



**HospiceFriendly
HOSPITALS**

Putting Hospice Principles into Hospital Practice.



Competence & Compassion

End-of-Life Care Map



THE IRISH
**HOSPICE
FOUNDATION**



Féilthreasacht na Seirbhíse Sláinte
Health Service Executive



**PALLIATIVE
CARE**

2nd edition 2012–2013

Dying in Ireland

We only have one chance to get care right for patients at end of life

The majority of deaths in Ireland occur in acute hospitals. *The Network of Hospice Friendly Hospitals* works to ensure that end-of-life care is central to the mission and everyday business of the hospital. It promotes a quality service for all patients at the end of life, whether their death is expected or unexpected, and acknowledges the role of clinical, support and administrative staff in supporting the patient and family.

This map is designed for staff involved in any aspect of end-of-life care. It is intended to provide practical advice and prompts along the end-of-life journey. It is not designed to be read as a stand alone document, or to be prescriptive on an individual patient's care, rather it provides a set of key considerations for staff in end-of-life care.

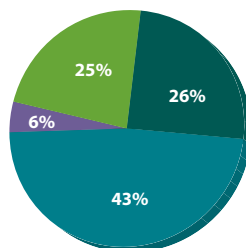
Some of the most important things people want at the end of life ¹

- To be surrounded by people I love
- To be free from pain
- To be conscious and able to communicate
- To be at home
- To have medical and nursing support readily available
- To have spiritual support available
- To be in a private space

The Facts ¹

- Almost 30,000 die in Ireland every year
- 67% of people would wish to die at home

Place of death in Ireland ³

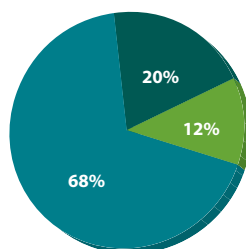


- 43% Acute hospitals
- 26% At home
- 25% Long-stay facilities
- 6% Hospices

Hospice care is a philosophy of care that aims to make sure that: ²

- People are treated with dignity and respect
- People are treated as individuals
- The physical, emotional, social and spiritual well-being of the person are given equal emphasis
- Family members and those important to the patient are included in the care approach

Place of death in hospitals ³



- 20% Critical care areas, e.g. ICU, CCU
- 12% Emergency departments
- 68% Wards

¹ A nationwide survey of public attitudes and experiences regarding death and dying (The Irish Hospice Foundation, Weafer & Associates 2004)

² Strategic Plan 2012-2015 (The Irish Hospice Foundation)

³ McKeown, K., 2012. Key Performance Indicators for End-of-Life Care: A Review of Data on Place of Care and Place of Death in Ireland, Dublin: Irish Hospice Foundation. Available at: www.hospice-foundation.ie

The Recognition of Progressive Deterioration in Health

Although the main focus of hospitals is maintaining health and preserving life, many deaths occur in hospital. Some of these are sudden, unexpected deaths.

Death may be as a result of an acute illness, even though the intention of treatment is cure. Death may also occur as a result of an acute deterioration in a chronic or life-threatening condition, for example an acute infective exacerbation of COPD or an acute deterioration in chronic cardiac failure. The intention of the management of this acute problem is to reverse the acute deterioration. The challenge for doctors and the healthcare team is to recognise that there will be a time, that despite the patient having a potentially reversible acute problem, the patient may deteriorate and die. Doctors, other healthcare staff, patients and their families can all find this challenging.

Goals of Care

If a patient has had multiple acute deteriorations, or continued deterioration in their condition and despite appropriate active management, continues to deteriorate, it may be necessary to review the goals of care, even if death is not imminent. It may be worth considering the question 'would I be surprised to hear that this patient dies within the next year?', or considering disease-specific evidence-based prognostic indicators where available, and considering if advice from a specialist is needed. Goals of care should be reviewed which includes comfort while continuing active management, or focusing on comfort only which may also mean continuing active management, for example, diuretics in severe heart failure.

Communicating with Patients & Families

Patients need the opportunity to discuss the likely future course of their health. Families should be involved if this is what the patient wishes. Patients should be given the opportunity to discuss future care goals, including the opportunity to discuss care they would wish to receive if they are not able to engage in decision-making (advance care planning). Principles discussed in the sections on communicating in difficult circumstances and care planning should be used here.

