

End-of-Life  
Care Resources

# Caring for a Dying Patient



The information below is from the Hospice Friendly Hospital Programme's *Map for End-of-Life Care*

## Caring for a Dying Patient

This section details key areas to consider when caring for a patient where death is imminent.

When possible it is important to agree goals for end-of-life care with the patient, 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 patient involves:

1. Identifying that the patient 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

### Strategic goals for the dying patient

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

### Clinical goals for the dying patient

- 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 patient

- Patient 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 – patient is free from bowel problems causing distress
- Urinary status – patient has appropriate aids
- Eyes, mouth & lips clean & moist - consider family involvement in these tasks, if appropriate
- Emotional & psychological care– patient and family have appropriate support
- Spiritual, religious and cultural support – needs are assessed and supported
- GP and community team informed of the patient’s condition
- Goals to support the family as the patient nears death
- Next-of-kin / significant others identified & contact details recorded.
- Family prepared as far as possible for the patient’s death
- Details of facilities provided e.g. free car parking, washrooms, visiting times, family room.

5 physical symptoms associated with dying	Regular / PRN subcutaneous medications
1. Pain	Analgesics (e.g.morphine)
2. Agitation & distress	Sedatives (e.g. midazolam)
3. Respiratory tract secretions ('noisy rattle')	Anti-cholinergics (e.g. hyoscine hydrobromide)
4. Nausea & vomiting	Anti-emetics (e.g. metoclopramide )
5. Breathlessness	Anxiolytics (e.g. midazolam)



## When a Patient is Dying

A guide for staff on the process & symptoms of dying.

The contents of the booklet are included on the following pages.

**This booklet is also available to download at [www.hospicefriendlyhospitals.net](http://www.hospicefriendlyhospitals.net)**

- Why is End-of-Life Care Difficult?
- How do we know if somebody is dying?
- Patterns of dying – dying trajectories
- Process of dying
- Management of the dying process
- Difficult death
- Handling difficult questions
- Spiritual care
- Pronouncing death and death certification
- Care after death
- After death analysis

### When a Patient is Dying

Looking after patients who are dying makes many of us feel a little uncomfortable. What we should be doing or saying is often unclear. Although we feel we should be doing something “to help” we can often be uncertain what that “something” is. Some of this uncertainty arises because being in contact with people who are dying is neither a common experience nor is it easy to talk about or seek advice on how we should be responding and helping.

Some people deal with this part of being a health professional by developing a black sense of humour, others retreat to avoid all but the most minimal contact with the dying and their relatives. Even though staff may have been working for many years they may not have learned or developed their skills and knowledge in this very important part of our work.

This section aims to outline some of the important facts about end-of-life care in Ireland and provide practical advice about managing this particularly significant part of life.

### Facts About People Dying in Ireland

About 30,000 people die in Ireland each year, 48% in acute and 23% in longterm care facilities.

- A third of these deaths (10,000) occur as a result of organ failure, e.g. heart failure or chronic obstructive pulmonary disease.
- A third (10,000) are as a result of generalised frailty and dementia.
- A quarter (7,000) are due to cancer.
- A twelfth (2,400) are sudden unpredicted deaths.

### Why is End-of-Life Care Difficult?

It can make health care workers feel uncomfortable that in some way we have failed to make this patient better - what do you do when there is nothing more “curatively” that can be done?

We can be uncertain what is appropriate to say or do when we are with such patients and their families.

While each death is a unique and profound event, paradoxically, many of the most crucial components of care of this especially vulnerable group are universal, and need to be anticipated and planned for in a practical and rigorous manner within hospital systems and practice.

It can make us feel uncomfortable either by reminding us of our own mortality or of a bereavement we ourselves have experienced.

It may seem strange that we who manage care of people at the end of life can so quickly feel out of our “comfort zone” in such situations.

## The End of Life

The process of dying can be compared to the process of giving birth in that they are both intensely personal and emotive events, and yet each birth and each death also share a great deal in common with every other birth or death. This means we have to both ensure that the common needs of those at the end of life are anticipated and where possible we must be open to responding to individual preferences. Thus, even though end-of-life care is a very particular and important part of our service, it is both unique and common. Much of the care that people need at this time can be planned for and anticipated.

