



A Good Death: Progress Report



Ombudsman

Developments in **End of Life** Care in Irish Hospitals





Ombudsman

2018 Office of the Ombudsman

Office of the Ombudsman
18 Lower Leeson Street, Dublin 2

Lo-call: 1890 223030 Tel: 01 639 5600

Website: www.ombudsman.ie

Email: info@ombudsman.ie

Twitter: [@OfficeOmbudsman](https://twitter.com/OfficeOmbudsman)

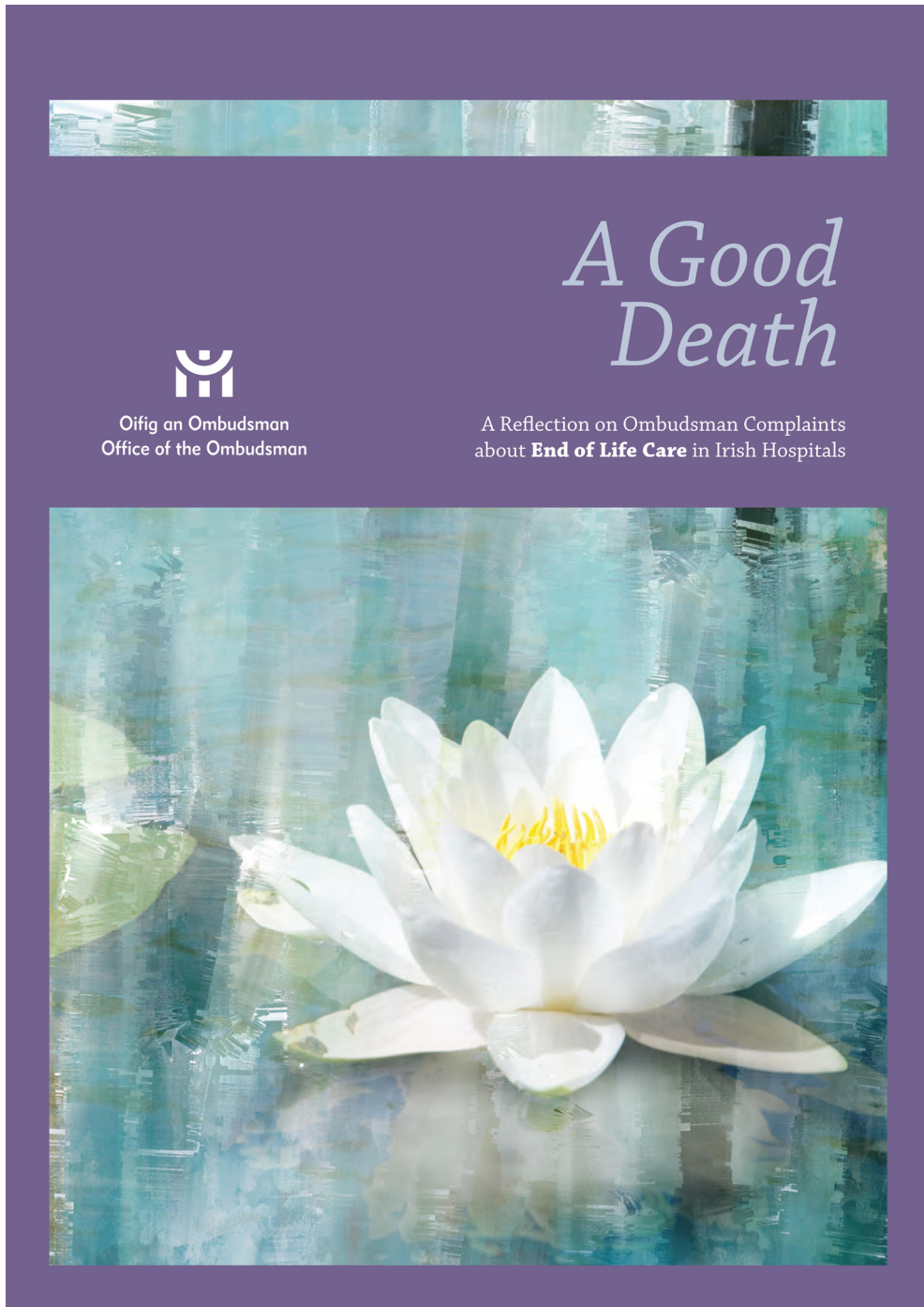


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A Good Death: Progress Report

*Developments in End of Life Care in Irish Hospitals
since the publication of the Ombudsman's report in 2014.*

September 2018



Front cover of *A Good Death*, published by the Ombudsman in 2014.

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Foreword

What do we mean when we talk about a good death? For most of us, it would mean dying without pain, with dignity, in a familiar room in our own home with people we love around us. Statistically speaking, though, most people are likely to die in hospitals, hospices or residential care often not knowing what to expect. That is why it is important that good care is provided during this critical time for the sake of the dying person and for their loved ones.

As Ombudsman, my role is to examine complaints about the administrative actions of public bodies (which, since 2015 also includes most private nursing homes). While I cannot examine complaints about clinical judgement, I can look at a range of other actions that often result in poor care. I can suggest redress, if appropriate, and improvements in practices and procedures.

Every year, 29,000 people die in Ireland and up to 290,000 are newly bereaved. At some point, dying, death and bereavement affects us all. Not everyone will be able to die at home, so the need to improve the experience of dying in hospital for patients and their families must be an important consideration. Patient choice and autonomy will be enhanced once the Assisted Decision Making (Capacity) Act 2015 is fully commenced.

In 2014, I published “A Good Death” report that reflected on complaints that my Office had examined about the care provided to dying patients and how this had affected their families. I welcome the focus that the report has brought to end of life care in acute hospitals and residential care settings. While the volume of complaints I receive about end of life events continues to be relatively low, each is unique and can provide valuable insight into the lived experience of the bereaved family. We must do all we can to learn from them.

