuring adequate specialist provision, improved services, universal provision of basic equipment and facilities, and investment in physical infrastructure.

In this regard, the NCAOP and IHF welcome the commitment to the development of a National Positive Ageing Strategy and recommend that the Strategy recognise and support this end-of-life model.

Reform of end-of-life care in Ireland is driven primarily by the hospice and palliative care movements and by those committed to, and engaged in, promoting standards of quality in long-stay residential care. The NCAOP and the IHF recommend that this advocacy base be broadened to include all those agencies with a stake in promoting quality of life at the end-of-life in Ireland. They note that the Quality End-of-Life Care Coalition Canada (QELCCC)1 is a key driver of policy reform in that country and they recommend that a similar initiative be established in Ireland. The aim of the initiative will be to improve the quality of life of Irish people at the end of their lives.

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1Mission Statement: The Quality End-of-Life Care Coalition believes that all Canadians have the right to quality end-of-life care that allows them to die with dignity, free of pain, surrounded by their loved ones, in a setting of their choice. The Coalition believes that to achieve quality end-of-life care for all Canadians there must be a well-funded, sustainable national strategy for hospice, palliative and end-of-life care. It is the mission of the Quality End-of-Life Care Coalition to work together in partnership to achieve this goal.
11. Legal and Ethical Considerations

The Study includes a comprehensive account of current legal issues surrounding end-of-life decision-making in this country. The NCAOP and the IHF agree that a robust legal framework is required to guarantee autonomy in decision-making, which is important for quality of life at the end-of-life. Both agencies also agree that this autonomy 'is not a standalone concept that exists in a vacuum, but rather is 'developed, enunciated and ultimately exercised in the embrace of others' (O'Neill, 2001; O'Shea et al., 2008).

They recommend the enactment of legislation on mental capacity and guardianship without delay, as set out in the Draft Scheme for a Mental Capacity and Guardianship Bill, published by the Law Reform Commission (LRC) in 2006. This takes a functional approach to capacity, rather than a status or outcome approach. The functional approach assesses capacity on an issue-specific and time-specific basis.

The NCAOP and the IHF endorse the LRC’s recommendation that a Working Group on Capacity to Make Healthcare Decisions would be set up under the legislation to provide guidance on the assessment of capacity.

The NCAOP and the IHF note that the National Quality Standards for Residential Care Settings for Older People in Ireland (HIQA, 2008) support the functional approach to capacity, indicating that 'a resident's lack of capacity to give informed consent on one occasion is not assumed to be the case on another' (no. 3, Section 1: Rights). The standard on consent also states 'where there is any doubt as to the resident's capacity to decide on any medical treatment or intervention, his/her capacity to make the decision in question is assessed by a suitably qualified professional using evidence-based best practice'. This lends urgency to the recommendation to establish the above-mentioned Working Group.

The NCAOP and the IHF note the complexity of the philosophical, ethical, religious and legal issues surrounding advance healthcare directives or living wills, and the corresponding need for much better public understanding and debate of the issues surrounding them. They also note that the term 'advance care planning' may be considered a more appropriate term by some than 'advance directive', which connotes an order rather than a discussion of patients' values with their clinicians (Irish Medical News, 18/02/2008).

There is no legislation governing advance care directives in Ireland, nor are there medical guidelines covering them in the Medical Practitioners Act. There is also some confusion among healthcare professionals, patients and families regarding decision-making about care in general. For example, as noted by Full Time Commissioner Patricia T. Rickard-Clarke at the NCAOP/IHF seminar, contrary to the commonly held view, there is no legal basis for next-of-kin to consent to medical treatment on behalf of an incapacitated person. The NCAOP and IHF therefore welcome the intention of the LRC to prepare a consultation paper on advance care directives and to facilitate discussion of the subject, which will be informed by measures taken to address the issue in other countries. Of particular importance will be the discussion of whether we should adopt a prescriptive or guideline approach to the regulation of advance care directives in this country.
The NCAOP and the IHF support concluding comments of the Irish Council for Bioethics in its opinion, *Is it Time for Advance Healthcare Directives?* (2007), which state that 'there is a need for increased awareness of and education about the issues surrounding advance directives for all concerned from the general public to doctors and all healthcare professionals', and 'increased communication and discussion between all parties, i.e. individuals, their families and others close to them, doctors and other healthcare professionals, will not only help to provide an insight into an individual's preferences regarding future treatment and care. It will also enable all parties to be better prepared for these and other future treatment situations'. Future legislation should therefore require that patients' wishes with regard to current and future care be checked, recorded and implemented.