The Surprise Question ⁴

'Would you be surprised if this patient died in the next 12 months?'

This is an intuitive question that is helpful for clinicians to recognise when a patient with an advancing life-limiting illness may be near the end of his/her life. Earlier recognition of people nearing the end of their life leads to earlier planning and better care.

The next question then is 'What do I need to do now for this patient?'

Diagnosing Dying

Recognising Where Death is Imminent – The 'Terminal' Phase⁵

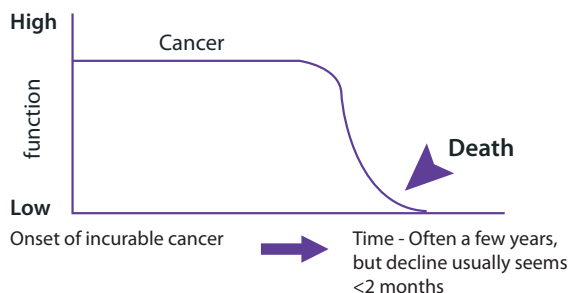
Diagnosing that someone is dying is a *process* with significant implications and one which is best carried out by a team of professionals. It is important that dying is diagnosed in a timely manner as this can ensure that the appropriate care and communication needed by patients and families is anticipated and provided. It also allows the clinical team to prioritise the goals of comfort and support based on the patient's preferences. Patients themselves may already be aware that they are dying, often before healthcare professionals.

The recognition of dying is always complex irrespective of the person's diagnosis or history and uncertainty is an integral part of dying. There are occasions when a person who is thought to be dying lives longer than expected and when a person dies more quickly than expected. Seeking a second opinion or specialist palliative care support, as needed, is recommended.

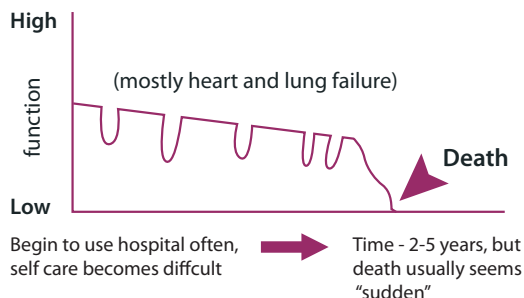
Patterns of dying – dying trajectories⁴

Thinking about the different common patterns of dying allows us to anticipate particular needs for patients and families.

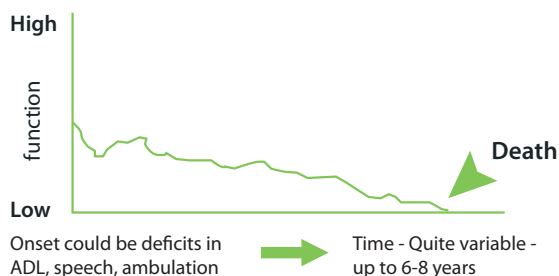
Cancer



Organ systems failure



Frailty/Dementia



⁴ When a Patient is Dying booklet, Hospice Friendly Hospitals Programme, 2008

⁵ Lynn J., 2004. Sick to Death and Not Going to Take it Anymore!, University of California Press, Berkeley, CA: 2004.

Communicating in Difficult Circumstances

Communicating with patients and families at end of life can be very difficult for staff. The quality of communication in times of crisis can have long term implications for all concerned. **Any trauma on hearing bad news should relate to the actual news and not to the manner in which it is imparted.** This section focuses on informing patients of a terminal diagnosis and also how to break bad news over the phone. When you are informing a family of a patient's death, the same principles apply.

1. Preparing Yourself

- Set time aside. Organise a colleague to accompany you, if possible.
- Find a quiet private room and avoid interruptions (e.g. telephone, beeps). If a private space is not available, apologise, acknowledging the constraints.
- Avoid giving information in inappropriate places such as corridors.
- Know all the facts, make sure you have the right patient, confirm test results.
- Have options or treatment plans prepared to discuss with the patient as appropriate.
- Have tissues handy (discreetly).
- If an interpreter is required organise in advance and avoid delegating interpretation to a relative.
- Mentally prepare.