It is encouraging to see that most hospitals now participate in the Hospice Friendly Hospitals (HFH) programme, an initiative of the Irish Hospice Foundation (IHF) that has been in place since 2007. This programme helps to ensure that end of life, palliative and bereavement care is central to the everyday business of hospitals, and the best possible care and support is available to people at the end of their life and their loved ones. Many acute hospitals have access to specialist palliative care services. The HFH programme co-ordinates three networks for hospital staff to promote improvements in end of life care:

- Acute Hospital Network
- Maternity and Children’s Network
- End of Life Coordinator Network

An increasing number of hospitals have dedicated End of Life Care Coordinators who support the roll out of the HFH programme and many acute hospitals have established End of Life Committees. The focus that they bring to quality end of life care in acute hospitals is invaluable.

Last year, I was delighted to learn that the HSE, in association with the Irish Hospice Foundation, had established a Joint Oversight Group. The Group, chaired by Professor Cillian Twomey, aims to support the embedding of the HFH Programme within HSE structures. It is examining ways to expand and develop the programme across the hospital system. Membership of the Group, which includes experts from clinical programmes in palliative care, older persons, emergency department and paediatric care, also includes a representative from my Office. During the year, I met with representatives from the Oversight Group to discuss the valuable contribution it is making in this important area.

Also during 2017, the Mater and St James's Hospital undertook the largest survey of bereaved relatives in two acute hospitals in Ireland. I had the pleasure of launching the results of this informative survey, otherwise known as the Survey of Bereaved Relatives: Voices MaJam. I have highlighted the results of the survey and its recommendations in this progress report. Clearly, hospital specific surveys of this nature provide excellent real time insight into all aspects of end of life services. Crucially, they provide hospitals with vital information about shortcomings in service delivery. As a result, I would encourage all health service providers to undertake regular surveys of this kind.

Furthermore, last year the HSE's Primary Care Division published a Three Year Development Framework (2017 – 2019) for Palliative Care Services. The objective of the Framework is to inform and direct the development of adult palliative care services, both generalist and specialist, over the three-year period. The Framework made a series of recommendations and identified action points for consideration in the development of the services.

I would also like to take this opportunity to pay a special tribute to the IHF for launching the Compassionate End of Life Care (CEOL) programme to support staff in the residential care sector. This is a continuous quality improvement approach to end of life care in these settings. Each year, some 7,000 people die in residential care so this is an important programme for residents, their families and the staff who care for them. Another important development was the commencement by the HSE of Project ECHO (Extension for Community Healthcare Outcomes) for nursing home staff in the South Dublin area. Further information about these projects is contained in this report.

This progress report focuses on the many improvements that have taken place in the provision of end of life care, together with some of the key areas that need attention. Specifically, focus must be on the variation in access to specialist palliative care across our acute hospitals (including out-of-hours services), staff education and training, additional end of life coordinators, and the continued development of single rooms for dying patients and facilities for their families in all of our hospitals. I would like to congratulate the staff of the HSE, the IHF and all those involved for their dedication to this work, which will ultimately benefit us all.



A handwritten signature in black ink, appearing to read 'Peter Tyndall'.

Peter Tyndall
Ombudsman
September 2018



Delegates from the HSE/IHF Joint Oversight Group meeting with the Ombudsman

Introduction

As this report outlines the progress that has been made in relation to end of life care since the publication of A Good Death report in 2014, the same headings have been used to chart the developments.

The three key areas of progress identified in this report relate to:

- A significant increase in the range and volume of education and training in end of life care for staff in both acute hospitals and residential centres;
- Improved physical facilities for dying patients and their families; and
- Greater emphasis on the provision of information for patients and their families on all aspects of end of life.

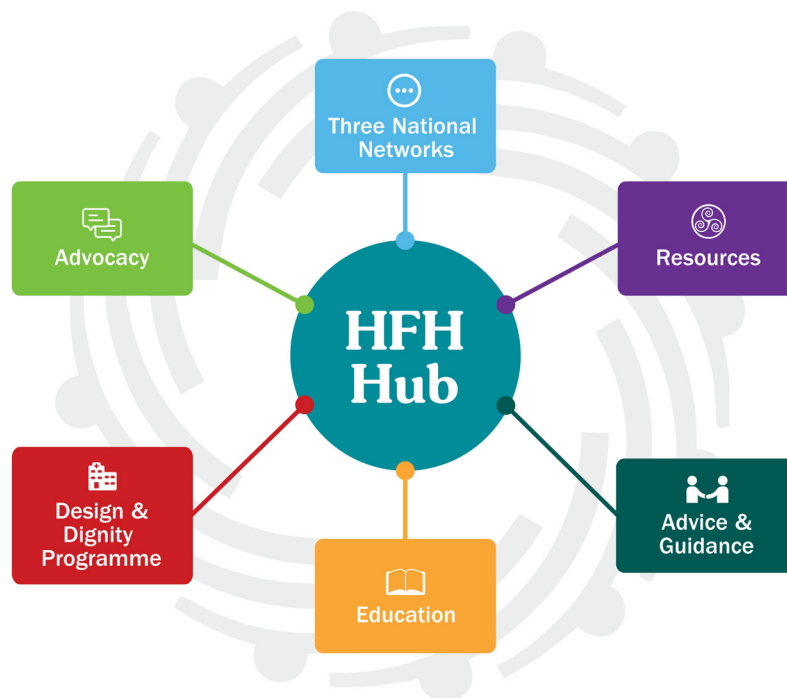
The relevant details are set out in the report along with some of the best practice initiatives taken by hospitals to meet the ongoing challenges of providing compassionate end of life care in our hospitals and residential care settings.

The key to improving services is through measuring and monitoring performance against best practice standards. The issues raised by complaints and the feedback given by relatives as part of hospital surveys also make an important contribution towards improving standards of care.

Communication

Almost all of the complaints that come to the Ombudsman feature some elements of poor communication as an aspect of the grievance. This is particularly true of complaints about end of life care. “A Good Death” described how inadequate levels of communication affected patients and their families. One of the key challenges that continues to face clinical staff is how to hold sensitive conversations about end of life with patients and their loved ones. Good communication in the context of end of life care is about taking the time to explain what is happening, to keep people informed and to answer questions or concerns in a sensitive and empathetic way.

