



A Good Death



Oifig an Ombudsman
Office of the Ombudsman

A Reflection on Ombudsman Complaints
about **End of Life Care** in Irish Hospitals





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Office of the Ombudsman

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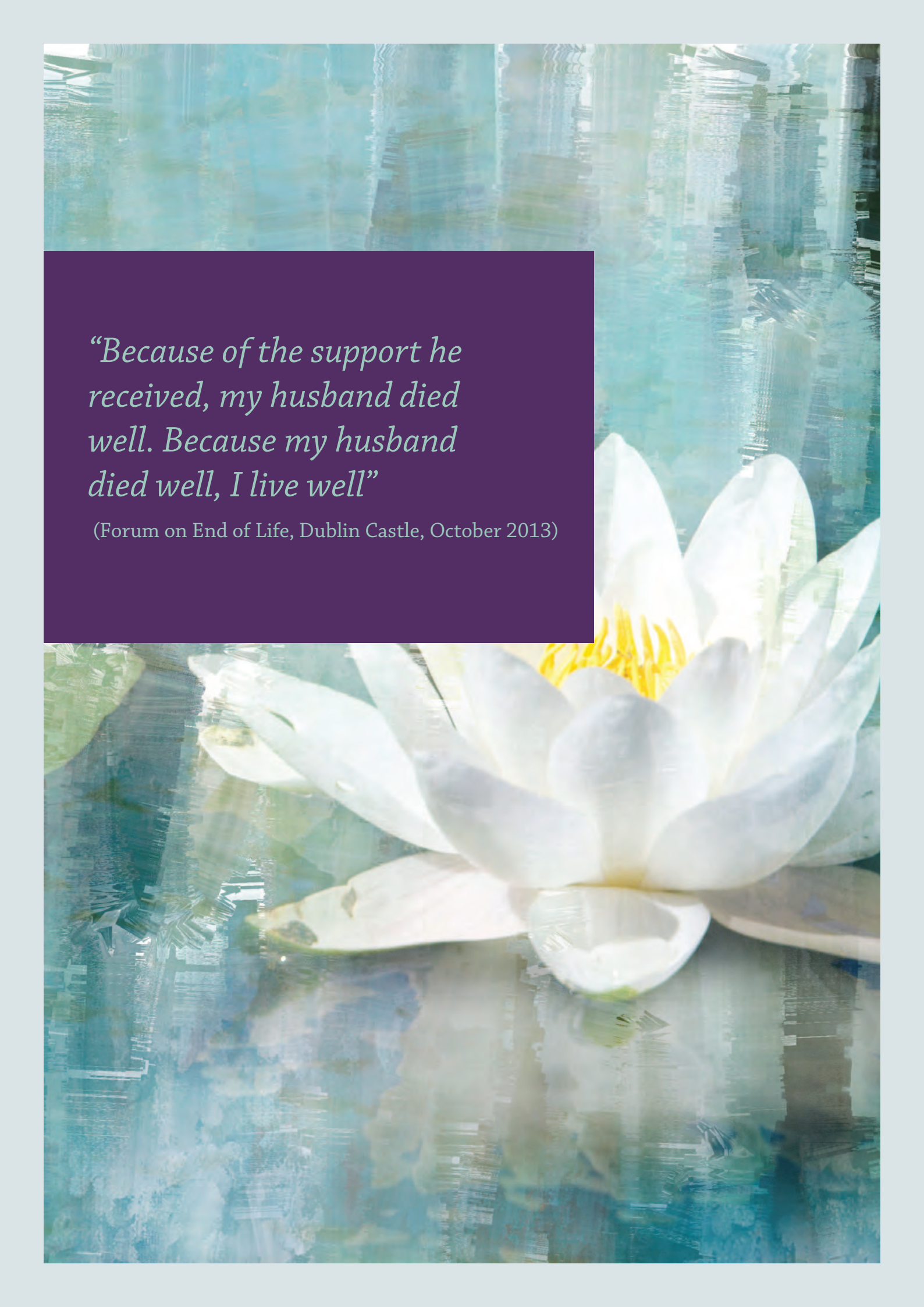
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Contents

Introduction	3
How can the Ombudsman contribute to the debate on End of Life Care?	4
The National Context	6
Complaints included in this review	7
Communications	8
Patient Autonomy	12
Specialist Palliative Care	16
Support for Families and Friends	20
Post-Mortem Examination	26
Returning the Deceased Person's Belongings	30
Managing Complaints	32
Conclusions	34



*“Because of the support he
received, my husband died
well. Because my husband
died well, I live well”*

(Forum on End of Life, Dublin Castle, October 2013)

Introduction



Death is something we will all experience, when our loved ones die, and when we come to the end of our own lives. Some people live with life limiting conditions for some time; others die suddenly or with little warning.

As individuals we want our experience of dying to be peaceful and dignified. As family members and friends, we want to know that our loved ones were pain-free and comfortable and that we can grieve in privacy at the time of death, and with the supports we need afterwards.