## How Do We Know If Somebody Is Dying?

Little formal training is given to nurses and doctors in developing skills in diagnosing dying. Yet it is a very important clinical skill and one that can lead to a real improvement in the quality of care received by patients in those very significant last weeks and days of life. Studies have shown that it is often domestic assistants and families who are better at predicting death than doctors or nurses. In part this may be because doctors and nurses have to maintain a clinical focus which can sometimes make maintaining a holistic approach difficult. Diagnosing that somebody has entered the dying phase is a process with crucial implications and one which is best carried out by a team of professionals after discussion and review. Who first raises the question, “Is this patient likely to die soon?”, is not as important as what is done in response. It is a vital diagnosis to make. It helps to ensure that the appropriate care and communication needed by patients and families at this time is provided. It also allows the professional team to prioritise the goals of comfort and support.

As hospital staff we only have  
one chance to get end-of-life  
care right for each patient.

There are a number of signals indicating that a patient is dying. It is likely, for example, that an advanced cancer patient with no chance of a cure is entering the dying phase when they have been deteriorating over a period of days or weeks and when two of the four criteria listed below apply.

The patient is:

- Bed bound
- Semi-comatose
- Only able to take sips of fluid
- Unable to take tablets

Such a patient is entering the dying phase and will benefit from the appropriate physical, psychological and spiritual care.

Such criteria may not be appropriate in patients who do not have cancer but may still provide a useful guide.

### Patterns of Dying - Dying Trajectories

Thinking about the different common patterns of dying for people in Ireland allows us to anticipate particular needs that such trajectories will cause for patients and their families.

Such different trajectories create different end-of-life care needs for patients and their families:

- Mrs. A and her family are most likely to be prepared for her end of life, but may experience a sense of abandonment when the oncology services no longer have options to control the cancer after a long period of monitoring and treatments. Mr. B's family may find it hard to understand how after four previous successful acute admissions he failed to respond on the fifth as they expected.
- Mrs. C's very slow and gradual deterioration coupled with her increasing dementia makes for a very different kind of end-of-life pattern, with slow multiple losses. Her family may have different bereavement needs as the months and years of the dying process can generate a wide range of contradictory and difficult feelings when she dies.

ILLNESS TRAJECTORIES

GP's workload - Average 20 deaths/GP/yr (approximate proportions)

Figure Copyright Gold Standards Framework Joanne Lynn, Centre to Improve the Care of the Dying George Washington Medical School.



TRAJECTORIES

"Cancer" Trajectory: Diagnosis to Death



Organ Systems Failure Trajectory



TYPICAL CASES

Cancer

1) Mrs A - a 54 year old woman with cancer of colon with liver secondaries and requiring a stent for jaundice who is feeling increasingly weak and tired



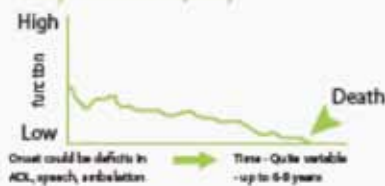
Organ Failure

2) Mr B - A 76 year old man with heart failure with increasing breathlessness on walking who finds it difficult to leave his home has had 2 hospital admissions in the last year and is worried about the prospect of any more emergencies and coping in the futures



TRAJECTORIES

Frailty / Dementia Trajectory



Sudden Death trajectory



TYPICAL CASES

Frailty/Dementia

3) Mrs C - an 81 year old lady with COPD, heart failure, osteoarthritis and increasing forgetfulness, who lives alone. She fractured her hip after a fall, has a poor diet and finds mobility difficult. She wishes to stay at home but is increasingly unable to cope and appears to be 'skating on thin ice'.



Sudden Death

4) Mrs D - was brought into A&E department by the emergency services following a high speed car crash. She was dead on arrival.