The Hospice Friendly Hospitals programme seeks to ensure that end of life, palliative care and bereavement care are central to the everyday business of hospitals.



Emerging from the HFH hub, are a range of supports and initiatives to help hospitals prioritise improvements so that people who are dying in hospitals and their relatives receive the best possible care and support at such a vulnerable time, and staff are resourced to deliver compassionate care at end of life. A key aspect of the work of the Hospice Friendly Hospitals programme is the delivery of communications training for staff.

Communication in the hospital setting

Through participation in the Hospice Friendly Hospitals Programme, hospitals offer staff two separate educational courses designed by the Irish Hospice Foundation (IHF), which play a key role in helping to improve communication and care around end of life. These are:

a) The Final Journeys Programme:

This is a one-day workshop which improves end of life care through empowering staff to be competent and compassionate when dealing with patients and families.

b) Delivering Bad News:

This is a half-day workshop which helps healthcare professionals develop the communication skills necessary to deliver bad news well - a vitally important aspect of communication at end of life. The workshop also shows participants how to provide support and care to those who have received bad news. A version of this workshop has been adapted and is now being rolled out nationally as part of the National Cancer Control Programme.

In addition, some hospitals have developed training and education sessions relating to end of life care responsive to staff and service needs. Some of the areas covered include:

- Challenging conversations at end of life
- Communicating with bereaved relatives about post-mortem examinations

Communication in the Nursing Home setting

In November 2017, the IHF formally launched the quality improvement initiative on compassionate end of life care in residential care centres known as the CEOL Programme. This programme encourages open discussions on end of life care, dying, death and bereavement between residents, their families and staff. Most importantly it provides a framework for staff to reflect, review and enhance end of life care provided in nursing homes and a system for introducing improvements in the setting.



The programme is facilitated on-site over a period of 6 months, and a wide range of staff working in the centre form the CEOL group. As well as receiving formal training sessions on end of life care and how to conduct reviews of the care of a deceased resident, this group also identifies and introduces the care practice, system and environmental changes needed within the centre so that there are continuous improvements in end of life care in the setting.

An outline of the programme is summarised below.

1. What Matters To Me Workshop

- a. Exploration of what is involved in good end-of-life care
- b. Seeing things from a resident's perspective – what matters most to each individual
- c. Communication with residents about future wishes and end-of-life care
- d. Communication with family members about end-of-life care
- e. How to support residents when they are dying

2. CEOL Review Process Workshop

- a. Facilitating a multidisciplinary CEOL Review meeting after the death of a resident
- b. In-depth exploration of the nine domains of care that impact on the quality of end-of-life care
- c. The role of staff support in end-of-life care
- d. Contacting bereaved relatives and friends – CEOL Questionnaire
- e. Supporting a continuous quality improvement approach

3. Action Meeting

- a. Maintaining the integrity of the CEOL Review Process
- b. Supporting and strengthening of the CEOL Group
- c. Transforming learning from CEOL Reviews into action

Two very important aspects of the programme are seeking the views of the bereaved relatives and ensuring residents are aware of, and can participate in, the CEOL group/programme.

The CEOL programme was introduced into over 100 sites across Ireland in its pilot phase (2014-2016). The evaluation found that CEOL has the capacity to improve end of life care in residential care centres and its findings noted a greater sense of preparedness when a resident is dying, and staff are more confident in supporting their wishes. In addition, staff are working closer with families and have earlier engagement with specialist palliative care and GP services. Sites have reported that there is greater continuity of care and staff are less likely to transfer patients to hospital towards the end of their life, unless absolutely necessary. As well as improvements in care practices several sites have made changes to the physical environment and staff, family and residents are increasingly more involved in the bereavement rituals following the death of a resident.

In addition to CEOL, the IHF also provide the following communication workshops which specifically address communication issues that arise within the nursing home setting:

- Supporting Families – How to communicate with, and support families, around End-of-Life Care
- Planning Ahead – How to talk to residents about Advance Care Planning and Advance Healthcare Directives

“Before if a resident brought up the subject of death and their death in particular I’d run a mile. I used to tell them they were well and why would they be worrying about that and change the subject. I don’t do that anymore, instead I ask them to tell me more....”

Nursing home staff member

The “A Good Death” report noted the need for improved communications in matters relating to end of life with patients and their families. The CEOL quality improvement programme and other IHF education programmes are a positive step forward to help ensure that nursing home residents and their families are involved and included in decisions about their care and they are more confident about the quality of care they will receive in the future.

However, despite these excellent educational initiatives for staff, complaints about poor communication during end of life continue to come to the Ombudsman. One complainant said she was left upset and confused about her husband’s prognosis when the doctor told her “he did not know when her husband’s demise would be”. Another family was told that their father’s condition was “incompatible with life”. In another case, a staff member told the complainant that her father was found “pulseless”. These conversations left the family members confused and distressed. It is clear, therefore, that on-going training must be available to support and guide clinical staff when bad news must be shared with patients and their families. In addition, hospitals must ensure that opportunities are available for staff to learn from others trained in this area.

Patient Autonomy

Autonomy is the ability of an individual to direct how he or she lives on a day-to-day basis according to personal values, beliefs and preferences. In health and social care, patient autonomy involves the person who uses services to make informed decisions about the care, support or treatment that he or she receives. Patient autonomy is a key element in enabling the delivery of quality end of life care. Every person who uses health and social care services has the right to have his or her autonomy respected.

To support patient autonomy, the “A Good Death” report noted that some hospitals had introduced guidelines on breaking bad news to patients – see example set out below:

- Patients have a right to receive or not receive bad news
- Patients have a right to decide how much information they feel they need
- Patients have a right to decide who should be present during the consultation (such as family members or friends)
- Patients have a right to ask that other members of the multi-disciplinary team (such as nurses, social workers) be present when bad news is being communicated to them or during ongoing consultations.

In 2015, a year after the publication of the “A Good Death” report, the Assisted Decision Making (Capacity) Act (ADMA) was enacted. This legislation promotes autonomy of a person to make decisions about their healthcare treatment. The Decision Support Scheme is developing a governance structure for advance healthcare directives which will help healthcare professionals by providing them with guidance as to how to support patients to exercise their autonomy and express their treatment preferences. The Ombudsman understands that the Decision Support Service will not be fully operational until 2019.