2. Preparing the Patient

- Find out what the patient knows and wants to know. Do they want all of the details? Would they like their family/friends present? Do they have any particular cultural/religious beliefs/needs?
- Sit down at the patient's level and introduce yourself & your colleagues.

3. Breaking the News

- Give a 'warning shot' and pause.
Sample Phrase: "*I'm afraid it looks rather serious.*"
- Carefully break the news gently, slowly and clearly.
- Avoid jargon and euphemisms – use simple language/draw pictures.
- Chunk & check – break news into chunks & check understanding.
- Acknowledge reactions.
Sample Phrase: "*I can see this is a shock for you.*"
- Don't overload the patient with information.
- If necessary, repeat the information.

4. Supporting the Patient

- Deal with concerns before details - facts may not be remembered but the way they were communicated will be.
- Allow for silence and tears, and avoid false reassurances.
- Check understanding – repeat as necessary using supportive written information/diagrams if appropriate.
- Find out if they would like more information.

Breaking bad news is difficult. Seek support from colleagues.

5. Plan & Follow Up

- Provide a clear plan for the patient/family as to what will happen next.
- Have options or treatment plans prepared to discuss with the patient as appropriate and based on patient's response to the news.
- Avoid phrases like "there's nothing more we can do".
Sample Phrase: "*There isn't any specific treatment to make your illness go away, but there is a lot we can offer to help you to cope.*"
Give examples.
- Offer to meet relatives and/or other staff with the patient.
- Seek patient's permission before giving information to others.
- Provide contact name and number to patient if they have further questions or require support.
- Find out if there is anyone in particular the patient would like to talk to e.g. pastoral care.
- Share information with the healthcare team including the GP/ PHN and document (1) details of the discussion (using the same language you used with the patient) and (2) follow up plan in the patient's notes.
- Check back with the patient later.

Breaking Bad News over the Phone

- Find a quiet room and mentally prepare before dialling.
- Confirm identity and relationship to the patient.
- Suggest that the relative sits down.
- Give a warning shot and pause before breaking the news gently, using simple language.
Sample Phrase: "*I'm afraid I have bad news*"
- If there is anyone with them, offer to speak to them and/or offer to telephone another family member or friend. Repeat exactly what you said to the first person to confirm the message.
- Stay on the phone until relative indicates they are ready to end the conversation.
- Ensure relative has a contact name and direct line number for you/colleague, if available.
- Consider sending a taxi to collect the relative/friend.
- Contact the hospital reception/security desk and inform that family members will be arriving and if possible arrange for parking near the entrance to the hospital.
- Ensure a member of staff greets the family on arrival at the hospital and ward.
- Document and liaise with multidisciplinary team.



Care Planning⁶

“Have you thought about what you’d like to happen if...?”

Patients should be regularly offered opportunities for discussions regarding their prognosis, concerns, and needs and wishes at end of life. Such discussions could include a wide range of matters from preferred place of care to funeral arrangements.

A care planning discussion might include ⁷

- the patient’s and/or family’s concerns
- their values and personal goals for care
- their understanding about the illness and prognosis
- preferences for types of care/treatment that may be beneficial in the future

Timing of Discussion

Consider introducing the topic in the following circumstances:

- When it is clear the patient has a life-limiting advanced progressive illness
- When you can answer no to the **surprise question** - “*would you be surprised if the patient died within 12 months?*”
- If the patient/family have expectations inconsistent with clinical judgement
- When there is a significant deterioration in the patient’s condition
- When a treatment decision needs to be made
- If disease-specific treatment is not working
- At the time of referring the patient to specialist palliative care services

Preparation

See ‘Preparing Yourself’ in the ‘Communicating in Difficult Circumstances’ section