### Process of Dying

While there may be many different ways of dying the most common mode of dying involves the following:

- A period of increasing weakness and tiredness resulting in the person spending more and more of their time in bed.
- A period of withdrawal with the person spending less time awake and increasing time asleep, decreasing intake of food and medicine, and decreased interaction with others.
- A period of unconsciousness with no waking.
- A period of shutting down important life processes.
- Cooling of peripheries as the blood circulation is diverted to central processes.
- Irregularities of heart beat due to metabolic or vascular changes.
- Stiffness caused by immobility.
- Breathing patterns change as the person becomes more deeply unconscious and control of breathing is driven by the build up of carbon dioxide in the system. When the level of carbon dioxide is low, there is no drive to take a breath and so there may be long gaps without breathing. Then when the carbon dioxide builds up in the system this will eventually cause the body to take several big breaths to expel carbon dioxide. This pattern of intermittent breathing is called cheyne stokes breathing.
- Difficulties in swallowing often occur in the days or hours before death and may lead to pooling of saliva at the back of the throat. This can cause noisy breathing often referred to as the 'death rattle'. This can be very distressing for relatives and carers but is not thought to cause upset for the unconscious patient.

### Management of the Dying Process

Some people die without pain or distress even when death is expected. However there are five symptoms specifically associated with the dying process in addition to the indicators above. Therefore it is important that there is a plan for when they arise so that symptom management is optimised. Not every dying patient experiences these symptoms but some may experience all five. Often clinical staff have the skills and knowledge to effectively manage the symptoms of dying. However, there are occasions when the input of a specialist palliative care service will be required particularly when symptoms prove refractory or difficult to control.

The five symptoms associated with dying are:

- Pain
- Nausea and vomiting
- Agitation and distress
- Respiratory tract secretions ('death rattle')
- Breathlessness

### Anticipatory Prescribing

It is important to have a planned approach and to anticipate what may happen. Anticipatory prescribing of drugs is important to guard against a patient being left in pain and distress for a period of time until a drug can be prescribed. Healthcare professionals need to be enabled to respond quickly should a symptom arise or when swallowing becomes difficult. It is important to refer to local guidelines as practice may vary. Specialist palliative care teams should be contacted when there is concern or uncertainty about prescribing for patients at the end of life. In providing end-of-life care it is essential that:

- Every effort is made to optimise symptom management.
- Dignity, respect and privacy are provided and maintained.
- The individual needs and preferences of the patient are ascertained and fulfilled insofar as possible.
- Communication is optimised for all people involved (patients, families, staff).
- The patient and family feel unhurried and valued, and,
- Staff are enabled and supported to deliver the highest standard of end-of-life care possible.

### Standard of Care

**The standard of end-of-life care by which we should judge the care that we deliver is whether we would be content if that same care was given to our own family or to ourselves.**

### Difficult Death

Even with years of experience and preparations in place to reduce the difficulties associated with death, dying and bereavement there will be particular deaths which will be difficult for all involved.

1. Unexpected death can completely overwhelm relatives and can lead to great fear and much anxiety. Acute bereavement has been compared with overwhelming fear. The bereaved at such times need accurate information, support and time. As staff, we need to remain calm, unhurried, mindful and gently constructive. Often the presence of someone who knows the procedure and what comes next is very reassuring for families.

Never say “I understand how you are feeling.” However, acknowledging to the family that you are aware of the difficulties of this time can be much appreciated. “This must be so hard for you.”

2. Death due to trauma or violence has particular difficulties. “Death without meaning” is particularly devastating and support for family will require a multi-professional approach.
3. Death where there is emotional discord or unresolved conflict can be draining for families and for staff who are often left trying to balance the different needs of those involved while trying not to take sides. Team work and supporting and using your colleagues’ skills to meet such difficult situations is crucial.
4. As human beings, even if we are professionals, it is normal and appropriate to feel sadness when someone whom we have been looking after and got to know dies. Acknowledging this loss is important and appropriate. In addition because death and dying are such potent experiences we may find that memories of personal deaths we have experienced in the past and issues arising from them may resurface for us. This is not unusual, but it does require us to acknowledge the impact that it is having to a senior colleague and for units to ensure that regular support is available for staff that frequently have to deal with such losses.

Lack of such support may lead to increased sick leave, lowering of morale and an increased turnover among staff. Such support might include:

- An opportunity to review deaths regularly in a supportive setting.
- A culture of acknowledgement of quality care.

## Difficult Questions

Difficult questions can be asked of any members of the hospital staff, and may reflect when a patient feels they can trust you. More important than any particular answer is the need for patients to feel that they are being answered honestly and authentically. CHECK and CHUNK – CHECK WHY the patient is asking a particular question at that time, and and CHUNK your answer into manageable parts that are appropriate to the patient’s emotional state and ability to understand. Throughout the process it is important to keep checking that the patient understands and also that they continue to want to receive the information.