The ADMA, as well as encouraging people to fill out an advance health care directive, will also help patients in hospitals and nursing homes to reflect upon and discuss the goals, values and preferences for their future care. Some people elect to complete an Advance Healthcare Directive as this is a formal record to be used to inform family, friends and doctors of wishes and refusals for treatment in the event they can no longer communicate for themselves. In the event that someone can no longer communicate their own wishes for their treatment and in the absence of a completed advance health care directive, it is the medical team that will make these decisions. However, family and friends are usually consulted as to what would be the patients will and preference for treatment. Contrary to common opinion, families do not have authority to make treatment decisions on behalf of their dying relative. This lack of clarity can sometimes lead to challenging conversations between medical staff and families during an emotional time.

While the enactment of the ADMA will support patient autonomy, it is recognised that further training and guidance is required for the public and staff to aid its implementation in healthcare settings as well as clarifying the role of families. Since the publication of the “A Good Death” report, public health campaigns and advocacy groups have highlighted the value of using the Think Ahead form which

includes an Advance Healthcare Directive. This form contains valuable prompts for discussion and consideration about planning for the future. If completed, it can give clarity and direction to family members and of course healthcare staff in the event the person cannot communicate their views or loses their decision making capacity. In addition to Think Ahead, the Irish Hospice Foundation also has training programmes for staff and families (Advance Care Planning & Advance Healthcare Directives; Supporting Families) as well as a suite of information materials for people with life limiting illness to help them plan for their future.

The Ombudsman is pleased to have observed that patients, relatives and service users are increasingly being involved in a formal way in the development of resources, policies and services related to end of life care.

“There are steps which any adult can take while they have full capacity to prepare for the possibility that at some future point they will not. The 2015 Act develops new procedural measures in relation to:

– Enduring powers of attorney: these allow an adult who has full capacity to appoint a trusted relative or friend to step in and make important decisions on their behalf if this becomes necessary in the future;

– Advance healthcare directives: introduced for the first time, these enable an adult with capacity to state their wishes with regard to future medical treatment, including life-sustaining measures, and to appoint a representative to ensure that these wishes are observed.

Responsibility for much of the implementation of this will rest with a new office within the Mental Health Commission called the Decision Support Service (DSS). Intensive work is under way to make the DSS fully operational. An inter-departmental steering group was established in 2016 and significant preparatory work has already been carried out, particularly with regard to writing draft codes of practice for professionals and interveners.

The changes brought about by the 2015 Act and the Decision Support Service will have significance for all those caring for and advising vulnerable people and their families. It will affect the work of healthcare and social care providers, lawyers and financial professionals.

We are an ageing population, with longevity and levels of age-related cognitive impairment increasing all the time, so these are changes which could reach into every home in Ireland”.

Ms Aine Flynn, Director of Decision Support Service,
Mental Health Commission

Specialist Palliative Care

Access to specialist palliative care in acute hospitals

The Survey of Bereaved Relatives: Voices MaJam 2017 noted that the assessment and management of physical pain and other symptoms is a major focus of end of life care. Indeed, the Ombudsman has received complaints in which relatives have expressed concerns about symptom management, particularly pain management, in the context of a loved one's death. Some of the relatives surveyed had an extremely positive experience of the specialist palliative care team's involvement and valued the expertise and unique skills that this team could offer.

"...Towards the end, the last 5 days, the palliative care team dealt with us in a totally professional and gentle manner. This was our first time dealing with a relative with a terminal illness in a public hospital and we were very impressed with the staff and level of care provided".

"The palliative care team were particularly helpful in every way, explaining her options in detail, arranging a private room straight away, and unrestricted visiting".

However, some of those surveyed also expressed surprise and dissatisfaction that there was no access to specialist palliative care, particularly at weekends. They made the following comments:

"We watched my mam suffer because the palliative care team was not available to help control the distressing symptoms she had due to widespread cancer".

"People who are dying and their carers suffer because of the difficulties in getting palliative care outside normal working hours. This needs to be addressed urgently".

"It is not adequate to provide palliative care on a 5 day week basis. It is very specialised knowledge and it cannot be expected that mainstream doctors are adequately trained for the situation. In my view, it is imperative that palliative care be available 24/7".

Four out of five relatives surveyed said that the person's pain was relieved in the last two days of life. Therefore, they stressed the need for access to specialist palliative care outside core working hours, that is, after 5.00 pm and that there should be no restriction to this service at weekends. The reality is that the vast majority of hospitals only have specialist palliative care phone call advice available to them in out of hours periods (i.e. overnight and on weekends). In a handful of hospitals (less than six), there is limited cover on a Saturday/ Sunday morning provided by a palliative care registrar, or sometimes a consultant. The Cancer Strategy recommends moving towards 7-day service provision on a phased basis in Cancer Centres. Clearly, there is a clinical need for increased specialist palliative care service availability in the hospital setting and the Model of Care recommends this.

The Voices MaJam Survey recommended:

- that hospitals should review how they manage the multiple and more complex care needs of dying patients, and that
- consideration should be given as to how those needs are specifically addressed outside of core working hours.

Access to specialist palliative care in the Emergency Department

Pilot Project in Emergency Department of St Vincent's University Hospital

St. Vincent's Hospital, Dublin introduced new guidelines and systems for the early identification of patients with palliative care needs in the Emergency Department (ED). A Clinical Nurse Specialist in Palliative Care was employed in the ED to facilitate the early and rapid review of patients. The impact of this pilot project on both patients and staff alike has been very positive. Patients not known previously to palliative medicine services were identified and a palliative medicine consultation in the ED (versus later in the hospital stay) was significantly associated with reduced length of hospital stay as well as reduced laboratory tests.