Recommendations

- Find out the patient’s level of understanding– this helps establish a common ground. Or it may be worth summarising what has happened in the patient’s illness before moving on to the current situation.
- Always give the patient the option not to discuss these topics or to defer the discussion to another time.
Sample Phrase: “*I am very happy to talk to you about any concerns or questions you have about this now or later, is there anything you would like to ask me about?*”
- Do not make assumptions about the patient’s and family’s information needs. Clarify what the patient wants to know and the level of detail preferred before giving new information.
Sample Phrase: “*Often people with conditions like yours have a lot of questions that are sometimes scary or sometimes they’re not certain if they want to know the answer. So if there’s anything you’d like to know, feel free to ask me and I’ll answer as best I can.*”
- Explore the patient’s concerns, expectations and fears about the future.
Sample Phrase: “*What is your biggest concern at the moment?*”

- Offer to support the family (as long as the patient has given consent).
Sample Phrase: “*Would you like me to tell...what we’ve discussed?*”
- To explore and address different information needs, consider joint as well as separate discussions with the patient and family (once the patient has given consent).
- Encourage the patient to ask questions and express their wishes.
Sample Phrases: “*Is there anything else you’d like to discuss?*” “*Have you ever thought about where you would like to be cared for in the future?*”
- Once a terminal diagnosis is made patients can feel abandoned. It is important to reassure the patient that you/the team will be there for them throughout their illness. If this is not possible, it is vital that alternative arrangements are spelled out and are reliable.
Sample Phrases: “*We will do what we can to manage your symptoms and link you in with the services that will support you and your family. You will not be alone in this.*”
- Emphasise the available support, such as the palliative care team.
Sample Phrase: “*We have different ways to relieve (pain/nausea/ breathlessness) and other symptoms.*”
- It is important to enable the patient to feel control over their illness. Help the patient to identify where control can be fostered e.g. tidying up unfinished business, arranging to attend a particular event.
- Encourage patients to share in decision making according to their desired level of involvement.
Sample Phrase: “*People vary in how they want to make medical decisions. Some people want to make decisions themselves, some want to share decision making with the doctor. What would you like?*”
- Always end discussions with a follow-up plan. Patients may need time to consider decisions or reconsider what has been discussed. Discussions such as these should be ongoing and patients should be reassured that they can change their mind at any time.
- Share information with the healthcare team including the GP/PHN and document details of the discussion and follow-up plan in the patient’s notes.
- **The HSE is currently developing an advance care planning document and rapid discharge guidelines. Please refer to these once available.**

⁶ Medical Journal of Australia – Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers (2007)

⁷ <http://www.endoflifecareforadults.nhs.uk/eolc/acp.htm>

Communicating CPR Decisions with the Patient/Family

The following outlines some recommendations for clinicians to consider.

1. When a clinical decision is made that CPR should not be attempted and the patient has not expressed a wish to discuss CPR, it is not necessary or appropriate to initiate a discussion with the patient.
 2. If a **patient has capacity** and wishes to participate in decision-making about CPR and DNAR (do not attempt resuscitation) decisions, their input is important.
 3. A patient who has capacity has the right to refuse medical treatment.
 4. When the wishes of a patient who lacks capacity are not known, treatment decisions about CPR must be based on a judgement about its benefits and burdens for this patient in this particular condition.
 5. The overall clinical responsibility for decisions about CPR and DNAR for **patients who lack capacity**, rests with the most senior clinician in charge of the patient's care.
 6. Where the patient lacks capacity, the nature, benefits and risks of CPR as they apply to the patient's situation should be explained to the family and the CPR decision should be conveyed to them.
 - When a patient is in the final stages of an incurable illness and death is expected within a few days, the success rate of CPR is between 0-2%⁸
 7. Any decision that CPR will not be attempted should be documented on the patient's records and details given of components that went into the decision.
- 8. Patients/families should be reassured that declining CPR does not result in the denial or withdrawal of other treatments that might be thought helpful e.g. antibiotics, radiotherapy**

For more information, refer to the Ethical Framework for End-of-Life Care (Module 6, Section 6: The Ethics of Life Prolonging Treatments) at www.hospicefriendlyhospitals.net

Refer to the HSE guidelines on consent, when available.

Eligibility Criteria for Access to Specialist Palliative Care Services⁹

Patients with both

- An advanced, progressive, life-limiting condition and
- Current or anticipated complexities relating to symptom control, end of life care-planning or other physical, psychosocial or spiritual needs that cannot reasonably be managed by the current care provider(s)

It is recognised that there are "grey areas" and individual referrals may be discussed with the local SPC team so as to assess their appropriateness. SPC teams are always available to advise or support other professionals in their delivery of palliative care.