Talking about death is not easy. It is clear however that as individuals and society we need to have a frank and honest conversation about it. We need to create for ourselves the best chance of having a good death and allowing those who remain behind to experience a healthy grieving process.

Many public bodies and voluntary groups have responsibility and interest in this area. These include the Health Service Executive, the Health Information and Quality Authority, the Irish Hospice Foundation, the Forum on End of Life and the many organisations representing professional and patient interests.

The Irish Hospice Foundation and the Forum on End of Life are working to promote openness about the issues of where we die, how we die and how we should plan for it. They have highlighted the need to talk, plan and act in order to ensure a dignified death for as many people as possible and a peaceful life for those who are bereaved.

Our legislators recognise this. The Oireachtas Committee on Health and Children spent a significant period of time in October and November 2013 listening to the views of experts and interest groups on the challenges posed by this 'taboo' subject, so that they could familiarise themselves with the problems and possible solutions.

The Ombudsman too can play a role in the national debate and exploration about death. Despite the personal trauma involved, the experiences of most patients and their relations in care settings reflect a service which is caring, professional and dignified. However, over the years, the Office continues to receive many complaints relating to end of life events. The numbers may be low, but the experiences are unique and in many instances, had a profoundly disturbing effect on family members. We decided to reflect on some of the complaints we received in recent years and to draw from them common themes that may assist service providers and policy makers to improve practice. Some of the stories shared here are sad and reflect the intense emotion of those directly involved. However in order to improve the experiences of people in the future we need to tell their stories and learn from our mistakes.

We hope these reflections will make a positive contribution to the national debate on end of life care and the campaign to make Ireland a good place to live in and to die in.

If there is one message to be learned from complaints brought to us, it is that small things make a big difference. Those moments at the end of a loved one's life are extremely precious and will be relived again and again. Excellent communication and a positive, respectful attitude are required from all people associated with the care of the dying person and their loved ones. I hope that the stories related here will remind us to keep this in mind at all times.

Peter Tyndall
Ombudsman
2014

How can the Ombudsman contribute to the debate on End of Life Care?

Role

The Ombudsman examines the administrative actions of a wide range of public bodies. Where complainants have not been dealt with properly and fairly, the Ombudsman suggests appropriate redress and, where appropriate, he recommends improvements in practices and procedures in order to avoid the repetition of mistakes or the recurrence of poor service. In 2013 the Ombudsman assisted over 11,000 people with enquiries and went on to examine over 3,200 complaints.

Health Complaints

In 2013, 17% of all complaints examined by this Office were about the HSE. Approximately 130 complaints were about acute hospitals and long stay care settings. When we consider the high volume of interactions that the public have with acute hospitals over the course of a year, we can see that the annual number of complaints that reach the Ombudsman is relatively low. There are many reasons for this.

It is important to note that the Ombudsman cannot by law examine complaints about clinical judgement, that is, the judgement of a clinician in deciding on a diagnosis or a particular course of treatment. The Ombudsman can however look at a range of other actions that often result in poor care, for example, poor communication, breach of procedure, or poor administrative practices.

Making a complaint

There are many ways to make a complaint about a poor health or social care service. Usually it is best to complain at the source of the problem. Evidence shows that many people have difficulty knowing what to do when they are unhappy with a service and are often anxious about making a complaint. As a result, an on-line resource has been developed to assist members of the public with the process. www.healthcomplaints.ie is an online information portal which provides information on how to make a complaint, the range of bodies that handle health complaints and provides sample letters and case studies to assist with the process. The site and related resources were developed by a group of 17 agencies, chaired by the Ombudsman's office.

Complaints provide valuable information to service providers about aspects of their service that is poor or indeed unacceptable. Complaints about end of life care are often the most urgent and compelling.

“The family would like to know the steps taken by the hospital to ensure that all these shortcomings do not happen to someone else as they could easily have been avoided.”

Quote from a complainant to the Ombudsman

“We have only one chance to get this right”

[Sharon Foley CEO of the Irish Hospice Foundation speaking to the Oireachtas Committee on Health and Children]

If something goes wrong with the care provided at the end of life, nothing can be done to put matters right for the person most affected. The impact on the bereaved can be traumatic and lasting. Complainants are regularly passionate and determined to ensure that the wrong is recognised and lessons are learned to prevent any other person or family experiencing the problem again.

Purpose of these reflections

The purpose of this publication is not to point the finger or lay blame on particular institutions or professions. This is purely a reflective and learning exercise. For that reason the anonymity of settings and of individuals has been preserved.

The National Context

Dying in Ireland

Each year 29,000 people die in Ireland and as many as 290,000 people are left bereaved. Research carried out for the Irish Hospice Foundation (IHF) has found that most people, 67%, would prefer to die at home. In reality only 26% will die at home, 43% will die in an acute hospital, 25% in a long stay setting and 6% in a hospice. The IHF research has also found that where appropriate support can be provided, the number dying at home rises significantly.