As a consequence of the project, doctors and nurses working in the ED:

- Developed a broader understanding of the nature and role of palliative medicine service and, in particular, early referral;
- Became more confident and competent in dealing with all aspects of palliative care, including symptom management, end of life care, communication and dealing with difficult ethical dilemmas;
- Rated the presence of the palliative medicine team in the ED each day as the most valuable of the four components of the project's intervention.
- Wanted access to the specialist palliative medicine service 24/7 in the ED.
- Welcomed the introduction of the "Flagging" system and further education in palliative medicine.

St Vincent's Hospital has extended the project and it is about to be introduced in the Mater University Hospital.

Specialist palliative care for people with dementia

The IHF launched a suite of seven guidance documents to improve palliative care for people with dementia. The documents are designed to support healthcare staff in addressing specific aspects of dementia palliative care in all care settings.

The guidance documents can be read on the IHF website, www.hospicefoundation.ie.

Palliative care training and support for staff in Nursing Homes

HSE's Project ECHO (Extension for Community Healthcare Outcomes) - Our Lady's Hospice & Care Services & nursing home staff in South Dublin – Phase 1

Background

Care provided within nursing homes is under increasing public scrutiny. A recognised requirement within nursing homes is the adequate provision of care that supports those living with incurable illness to live as well as they can during the last phase of their life. It is also important to consider a resident's personal wishes regarding disease management and place of death. In order to provide such care, all nursing home staff require appropriate mentoring and career development. At a time when health care providers are under mounting pressure to do more and spend less, Project ECHO provides an affordable solution to address the growing need to provide palliative care training and support to healthcare professionals working within the nursing home sector.

The project uses videoconferencing technology to improve access to specialised care through supporting and training nursing home teams remotely from a centralised group of experts. It provides an innovative alternative to face-to-face training, with a high quality development programme designed to help nursing home staff support residents and their families with palliative care needs. The sessions included specialist led training followed by case presentations from the nursing homes.

Project ECHO's objectives are to increase participants' knowledge and skills, and change attitudes, as defined in the Palliative Care Competence Framework (HSE, 2014).

The project allows staff to train through video conferencing without having to leave their place of work, providing (nursing profession accredited) training within existing resources. To complement the online training sessions a Learning Platform zone within thepalliativehub.com provided unlimited participant access to recorded lectures, handouts and further reading.

Two Phases of this Programme:

To date, two phases of this programme have been completed. The first phase brought the palliative care multidisciplinary team from Our Lady's Hospice & Care Services and other invited subject experts together with nursing home staff in the South Dublin area. Ten educational sessions were delivered to some 353 nursing home staff.

Typical topics chosen by participants for the ten ECHO sessions are:

1. Advance care planning
2. Nutrition and hydration at end of life
3. Medication management of older person's pain
4. Specialist Palliative Care Needs Assessment
5. Managing difficult behaviour and refusal of treatment
6. Recognising dying
7. Anticipatory prescribing
8. Management of restlessness and agitation in end stage dementia
9. Breathlessness management
10. Managing conflict at end of life

Phase 2 expanded the reach of the programme to other nursing homes in North Dublin and will also see the establishment of a similar project outside Dublin. Project ECHO's vision is to help ensure that the palliative care needs of residents in nursing homes are routinely addressed.

These important initiatives within the nursing home sector are welcomed and show the genuine commitment to the development of quality end of life care for residents outside of the acute hospital care setting.

Support for Family and Friends

The Ombudsman's "A Good Death" report (2014) noted that families have certain practical and support needs when dealing with the end of life care and death of their loved one. Every death is unique for families. Every death, even when it is expected, is deeply emotional. It is natural that they will look first and foremost to the setting where the person has died for advice and guidance. They will expect clear information and good effective support from that organisation. The quote below from the Survey of Bereaved Relatives: Voices MaJam report (2017) reiterated this need:

'Healthcare staff need to consider the support needs of relatives, specifically the provision of information to relatives on how they can support the person who is dying. This includes how they can support the person with personal care, and with emotional and spiritual matters, including how to talk to the person about dying if that is the person's wish and preference.'

Hospitals that are part of the Hospice Friendly Hospitals programme have introduced a range of supports for families and friends that are considered best practice. These initiatives include practical supports, bereavement rituals and transforming hospital spaces that are designed for people at end of life (the Design and Dignity Project).

Practical Supports

- Car Parking – several hospitals arrange free or reduced car parking for relatives of dying or critically ill patients.
- Family Rooms – most hospitals have at least one family room, allowing relatives and friends to gather in a private space as they take turns to sit with the person close to them who is dying. Many of these rooms are equipped with overnight and catering facilities.
- Visiting Times – flexibility is given to the usual restrictions on visiting times with access extended out of hours and for children.
- Information and guidance – as well as providing local information, a series of national information booklets is being developed on topics such as understanding post mortems and coping with bereavement. The first booklet 'When someone you care about is dying in hospital – what to expect' has been completed, and provides sensitive information about the changes that can occur when a person is dying in an acute hospital and how relatives can support the dying person.

- End of life Symbol is used as a visual means of communication that someone has died and helps to ensure a dignified environment for all concerned.
- Multicultural guides have been developed in recognition of the different ceremonial resources and rituals that reflect the different religions and faiths.
- Handover Bags (pictured below) that are purposefully designed for the personal belongings of the deceased are used as standard practice in all HFH hospitals.

Bereavement rituals

Annual remembrance services for patients who have died are held in most hospitals and sympathy cards are usually sent to relatives of the deceased. In instances where infants and children have died, some hospitals arrange for ‘footprints in our hearts’ memory books and keep sake quilts for bereaved parents, as well as ensuring appropriate small remains carriers are available for dignified transfer of stillbirth or miscarriage remains. Communication arrangements are also put in place to ensure sensitive management of any follow up care.

Design and Dignity Projects

The Design & Dignity Project aims to transform the way hospitals are designed for people at the end of their lives and specifically enhance the physical environments of hospitals and these projects are funded jointly by Irish Hospice Foundation and HSE programmes, along with contributions from individual hospitals. Since it was established in 2010 commitment has been given to 30 capital refurbishments in hospitals nationally, and these include family rooms, palliative care comfort suites, bereavement suites, and mortuaries.