⁸ Newman R. Developing Guidelines for Resuscitation in Terminal Care. *Eur J Pall Care* 2002; 9(2):60-63.

⁹ Palliative Care Clinical Programme, HSE, 2012

Caring for a Dying Person

This section details key areas to consider when caring for a person where death is imminent. When possible it is important to agree goals for end-of-life care with the person, family and staff involved in delivery of care. Communication is crucial to ensure that key messages are appropriately shared. It is also important to document the decisions relating to patient care, key conversations and the day-to-day goals of care.

Always consider if the Specialist Palliative Care Team needs to be consulted, to help in patient management, particularly when there are:

1. Complex symptom control issues
2. Complex emotional issues
3. Children or vulnerable adults who are facing bereavement

The key to managing and supporting the dying person involves:

1. Identifying that the person is dying
2. Continuous assessment of symptoms & psychological/spiritual needs
3. Anticipating likely problems before they arise so that treatments are readily available
4. Appropriate & prompt management of symptoms

Goals for the dying person

- Both the person's/family's awareness & understanding of diagnosis of dying is communicated and documented.
- The person is assessed and a care plan is developed in line with the person's/family's wishes & needs.

Clinical goals

- Current medication assessed & non-essential medicines discontinued
- PRN subcut meds/fluids written up as appropriate - see table below
- Inappropriate interventions discontinued e.g. blood tests, BP monitoring
- Cardiac defibrillators (ICDs) deactivated in consultation with cardiologist
- DNAR order completed
- Organ donation considered

Ongoing assessment goals for the dying person

- Person is free from pain, agitation, excessive respiratory tract secretions & nausea/vomiting, severe breathlessness
- Pressure care - if death is imminent, reposition for comfort only – consider pressure relieving mattress
- Bowel care – person is free from bowel problems causing distress
- Urinary status – person has appropriate aids
- Eyes, mouth & lips are clean & moist - consider family involvement in these tasks, if appropriate
- Emotional & psychological care– person and family have appropriate support
- Spiritual, religious and cultural support – needs are assessed and supported
- GP and community team informed of the person's condition

Goals to support the family as the person nears death

- Family members/significant others identified & contact details recorded.
- Family prepared as far as possible for the person's death
- Details of facilities provided e.g. free car parking, washrooms, visiting times, family room.

5 physical symptoms associated with dying

1. Pain
2. Respiratory tract secretions ('noisy rattle')
3. Nausea & vomiting
4. Breathlessness
5. Anxiety
6. Delirium

Seek advice from senior colleagues, local palliative care services and/or refer to the BNF.

You can also seek advice from Our Lady's Hospice Palliative Meds Info Helpline: 01 491 2578

When a Person Dies – “What happens next?”

Caring for a deceased person is one part of the overall continuum of care given to people at the end of life and those close to them. At all times dignity and respect of the deceased person should be maintained. Below is a sample checklist for the care of the deceased patient. Refer to your hospital's policy.