People can find it very difficult to deal with uncertainty. Once a person knows what is likely to happen they can begin to adapt accordingly, whereas the unknown is often more distressing.

## Handling Difficult Questions

- Check the meaning of the question.
- Acknowledge the importance of the question.
- Check why it is being asked.
- Check whether the patient really wants to know.
- Check what the patient may be thinking.
- Is there a clear answer?
- Will the answer leave the patient with uncertainty?

Here are some examples of difficult questions:

## Questions Patients May Ask

### **‘Am I Going To Die?’**

You need to find out what is the major concern, i.e. fear of the process of dying is very different from the fear of being dead or of leaving family.

One strategy would be to ask the patient: *“What do you mean? What are you most worried about?”*

Another very straight forward answer could be:

*“That’s a difficult question, there are no simple answers, we can hope to control your illness, but we can’t hope to cure it.”*

Do give hope, but not false hope.

*“We can not cure you, but we do hope to control your symptoms.”*

### **‘How Long Have I Got Left?’**

Different people will have different worries and fears behind this question that need to be clarified and then addressed.

*“It is difficult to give an exact timeline as to how your illness will progress. What are your biggest concerns surrounding time?”*

The “time left” question can also be discussed in terms of scaled blocks, i.e., hours to days, days to weeks, weeks to months and months to years. Create flexibility, e.g., “*You may have a number of months*” or “*You may have months rather than years.*” Avoid giving a prognosis with a definite time scale and always be clear to express the uncertainty involved.

### **‘Is There No Hope?’**

Avoid the idea that “*nothing more can be done*”. It is important to offer hope at some level, e.g., “*We can not cure your disease, but we hope to keep you comfortable.*” You could also ask: “*What keeps you going? What is important to you now?*”

### **‘Will I Suffer a Lot of Pain?’**

*“I can’t promise that you won’t have any pain, but pain management techniques are very good these days.”*

### **‘What Does Dying Feel Like?’**

Do not be afraid to say, “*I don’t know*” or “*It is impossible for me to know that, but with good care many people with your condition appear to have a calm and peaceful death.*”

You could also ask: “*Do you have particular concerns in relation to dying? Do you want to talk about those?*”

### **‘What Should I Do About Work?’**

*“What would you like to do about work? We can’t predict things exactly. Try to organise your work so that you are feeling that you are where you most need to be.”*

## Questions Families May Ask:

### 'How will we know Mum is dying?'

*"When we see some deterioration week-by-week we talk in terms of weeks, day by day we talk in terms of days."*

### 'How Can I Tell the Children?'

Parents have different approaches. Children of different ages and stages of development need to know different things. There are many books written in this area. Generally it is better that children are told the truth. Usually it is better for children to be told by their parents or other family members to whom they are close, and it is our role as professionals to support the family member to do the telling. Although the family member will know the child much better than the professional, passing on serious news can be very daunting. One approach could be to open up the discussion by asking questions to find out what the child's level of understanding and fears are:

*"How do you think Daddy is getting on at the moment?"*

*"How does this make you feel?"*

*"Do you feel worried about Daddy and about all of us because Daddy is ill? What worries you most?"*

Being truthful and using words that children will comprehend is essential.

- **Inform Children-** Give children appropriate information for their age and stage of development.
- **Involve Children** – Don't exclude them. Explain what is happening to prepare them. "Tomorrow is Daddy's funeral, when we'll go to church with all our friends and relatives to think of Daddy and to remember him in a special way."
- **Reassure Children** – Children are likely to need extra reassurance at this time. Assure them that they are safe and loved. Familiar routines may help them to feel more settled.
- **Encourage Children to Express their Feelings** – Children will grieve in a more healthy way if they know that it is good to talk about how they are feeling. They will take their cue from the adults around them.