Information booklet ‘When someone you care about is dying in hospital – what to expect’



Handover Bags are purposefully designed for the personal belongings of the deceased

List of Design and Dignity projects funded

Type of project	Hospitals	Number of projects
Mortuaries	Beaumont, Coombe, Limerick, Mercy, Sligo, Roscommon, Mullingar, Portiuncula, Mayo, Kerry	10
Mortuary family room	St James's	1
General family rooms	Beaumont, Connolly(2), Mayo, Navan, Nenagh, Portiuncula, Roscommon, St John's Limerick, Mercy	10
Bereavement suites (viewing room and family room)	St James's Emergency Department, Tallaght Emergency Department, Ennis	3
Maternity inpatient rooms	Galway, Portlaoise	2
Palliative Care Comfort Suite	Mater	1
ICU family rooms / waiting areas	Mater (2), Beaumont, St James's	3

In addition, a number of hospital spaces have been renovated outside of the HFH Design and Dignity Grant Scheme with hospital staff and bereaved relatives undertaking fundraising for these projects. Some of these include:

- Six family rooms in the Mater Hospital
- Renovation of family room in Ennis General Hospital
- Family room in Naas General Hospital

Family rooms provide a private comfortable space allowing families to rest and gather together as they anticipate the death of their family member.

“It was just lovely that we had somewhere to go that wasn't a hospital ward or room”.

Connolly Hospital Family room



Mater University Hospital Family Room



Mortuary refurbishments have been priorities for many hospitals and this was an area highlighted by “A Good Death” report as requiring improvement – so far nine mortuaries across the country have been funded. The new mortuary spaces include a dignified space for families to view the deceased, a comfortable waiting area and where possible a garden area.

Sligo University Hospital mortuary, before and after



Mercy University Hospital mortuary, before and after



Referring to the newly refurbished mortuary in Mercy Hospital Cork, a young bereaved wife said:

‘I was able to bring the children in to see their father, it was just a really nice place to be.’

As well as making a direct positive impact on patients and their families, the Design & Dignity Project also improves the culture of care, enhances staff morale, leads to improvements in care practices and service innovation, and influences future healthcare design.

As previously mentioned, the Mater Hospital and St James’s Hospital undertook a survey of 356 bereaved relatives known as the Survey of Bereaved Relatives: Voices MaJam in 2017. This was the largest survey of bereaved relatives undertaken in two acute hospitals in Ireland. The majority of those surveyed said that the quality of care provided was either good, excellent or outstanding. A key finding related to the difficulties experienced by terminally ill patients requiring admission to hospital, which is mostly via the Emergency Department. The bereaved relatives recommended that consideration needed to be given to the admission of terminally ill patients directly to the ward, bypassing the Emergency Department.

The recommendations from the Voices MaJam Survey are being implemented as resources allow and are set out on the following pages, courtesy of Mater Misericordiae University Hospital and St. James’s Hospital.

SURVEY OF BEREAVED RELATIVES

VOICES MaJam Results



356
Relatives



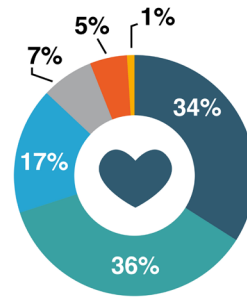
2 Hospitals



46%
Response Rate

Quality of Care

- Outstanding
- Excellent
- Good
- Fair
- Poor
- Don't know



Care Needs



79% of relatives indicated **pain was relieved.**



73% of relatives indicated **personal care** was provided to a high standard.



56% of relatives indicated **emotional needs** were met to a high standard.



61% of relatives indicated **spiritual needs** were met to a high standard.



90% of relatives reported that the patient was treated with **dignity and respect** all or most of the time.



75% of relatives indicated they were involved in **decision making.** However, 18% of relatives would have liked more involvement.



81% visited their relative outside of **regular visiting times.** 17% were not informed about this option and would have liked to visit.



17% spoke with a healthcare professional about their **bereavement,** and found it helpful. 29% hadn't but would have liked to.



Route of admission via the Emergency Department to hospital for terminally ill patients needs to be considered.



69% of patients died in a **single room.** Relatives viewed care in a single room as key in the provision of good care at end of life.



Family rooms with appropriate facilities were deemed as a necessity on hospital wards.



Surveying bereaved relatives proved a meaningful method of evaluating care at end of life.

SURVEY OF BEREAVED RELATIVES

VOICES MaJam Recommendations

Relatives Recommended



Improvements in communication to patients and their families relating to the progression of illness and dying.



Earlier conversations with patients and their families about advance care planning and end-of-life care preferences.



Timely help with meeting care needs.



Care in a single room in the days before a person dies.



Admission for terminally ill patients directly to wards bypassing the Emergency Department.



Family rooms on hospital wards to enhance communication and care experience.



Flexibility in visiting times, the availability of specialist palliative care to manage pain and other symptoms and access to the mortuary at weekends.



Standardised bereavement practices including the provision of information leaflets and access to bereavement support.

This research recommends



Healthcare staff participation in education programmes to enhance their skills and knowledge on care at end of life.



Surveying bereaved relatives by all hospitals and healthcare settings to ascertain the quality of end-of-life care and support quality improvement.

Post-Mortem Examination

“Families are often uncertain about the circumstances in which the Coroner may require a post-mortem to be carried out. They may be unaware that a hospital post-mortem can be carried out to determine the patient’s cause of death, even if not required by the Coroner, and are often unaware that they may also request such a post-mortem. Complaints have been received about delays in the arranging of post-mortems to be held and in having the remains released or available to view”.

- “A Good Death” report

Confusion about the need for, or right to, a post-mortem often compounds problems for the bereaved. A post-mortem (PM) is carried out to:

- Identify cause of death
- Confirm nature and extent of an illness
- Identify other conditions that may not have been diagnosed before death
- Assess the effects of treatments/drugs.

Approximately 20% of deaths in acute hospitals are followed by a post-mortem examination. A post-mortem examination is carried out in two principal circumstances – at the direction of the Coroner for the district in which the death occurs (Coroner’s Post-Mortem) or at the request of the family of the deceased, or the deceased’s clinician, with the consent of the family (hospital Post-Mortem).