Sample Checklist

- | | | | |
|--|--------------------------|---|--------------------------|
| 1. Inform doctor to pronounce patient's death and document date and time of death in the patient's notes. | <input type="checkbox"/> | 11. Allow time for spiritual care by spiritual support staff or others, as appropriate. | <input type="checkbox"/> |
| 2. Notify next of kin and provide support to patient's family. | <input type="checkbox"/> | 12. At an appropriate time, return person's valuables as per hospital guidelines. | <input type="checkbox"/> |
| 3. Inform pastoral care/spiritual support staff, if appropriate. | <input type="checkbox"/> | 13. Provide family with bereavement information pack, where available, drawing attention to mortuary viewing times & collection of death notification form. | <input type="checkbox"/> |
| 4. Doctor completes death notification form within 3 working days. | <input type="checkbox"/> | 14. Notify the mortuary porter to transfer deceased person to mortuary. | <input type="checkbox"/> |
| 5. Place end-of-life symbol at nurses' station to notify staff a patient has died. | <input type="checkbox"/> | 15. Once porter arrives, accompany family into a private room/space and provide tea/coffee while porter prepares person for transfer. | <input type="checkbox"/> |
| 6. Offer support and reassurance to other patients who may be aware of the situation. | <input type="checkbox"/> | 16. Porter transfers deceased person to mortuary, using end-of-life drape, if available. | <input type="checkbox"/> |
| 7. Contact bed manager and nursing administration. | <input type="checkbox"/> | 17. Document date and time person was transferred to the mortuary in patient's notes. | <input type="checkbox"/> |
| 8. To allow for the preparation of the patient's body, bring family to a private room, provide refreshments, use of phone, etc. | <input type="checkbox"/> | 18. Notify person's GP and any other relevant services in the community. | <input type="checkbox"/> |
| 9. Prepare and lay out deceased person using an end of life drape, observing rituals as appropriate and in line with the deceased person's wishes – all tubes and drains should be removed unless otherwise indicated, for example, in a coroner's case. | <input type="checkbox"/> | 19. Send sympathy card to the family, preferably within one week of person's death. | <input type="checkbox"/> |
| 10. Prepare family once again for viewing and advise the family of any change in the patient's appearance or of equipment that must be left in situ. | <input type="checkbox"/> | 20. Finance department delays hospital bill for at least 6 weeks after person's death to avoid it arriving on the person's month's mind. | <input type="checkbox"/> |
| | | 21. Out-patient department notified to cancel any planned appointments. | <input type="checkbox"/> |

Last Offices

Last offices, also known as the 'laying out of a deceased person,' refers to the care of a person's body after they have died. It is an ancient ritual providing an opportunity for people to offer a final mark of respect to the deceased person. Last offices occurs after the death of the person has been verified by the doctor and the family have been given the opportunity to view the deceased person. Precise procedural aspects may vary in different hospitals but usually include the following (whilst observing universal precautions):

- Washing the deceased person
- Straightening the deceased person's limbs
- Removal of mechanical equipment (unless otherwise indicated)
- Removal of jewellery as per hospital policy
- Covering of wounds with a waterproof dressing
- Dressing the deceased person's body in clothes or a shroud – find out what the family would like
- Labelling the deceased person's body
- Covering or wrapping the deceased person's body in a sheet and/or body bag as required

Refer to 'Health Services Intercultural Guide: Responding to the needs of diverse religious communities and cultures in healthcare settings', HSE, 2009.

Post Mortems

A post mortem (PM) examination (also called an autopsy) is a medical examination of a person that takes place after death.

Hospital Post Mortem Examination

- Usually initiated by a request from the medical team
- In some cases, requests may be initiated by the family themselves
- Carried out by the hospital pathologist
- Consent is required from the family of the deceased person for a hospital PM examination including the removal and retention of organs, tissues and/or other body fluids
- The family have the option of refusing consent or to limit the extent of the hospital PM examination

Communicating with families should include:

- Reason for requesting the PM
- Their right to refuse or place limits on the extent of the examination
- What a PM examination involves
- Where the PM will take place, how long it will take and whether it will delay the funeral
- Possibility of and reason for the retention of organ(s) (eg for a more detailed examination) & how they will be informed of any such retention – note specific consent is required
- What might be contained in the PM record e.g.
 - Tissue samples on slides/wax blocks
 - X-rays/clinical photographs
- How the deceased person will look after the procedure
- Options regarding the ultimate disposition of retained organs (continued retention with consent of family/ options for sensitive disposal (burial or cremation) by the family or the hospital (*see HSE Standards and Recommended Practices for options*))
- How the death is registered
- When the results will be available
- Communication of results - the family should be offered a meeting with the hospital team/consultant requesting the PM

Coroner's Post Mortem Examination

- Is a legal requirement for certain deaths
- Carried out by a pathologist who acts as the coroner's agent
- Consent is not required. However families will be asked to complete an acknowledgement form in relation to the information they have been given
- Formal identification of the deceased is required, (ideally by a member of the family) to a Garda
- All medical equipment must be left on the deceased person's body, unless permission to do otherwise is given by the coroner