### "How Long...?"

Families will often ask us how long the dying process will take, in order that arrangements can be

made or relatives called back from overseas. It is often difficult to predict when death will happen and we need to acknowledge this, while at the same time giving families our best guess so that they can take necessary steps. The following phrases may be helpful in giving a family an idea of how long is left, while at the same time avoiding being specific:

*“When we see somebody deteriorating on a week to week basis we are usually talking in terms of weeks.”*

*“When we see somebody deteriorating on a day to day basis we are usually talking in terms of days....”*

When asked specifically about how to advise a relative who is living far away from home about the need to come back it is important to be clear about four things:

1. Our responsibility is to provide as much information in as clear a manner as possible, provided we have the permission from the patient to do so.
2. It is not our responsibility to make the decision to travel or not to travel, as the individual can only make this for themselves once they have full possession of the available facts.
3. Family should also be strongly advised not to take it upon themselves to make proxy decisions for the distant relative to return or to stay away. This is because if the wrong choice is given long lasting family resentment can fester. It is up to the individual family member to make their own decision and to live with that decision.
4. Many cultures place great emphasis on being present at the actual time of death, even though by this time the dying person is often deeply unconscious. The patient may actually derive more comfort and benefit from being able to enjoy a visit while they are still aware, thus, if there is an option of coming sooner rather than later it is seldom regretted.

### Spiritual Care of the Dying Patient

It is important that the dying person receives appropriate spiritual care. This can be a comfort to the patient and to their family during this difficult time. Some patients may not wish to access such support and these wishes should be respected. It is good practice to check with the patient what they would like. If they are not able to do so themselves, check with a family member. When patients require spiritual care every effort should be made to contact clergy or pastoral carers from the appropriate faith group.

## Pronouncing Death

It is important to pronounce and confirm death in a professional yet compassionate manner, knowing that the family will remember acutely this time, your words, and the tone of your voice.

Listening for a heartbeat for a minute while observing for any signs of respiration allows you some time also to assess the relatives. It is often appropriate to select the person whom you know to be the 'chief mourner', move to their side, or sit beside them if they are sitting and speak to them directly in a clear and slow voice. It is also important to remember that the tone of your voice will be remembered as much as the words that you say.

It is important to be unequivocal in using clear language and to avoid euphemisms which could be misunderstood, "John, has died." It is also usually appropriate to extend some recognition of sorrow. "I am very sorry for your loss", and offer hand-to-hand contact.

Often not much more is required in terms of words at this point, though spending a few minutes silently with the family as they express their grief is often greatly valued. It can cause great offence to rush out of the room after pronouncing death as it can appear cold and uncaring at a time when families are particularly vulnerable and in need.

It can be very helpful to touch the body demonstrating that it is safe for the family to do so. If there are children present it is important that they are given clear information about what has happened and reassurance that everybody else is okay. If a nurse known to the family can stay for a period following death this is often greatly appreciated.

## Death Certification

A death certificate is available from the local registrar of Births Deaths and Marriages by providing the following details to register the death:

- Full name and surname of the deceased
- The deceased's Personal Public Service number (PPS number)



- Gender, marital status, occupation and date of birth or age of the deceased
- Date and place of death
- If deceased was married, the occupation of their spouse, or deceased spouse if widowed
- If deceased was a child, the occupation of the father or, if the parents were not married the occupation of the mother
- Death Notification Form of the Cause of Death

The death should be registered usually by a relative of the dead person (usually the next of kin), an occupier of the house where the death took place or by any person present at the death. The death should be registered as soon as possible but no later than three months after the death.

Registration of a death can be an emotionally difficult time for a family and the process can be made more difficult if they detect any lack of sensitivity. While the registrar may be involved with hundreds of such registrations, for the individual family this is a unique and often very poignant event. The use of information leaflets about the registration process can reduce much of the tension of this time.

In the hospital, staff commonly refer to the 'Death Notification' form sometimes also referred to as the 'Medical Certificate Stating, as a Death Certificate even though this is not the case as a Death Certificate is only issued by the registrar.

Only doctors who have been attending the dead person within the previous 28 days are eligible to complete the death Notification Form. The Doctor must be satisfied about the cause of death, and if not they should inform the Coroner who will decide if a post mortem is necessary. This can cause problems particularly with cross-cover at weekends and holidays when the doctors who knew the patient are unavailable. Each hospital will have a policy for dealing with this eventuality. It can help junior doctors if they are directed to patients who are likely to die when they come on duty. They can then visit them as a priority and thus be eligible to complete certification should death happen.