The HSE launched the Standards and Recommended Practice for Post-Mortem Examination Services in 2012. Hospitals use the HSE post-mortem standards and undertake continual reviews to ensure they are in line with best practice.

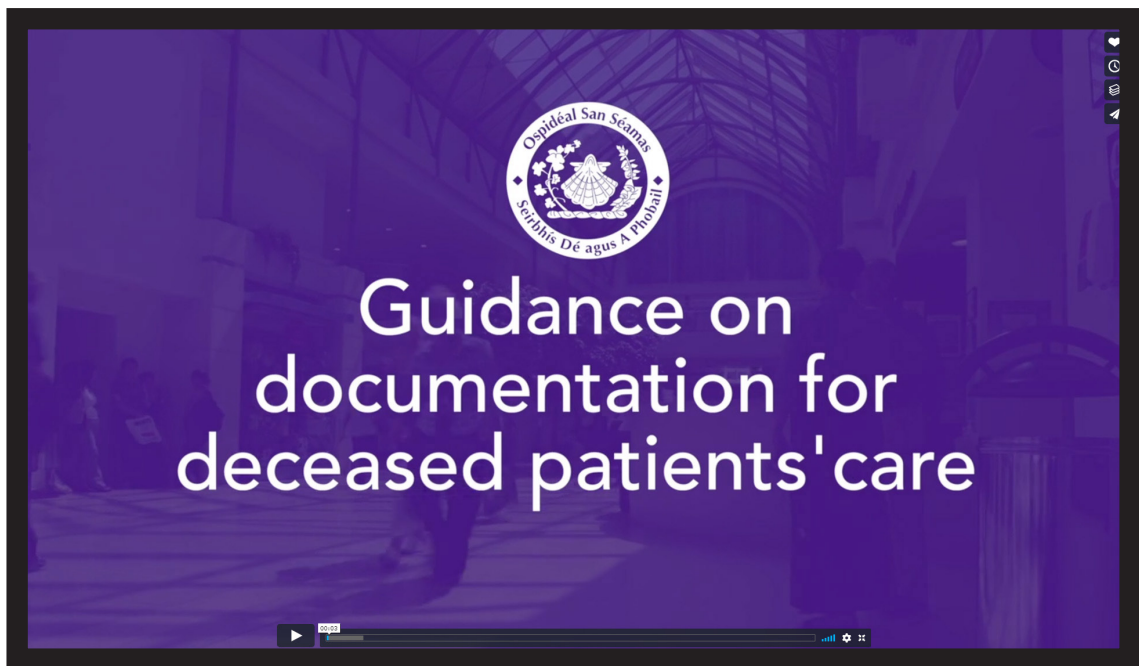
In 2016, the End of Life Care Coordinators Network discussed the challenges regarding post-mortem examinations and the fact that communication with families on the following topics continues to be a challenge:

- The possibility that a post-mortem may need to take place;
- What happens during a post-mortem;
- The legal issues associated with a Coroner’s post-mortem.

Information leaflets about post-mortems

In response to the need to make information more widely available the HSE/HFH Oversight Group recommended that a National Patient Information Leaflet about post-mortems would be developed. This will be based on the HSE Standards and Recommended Practices for Post-Mortem Examination Services document, and build on the existing staff resources on this topic, including the recent material developed by St James's Hospital.

The hospital has developed a ten-minute video detailing the range of documentation the different professions are required to complete when a patient has died. It provides a checklist for the care of the deceased patient and aims to support staff to undertake the steps necessary when caring for the deceased patient and his or her family. It is also used to communicate information from the ward to the mortuary and bereavement social worker. Short information videos are an excellent way of providing training and relevant details for staff and the hospital is to be commended for its initiative in this regard.



The guidance video is available at <https://vimeo.com/263514593>

Returning the Deceased Person's Belongings

The concept of the “Handover Bag” was introduced by the IHF some years ago, after the Ombudsman conducted an investigation of a complaint relating to one acute hospital. The complaint concerned the way the deceased patient’s clothing, along with plastic gloves and syringes, had been placed in black plastic bags and left for relatives to collect beside a Christmas tree on the ward. The Ombudsman’s investigation of the complaint found that the return of the patient’s personal belongings in refuse sacks was impersonal and lacked sensitivity towards the family.

Since then, most HFH hospitals use “Handover Bags” to return patient belongings. However, in a recent complaint to the Ombudsman, one family said that their late father’s clothing was returned to them in a black plastic refuse bag on top of which his slippers had been placed. These were the same pair of slippers which their father had worn on his admission to hospital a few days previously. The family said that this had caused them considerable upset and distress.

Hospitals need to ensure that all staff are familiar with end of life practices and that their focus is on maintaining patient dignity and respect at all times. They must also be mindful of the need to be sensitive in their interactions with recently bereaved relatives. It is disappointing to see plastic refuse bags still being used to return personal belongings when Handover Bags are readily available.



Managing Complaints

“We only have one chance to get this right”

- Sharon Foley, CEO, Irish Hospice Foundation

If something goes wrong with the care provided at the end of a patient’s life, it is too late to put matters right for the person who has been most affected. Dying with comfort and dignity is a human right and sadly, despite the best efforts of all concerned, some inequality still exists in our services. A poor experience of a loved one’s death in a hospital can leave a lasting negative impact on the family and will often serve to make the bereavement process so much more difficult.

Good complaints management is a key element of public administration. It is particularly important that complaints involving end of life care are handled sensitively and with compassion. It is also important that complainants have access to an open and responsive complaints system, which objectively identifies and acknowledges shortcomings when they have occurred and readily apologises for them.

Meeting with bereaved families to discuss their concerns is highly recommended, provided relatives feel supported and heard during this process. It is a good idea for hospitals to discuss the availability of advocacy services with relatives before such meetings take place. Because bereaved families are often distressed and upset about the death of a loved one, it can be difficult for them to formulate the questions they have and to hear the responses from hospital staff. The role of independent advocates is crucial in such situations. The National Patient Safety Office is currently developing a National Patient Safety Complaints Advocacy Service that will oversee the development of an independent complaints advocacy service for patients and their families.