Communicating with families should include:

- Why the death is reportable to the coroner
- Information on the office and role of the coroner
- Coroner's reason for ordering the PM
- What a PM examination involves
- The role of the Garda (see above)
- Where the PM will take place, how long it will take and whether it will delay the funeral
- Possibility of and reason for the retention of organ(s) (eg for a more detailed examination) & how they will be informed of any such retention
- What might be contained in the PM record e.g.
 - Tissue samples on slides/wax blocks
 - X-rays/clinical photographs
- How the deceased person will look after the procedure
- Options regarding the ultimate disposition of retained organs (continued retention with consent of family/options for sensitive disposal (burial or cremation) by the family or the hospital (*see HSE Standards and Recommended Practices for options*))
- Registration of death by the coroner
- The coroner's office controls the release of information regarding the findings of the coroner's post mortem – contact the coroner's office for local arrangements
- Also the family can request the coroner to issue the report to the GP

Apart from informing families regarding the possibility of organ retention, it may not be appropriate to give all of this information at one time. A **contact person** should be identified who can support the family through the whole process. Records of discussions & information given should be documented in the patient's healthcare record.

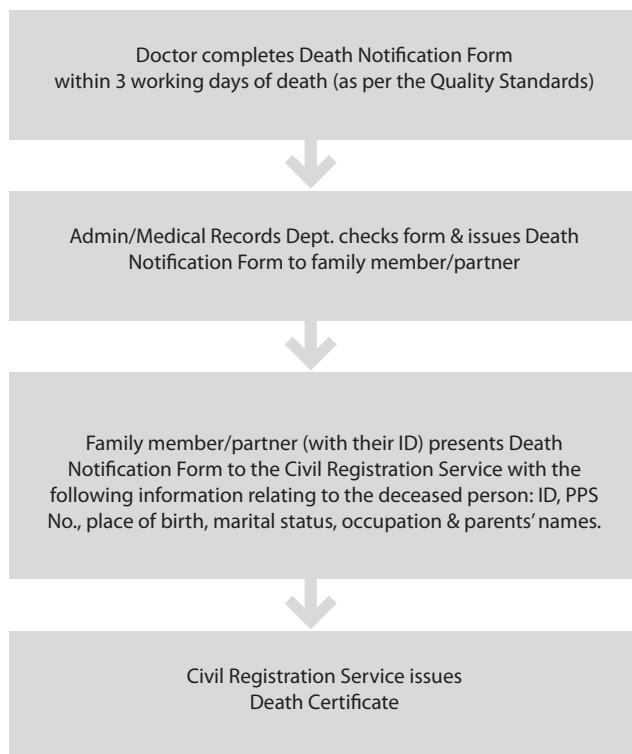
When to report a death to the coroner *

- The general rule is that all sudden, unexplained, violent deaths and death which is due directly or indirectly to any unnatural cause **must** be reported to the coroner
- **If a doctor has any doubt in the matter, contact the coroner for the district.**
- Refer to the HSE's Standards and Recommended Practices for Post Mortem Examination Services (Recommended Practice 4) for full details on deaths reportable to the coroner.

* Please note that reporting a death to a coroner does not necessarily mean a post mortem examination will be carried out.

Death Notification Forms/Death Certificates

It is now the responsibility of the family to register the death of the patient and obtain a Death Certificate.



Coroner's Post Mortem

In cases where a Coroner's post mortem is carried out, the Coroner issues the Death Notification Form directly to the Civil Registration Service.

The Coroner on request can issue a letter stating that a post mortem examination is being carried out. This can be used to obtain an **interim** death certificate for Social Welfare benefits.

After Death Audit & Review Meetings

Regular review meetings held with the staff at ward/unit level or one-to-one provide opportunities for supporting staff through debriefings, reflection and learning and also promotes a culture of continuous improvement in the care delivered to patients at the end of life.

Feedback from the bereaved relatives should also be considered.

Questions to consider

- What went well in the care of this person and their family at the end of life?
- What didn't go well?
- What would I do differently in the future when caring for people at end of life?
- Would the way this person died be acceptable to me?