Prompt completion of the Death Notification Form following death is a very important service to families and staff, as without it the important first stages of a family coming to terms with their loss are stalled. This is not just a task of administrative necessity as it has significant personal care effects for a family's bereavement journey at a time when they are particularly vulnerable. Taking time to fill the notification form promptly, accurately and sensitively is important as it will be looked at closely by the family. This form can have an almost sacramental role for a family with its short summary of a person's birth, address, occupation and death. (The practice of writing 'unknown' or 'OAP' for occupation can be perceived by family as demonstrating indifference and

lacks warmth).

If there is any new information on the form that the family may be unaware of, or may not understand, it is important that a member of the team gives the family a clear explanation. We cannot overestimate the value of having a protocol to ensure that all Death Notification Forms are given by clinical staff to relatives in privacy, allowing time for questions and explanations. This can prevent worries and concerns festering over months or turning into upsetting and lengthy complaints.

### Deaths Should be Reported to the Coroner in these Circumstances<sup>1</sup> :

#### Deaths Occurring at Home or Other Place of Residence:

- Where the deceased was not attended by a doctor during the last illness;
- Where the deceased was not seen and treated by a doctor within one month prior to the date of death;
- Where the death was sudden and unexpected;
- Where the death may have resulted from an accident, suicide or homicide;
- Where the cause of death is unknown or uncertain.

#### Deaths Occurring in Hospitals:

- Where the death may have resulted from an accident, suicide or homicide;
  - Where any question of negligence or misadventure arises in relation to the treatment of the deceased;
  - Where death occurred within 24 hours of admission;
  - Where a patient dies before a diagnosis is made and the general practitioner is also unable to certify the cause;
  - When the death occurred whilst a patient was undergoing an operation or was under the effect of an anaesthetic;
  - Where the death occurred during or as a result of any invasive procedure;
  - Where the death resulted from any industrial disease;
  - Where a death was due to neglect or lack of care (including self neglect);
  - Where the death occurred in a mental hospital;
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<sup>1</sup> [www.citizensinformation.ie](http://www.citizensinformation.ie)

Where a patient dies in hospital, having been recently transferred or discharged from a nursing home or other residential institution (including mental hospital or prison).

### **Deaths reported to the Coroner by an officer of An Garda Síochána:**

Where a death may have resulted from an accident, suicide or homicide;

Where a death occurred in suspicious circumstances;

Where there is an unexpected or unexplained death;

Where a dead body is found;

Where there is no doctor who can certify the cause of death.

### **Deaths reported to the Coroner by the Governor of a Prison in Ireland:**

Immediately following the death of a prisoner.

### **Other categories of death reportable include:**

Sudden infant deaths;

Certain stillbirths;

The death of a child in care;

Where a body is to be removed abroad;

The death of a person in residential care.

## Last Offices

It is important that the deceased's body is treated with respect and prepared appropriately for viewing by the family. Marking the death of a patient on a ward can be helpful for families, other patients and staff.

## Spiritual Care for Families Following a Death

It is usual for religious, cultural and spiritual sensitivities to be heightened around the time of death. Recording that a patient is "Catholic", "Buddhist" or an "Agnostic", is important. However, it provides limited help in deciding how best to respond to a family's needs at this time. This is because the patient may actually be non-practising, 'nominal' or a member of a particular group or subculture. Assumptions are unprofessional and are a common source of embarrassment or even offence. The key to facilitating spiritual care for families which is appropriate and meaningful is to ask what the person who has died would have liked. If families are in a state of emotional trauma and are unable to articulate their needs it may be helpful to offer a range of options which "others have found helpful," as a way to mark the dying process and to acknowledge its significance and meaning.

Providing such basic spiritual care is within the responsibility of all health care staff and is not dependent on staff beliefs.

With multiculturalism now a feature of Irish life and with patients and staff from many different cultures and faiths, it is important that staff are flexible and understand the importance of accommodating different needs at this time. It is, of course, important to have assessed the spiritual needs of the patient long before death occurs and to involve the appropriate spiritual caregiver.

### **Patients' Belongings**

As sensitivities are particularly acute around the time of death, there can be a projection of concern from the patient to the patient's possessions. These possessions, clothes and jewellery can adopt huge significance as they become tangible memorials of the dead person, invested with great sentimental importance. It is important that staff appreciate this and that possessions are recorded and handled with care. With families there can also be concerns as to whom should possessions be given, even if there is no obvious rift between family members. Having a policy which can be readily applied and is easily understood by families in this regard is helpful to staff and relatives.