The NCAOP and the IHF also recommend transparency and openness in respect of policies, procedures and guidelines - or the lack of them - governing Do Not Resuscitate Orders. They recommend transparency in practice: Who makes the Order? What terminology is used in making the Order? Documentation procedures must be such as to accurately reflect the steps taken by clinicians in making these decisions. They recommend that policies, procedures and guidelines governing practice in this area be open to public scrutiny, given the possibility of ageism affecting healthcare, or termination of healthcare, decisions. The NCAOP and the IHF recommend that a review group should be established by the Department of Health and Children as a matter of urgency to examine and address this issue, and should include representatives of the public interest.

The *National Quality Standards for Residential Care Settings for Older People in Ireland* (HIQA, 2008) will provide significant additional protection to older people ending their lives in long-stay care. Section 1 of the National Quality Standards sets out residents' rights on information, consultation and participation, consent, and on civil, political and religious rights. The NCAOP and the IHF therefore reiterate their recommendation that the Standards, and the statutory Regulations underpinning them, be introduced without delay.
12. Conclusions

The Study raises important issues for policy-makers, service planners and providers. Most fundamentally, it raises the question of the value placed by our society on how its members are supported and cared for at the end of their lives. It states that the way older people are cared for through the process of dying is reflective of broader social values, and suggests that 'the neglect of end-of-life care for older people may reflect ageist attitudes …’. Clearly, the eradication of ageism that tolerates the neglect of end-of-life care for older people must be a primary concern for leaders in society and those charged with promoting equality of treatment for all.

The NCAOP and the IHF are agreed that significant cultural change is still required to eradicate the ‘sequestration’ of the dying and discrimination against older people unable to access appropriate services and treatments at the end of their lives. They recommend a number of public awareness measures, as follows:

- The adoption of end-of-life as a theme for a future 'Say No to Ageism' campaign, organised by the Equality Authority, the NCAOP and the HSE under the Social Partnership Agreement, Towards 2016.

- A campaign to promote understanding, appreciation and a positive image of the workforce that provides long-stay residential care services to older people. This might be organised in association with the HSE, SIPTU, Nursing Homes Ireland, the voluntary residential care sector and the Carers Association.

- The promotion of public debate on attitudes and expectations regarding end-of-life care, on preferred place of death, and on the role of hospitals and long-stay residential care in the provision of end-of-life care and services to the dying.

- The provision of information for older people and their families to assist them with advance care planning and decision-making, and the provision of training in communication skills to assist staff initiate conversations in this sensitive area. As already suggested, the provision of relevant information might be undertaken in conjunction with an information initiative designed to assist older people when faced with the need to select a long-term care service.

- The development of initiatives to minimise the transfer of older people to acute hospitals from residential facilities (unless for clinical reasons) and to maximise the potential of community hospitals and nursing homes to provide high quality end-of-life care.

In view of the Study findings on education, training and practice development, the NCAOP and the IHF also recommend investigation of the following questions:

- What are the reasons for the shortages of trained staff, which seriously prejudice the quality of care and quality of life of very vulnerable older people at the end of their lives?
Why is the role and potential of healthcare assistants in promoting quality of life for older people at the end of their lives not better recognised and appreciated?

Why is the diversity of skills required for this work not acknowledged and the central role of workforce development in improving quality of life in long-stay and end-of-life care not better supported?

Are there service providers who are unable to access workforce development initiatives and why can they not do so?

Why do some policy-makers, regulators, service providers and members of the public not adequately recognise the importance and complexity of long-term and end-of-life care of vulnerable older people?

The constraints on interviews with patients currently imposed by research ethics committees limit the information it is possible to elicit on patients' experiences of end-of-life care. In the light of international research experience which indicates that some older people are happy to talk about death and dying if a sensitive approach is used, the NCAOP and the IHF recommend that research ethics committees review their approach to evaluating qualitative research and develop guidelines or seek further guidance if required. Building on this Study and its findings, the NCAOP and the IHF also recommend that further research be undertaken to deepen understanding of patient experiences of end-of-life care.
The process of dying can be likened to the process of giving birth, in that they are both intensely personal events, and yet each birth and each death also shares a great deal in common with every other birth or death. This means that we must ensure that the common needs of those at the end-of-life are anticipated and that we also respond to individual preferences. Death is a common occurrence but each death is unique. It is an event that raises profound issues and yet has many practical consequences.
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