Refer to www.hospicefriendlyhospitals.net for details regarding the National End-of-Life Care Audit System.

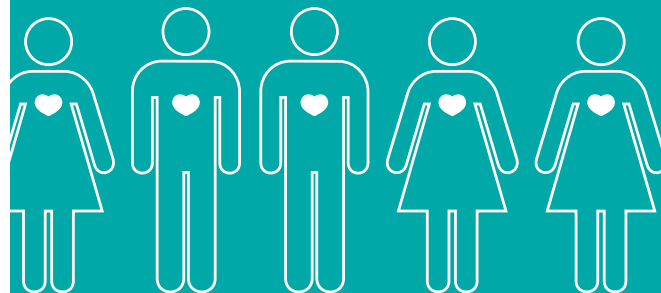
Bereavement Care

Bereavement care begins with sensitive support & information in the lead up to and immediately after a person's death. Be aware of the information resources & local services available to families so you can pass on information as required.

Refer to www.hospice-foundation.ie for a range of bereavement information leaflets.

Take Care - Staff are not immune to grief

End-of-life care can be difficult. It is important that staff support themselves & each other in this area of work. Staff can be supported through peer support, informal debriefing sessions or counselling as appropriate.



Resources

A number of resources are available to enhance the care of the dying or deceased patient. Check your local policies/intranet.

Ceremonial Resources - examples

- Ward Altar (multi-denominational)
- End-of-Life symbol (used to notify staff that a person has died / or is dying)
- End-of-life drapes – used for laying out a deceased person and/or transferring the deceased patient from the ward
- NorMors chin support (used when laying out a deceased person)
- Family handover bag (for returning a person's belongings)
- Sympathy cards (to be sent before the hospital bill)



Quality Standards

The Standards set out best practice in relation to the provision of end-of-life care. The Standards have as their core the need for greater engagement by hospitals around issues of dying, death and bereavement. They identify the essential elements that need to be in place to ensure a consistent quality approach for all end-of-life care across the hospital setting, whether death is sudden or expected.

The Four Standards

1 The Hospital

The hospital has systems in place to ensure that end-of-life care is central to the mission of the hospital and is organised around the needs of patients

2 The Staff

Staff are supported through training and development to ensure they are competent and compassionate in carrying out their roles in end-of-life care.

3 The Patient

Each patient receives high quality end-of-life care that is appropriate to his /her needs and wishes.

4 The Family

Family members are provided with compassionate support and, subject to the patient's consent, given information before, during, and after the patient's death.

For more information on related criteria supporting each of these Standards, refer to www.hospicefriendlyhospitals.net

National Audit

Some findings from the National Audit of End-of-Life Care in Hospitals 2008/9 which looked at 1,000 deaths from the perspectives of bereaved relatives, nurses & doctors

Comparative data	Doctors	Nurses	Relatives
Do you feel the way the patient died would be acceptable for you? [Scale: definitely not acceptable to v. acceptable]	81%	71%	67%
Patient had pain all or most of the time in the last week of life	10%	15%	23%
Patient care [Scale: not well to very well]	81%	75%	73%
Family support [Scale: not well to very well]	83%	83%	70%

Communication	Patients	Relatives
Discussions held re. end-of-life care	55%	96%
Discussions documented	76%	89%
Quality of discussion	73%	85%
Wishes expressed	32%	88%
Wishes met	68%	83%

Support for patients and relatives	
Multidisciplinary meeting held to discuss patient's care	44%
Patient/family present at a team meeting to discuss end-of-life care	68%
Patients /families informed of outcome of meetings where they were not present	17%
At least one person (relative/friend/staff) present at time of death	75%
Relatives offered information leaflets on dying, death or bereavement	15%
Number of patients who could have died at home if appropriate supports were available	20-25%
Hospitals which have policies & procedures on end-of-life care	33%
Ward staff who felt very upset after a patient's death during the past year	51%

Quality of care linked to disease
As assessed by doctors & nurses, care at end of life is best for patients with cancer, followed by circulatory diseases and respiratory diseases.
The least satisfactory care is for patients with dementia/frailty.

For the full Audit Report go to www.hospicefriendlyhospitals.net

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