Belongings should be returned to the family either in the suitcase or bag in which they were brought to the hospital or in an appropriate bag such as the Family Handover Bag produced by The Irish Hospice Foundation. It is not acceptable to return the last effects of a patient in a plastic hospital bag which is otherwise used for rubbish or dirty laundry.

### **Transport of the Body to the Mortuary**

When the family are ready to leave the deceased and the doctor has confirmed the death the body will need to be removed to the hospital mortuary. Different hospitals in Ireland use different methods to do this and some are more dignified than others. The remains must always be treated with respect, and at the same time the needs of the patient's family, other patients and staff need to be remembered. The physical moving of the body from the bed to the mortuary trolley should be performed in a dignified and respectful fashion.

There is a sacramental aspect to the removal of the body from the ward which needs to be

## acknowledged in some way and not hidden or made furtive.

- In a hospital in Japan when a body is removed from the ward the clinical staff will stop what they are doing and bow as the body passes them, in a similar way to parts of Ireland where cars will stop to acknowledge the passing of a hearse.
- In a Norwegian hospital when a patient's body is removed from the ward a candle is lit to acknowledge the death on the ward to staff and other patients.

Such practices can be very important in sensitively marking the significance of the event even in the midst of a busy ward and symbolise to staff and other patients that care and respect extends to the dead as well as the living.

With ever increasing pressures on filling beds it also is important for staff to have a means of punctuating the ending of a life and its significance. Lack of such acknowledgement breeds cynicism as staff protect themselves from the tide of life and death that has to be part of the culture of a busy modern hospital.

### Mortuary

A mortuary is not a place many of us would want to dwell upon, but it provides a vital role as a place of transition from hospital to funeral and where family can visit to pay their respects. Access to the mortuary for families can often be an issue for hospitals particularly in circumstances where families are reluctant to leave the remains but hospital routines demand that the mortuary be closed.

Families may ask ward staff about the mortuary and how it will be for their loved one. It is helpful to have visited your own hospital's mortuary so you can answer such questions and provide family with the assurance that continuity of care extends beyond death. A member of the ward staff accompanying the body to the mortuary demonstrates clearly to the family that care after death is but an extension of the care they received on the ward while they were alive.

### Teamwork

No single member of the hospital staff has all the answers to patients and families going through the experience of death, dying and bereavement. We must realise the role which each member of

the team can perform in helping and supporting families at this time.

The vital role that the unsung members of the team play is often ignored, unless a problem arises. Domestic assistants, porters, reception staff, mortuary technicians, allied health professionals, chaplains may all have contacts with patients and families which can be of great benefit. Equally the impact of the death of a well known patient on staff will extend beyond the immediate ward staff and should be remembered and acknowledged in some way.

*“...that’s the first time in seven years that anybody has asked me what I thought or how I felt. Some days our job is really hard. We are helping serve food in the morning. Then there is a death and we have to serve food again in the evening to a completely new patient as if nothing had happened. Nobody seems to notice or care about how we feel, but, sometimes I think we spend more time with the patients, like real time with them, than anybody else and some days I just feel really sad.”*

Interview with a Domestic Assistant, Dublin 2007

## Contact with Families After a Death

In a busy service the removal of the body from the ward signifies to many the end of our duty of care, though there remains a family or carers who have just embarked on a bereavement journey. Acknowledging that loss by sending a sympathy card, letter or by making telephone contact are valuable ways in which we acknowledge the significance of the person who has died and that hospital care extends to the bereaved family as well. Such a process is not unduly expensive or complicated to organise and examples of such cards are available from the HFH website. A copy of the card should be placed in the patient chart.

### After Death Analysis

There will be particular events surrounding a death which may raise major issues within a unit or team. There is often a great deal of learning available in considering the circumstances of a death both from a clinical and a systems approach.

Having a review of deaths on a regular basis provides an opportunity for a team of professionals to consider the service that they provide to patients and families at a crucial time.

The practice of reviewing births has reaped dividends in both highlighting the need for improvement and also excellent delivery of care. Having such a meeting on a regular basis

would surely do the same for our end-of-life care, which in fact is a clear indicator of our unit's general level of care.