From the Ombudsman’s perspective, a more consistent, timely and compassionate approach is needed in the handling of complaints about end of life care. Making a complaint can be a daunting prospect for people generally but this is particularly true of bereaved families who are grieving the loss of a loved one. It is vital that complaints officers are properly trained so that they can examine a complaint in an impartial yet empathetic manner. Delayed, defensive and incomplete responses only serve to heighten the sense of frustration, anger and upset felt by complainants who are recently bereaved.

Learning from complaints is a crucial component of the process. With the development of the hospital groups, there is greater opportunity for sharing the learning from complaints across the services.

Conclusions

Communication

Poor communication is a regular feature of complaints to the Ombudsman. Conversations about diagnosis, prognosis, ceilings of care or decisions about resuscitation all need to be had with sensitivity, in a way that patients and families can understand. The Final Journeys Workshop and the Breaking Bad News Training Programme are giving staff the confidence to hold compassionate and sensitive conversations with dying patients and their families. Many bereaved relatives who contributed to the Survey of Bereaved Relatives: Voices MaJam reported that hospital staff communicated with them in a kind, compassionate and caring way.

However, some respondents said that staff did not appear to have much time to talk to them, that doctors gave bad news in a blunt way in front of patients, or that patients were told about their diagnosis, without the option of family members being present to support them. The complaints made to the Ombudsman highlight the need for continuous training for hospital staff in this regard. Professionals need to be clear about the importance of these conversations at the end of life or after a death. Hospitals need to ensure that front line staff continue to receive the necessary training to help them communicate effectively and sensitively in these situations. In addition, people who handle complaints should receive training so that they understand the importance of interacting sensitively and compassionately with bereaved families.

Physical facilities and resources

Clearly, there has been a significant focus on improved physical facilities for dying patients and their families since the publication of “A Good Death” in 2014. For most people, this means access to a private room where families can spend time with their loved ones during the period in which they are dying and after death has occurred. The HSE and the IHF have worked hard to improve end of life facilities across many hospitals, which has made a tremendous difference to patients and their families. The majority of families in the Survey of Bereaved Relatives: Voices MaJam viewed care in a single room as key in the provision of good care at end of life. Therefore, emphasis must continue to be placed on the development of facilities that afford privacy for dying patients and their families.

The availability of information is also important for relatives who are trying to comfort and support a dying person. There is considerable variation across hospitals at present with regard to the availability of written leaflets on end of life matters. The HFH Hub and the work of the HSE/IHF Joint Oversight Group will help to ensure the availability and dissemination of relevant resources across all HFH hospitals.

Overall

There has been very considerable progress made since the publication of “A Good Death” report. The growth of the Hospice Friendly Hospitals Programme within most acute hospitals, the increased availability of specialist palliative care services in acute hospitals, the provision of improved physical facilities for patients and families, the increase in the number of End-of-Life Coordinators and Committees in hospitals and the focus on ongoing training for staff are to be commended. The collaborative work of the Irish Hospice Foundation, the HSE and the staff from the various Hospital Groups speaks volumes about the commitment being made to improve the standard of end of life care. As Ombudsman, I warmly welcome all of these improvements to the service.

I cannot stress enough the need to ensure that in delivering end of life services, we put the welfare and dignity of the dying person, the need to provide information with sensitivity and bring comfort to relatives, to the forefront of our thoughts. The pace of progress is very encouraging. However, there are still aspects of the services that require urgent focus and attention as highlighted by the Survey of Bereaved Relatives: Voice MaJam recommendations. I am pleased to endorse these recommendations, which are set out below.

The Way Forward

1. Ongoing education and training about end of life protocols and good communication for all relevant staff
2. Continued emphasis on improving physical facilities and resources for dying patients and their families
3. Increased access to specialist palliative care services in hospitals and in the community with particular emphasis on out of hours services and weekends
4. Terminally ill patients should be admitted directly to wards and not via Emergency Departments
5. Appointment of additional End of Life Coordinators and Committees in hospitals
6. Complaints about end of life care handled sensitively with a focus on learning and service improvement
7. Systems should be put in place to capture the views of bereaved relatives on a regular basis
8. Formal mechanisms should be in place to ensure adequate representation of patients and relatives in the development of end of life resources and services

Useful Links and resources

1. "A Good Death" – A Reflection on Ombudsman Complaints about End of Life Care in Irish Hospitals, 2014. Available from: www.ombudsman.ie
2. Irish Hospice Foundation, 2010. Quality Standards for End-of-Life Care in Hospitals: Making end-of-life care central to hospital care. Available from: www.hospicefoundation.ie
3. Palliative Care Competence Framework (HSE, 2014).
4. Health Information Quality Authority, 2012. National Standards for Safer Better Healthcare. Available from: www.hiqa.ie
5. HSE, 2017. Palliative Care Services – Three Year Development Framework (2017 – 2019)
6. Survey of Bereaved Relatives: Voices MaJam (Mater Misericordiae University Hospital and St James's Hospital). Available from: www.mater.ie/end-of-life-care/Survey-of-bereaved-family
7. List of Advocacy Services. Available from [www. HSE.ie](http://www.HSE.ie)
8. Irish Hospice Foundation. Think Ahead-Planning for Death and Dying, 2015. Available from: www.hospicefoundation.ie
9. HSE National Consent Policy, 2013. Available from: www.hse.ie/eng/services/list/3/nas/news/National-Consent-Policy.pdf
10. CEOL Programme - Compassionate End of Life care in residential care centres. Available from: www.hospicefoundation.ie
11. Seven Dementia Palliative Care Guidance Documents and accompanying factsheets. Available from: www.hospicefoundation.ie
12. Information video about documentation for deceased patient's care: vimeo.com/263514593
13. Think Ahead form: www.thinkahead.ie



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Office of the Ombudsman
18 Lower Leeson Street, Dublin 2

Lo-call: 1890 223030 Tel: 01 639 5600

Website: www.ombudsman.ie

Email: info@ombudsman.ie

Twitter: [@OfficeOmbudsman](https://twitter.com/OfficeOmbudsman)