Standards of Care

Given the diversity of settings where people die, it is not surprising that the approach to end of life care may vary depending on the setting and the business of that setting. The Health Information and Quality Authority (HIQA) has statutory responsibility for the development of standards in health and social care and for monitoring healthcare quality generally. The Authority has developed the National Standards for Safer, Better Healthcare in advance of the introduction of a mandatory licensing system for public and private health care providers. The standards, which include provision for end of life care, have been endorsed by government.

HIQA has already developed the National Quality Standards for Residential Care Settings for Older People and the National Quality Standards for Residential Care Settings for People with Disabilities. Both of these standards address the provision of end of life care.

The Irish Hospice Foundation (IHF) is a national charity dedicated to improving the quality of care available to people in life limiting circumstances and to the bereaved. The IHF is working to bring hospice care to hospital settings through the Hospice Friendly Hospitals Programme.

Hospice philosophy

“Our Vision is that no one should face death or bereavement without the care and support they need; Our Mission is to achieve dignity, comfort and choice for all people facing the end of life”

The Forum on End of Life in Ireland

Initiated by the IHF in 2009, the Forum’s objectives were to promote a national conversation about dying, death and bereavement and to establish what issues matter most to people regarding end of life from a wide range of perspectives: social, health, economic, legislative, administrative, educational, cultural and religious. The work of the Forum was driven by the principles and values of hospice and palliative care.

Complaints included in this review

The current objectives of the Forum include the development of recommendations for a national strategy to manage end of life issues in a comprehensive way; the promotion of public engagement and a debate on end of life issues in their broadest sense; the promotion of advance planning and the proposal that advance paramedics and senior nurses be authorised to pronounce death.

This review tells some of the many stories that people bring to the Ombudsman. All of the people in these stories have had highly regrettable experiences in public hospitals at the time of a final illness and death of a loved one. All of these people believe that they and their loved ones suffered great distress that could have been avoided. Their experiences are being retold to show how things can go wrong and to show how we can learn from past mistakes.

Most complaints made to the Ombudsman are multifaceted; a person may complain about communications, record keeping, pain control, nutrition, privacy, decision making and a wide range of concerns that arise when providing care at end of life.

This review groups complaints under recurring themes that present to the Office of the Ombudsman. These also broadly mirror the themes identified by the Hospice Friendly Hospitals Programme, such as patient concerns, staffing issues, organisational issues and support to families. Some complaints may appear under more than one heading. In certain cases the review concentrates on one aspect only of a complaint.

Communications

Misunderstanding about husband's cancer

Communicating Diagnosis

Mr Clarke was a 64 year old man who was receiving treatment in hospital for lung cancer. After his death, Mrs Clarke complained about her late husband's care in hospital, including the way in which news of his condition was given to her. Mrs Clarke said that following chemotherapy, she was told, that her husband's cancer was 'gone'.

The Consultant stated that while he would have said that he was pleased with the patient's response to chemotherapy, it would never have been his practice to say that a specific cancer was gone or resolved in the way that Mrs Clarke understood.

A case like this shows how easy it is in conversation for two people to have a very different understanding of a message. It shows how important it is for medical and nursing staff to check with patients and families that they have a clear understanding of the information being conveyed.



Family room in Nenagh Hospital Pic: Kieran Clancy

Critical information withheld from patient and family

Giving a Prognosis

Mrs Sullivan was being treated for lung cancer in hospital and underwent a number of diagnostic procedures and treatments. When she died, her family complained that they were not told about their mother's prognosis until she was unconscious.

Mrs Sullivan's daughter said that because she did not understand how ill her mother was, she had concentrated on encouraging her to eat and become stronger. In retrospect she and her sisters wished they had known that their mother's condition was terminal. If they had known just how ill she was, they believe that the family could have lived the final weeks with their mother in a different way and come to terms with her death more easily.

“As a family we should have been given the truth that would have allowed us in the last few weeks of her life to support and assist her in coming to terms with her prognosis. Instead we were trying to get her to eat, make her stronger and giving her hope.”

The Consultant in this case said that it was his practice to provide information about a patient's prognosis when it was requested and not as a matter of course. As far as he could remember, the patient in this case never looked for information about the probable course of her illness in spite of opportunities that might have prompted this.

“We need to help staff overcome their own fears about dying and end of life, overcome the ‘tyranny of the positive’ and inappropriate reassurance in place of real conversation.”

(Bryan Nolan, Communication Coordinator, IHF, to the Oireachtas Hearings)

Staff in hospitals must first and foremost respect the rights of their patients to choose how to share their diagnosis and prognosis with others. They must also be alert to how this has been done and be sensitive to the needs of both patients and their loved ones. Where appropriate, staff should offer support and reassurance.

Lack of understanding of DNR (Do Not Resuscitate) decisions

Explaining a DNR

What is meant by a 'Do Not Resuscitate' order or notice? The Ombudsman has received many complaints in this area and it is clear that patients and families are often confused about what it means. People are also unsure about who has the right to decide on this course of action / inaction for the patient.

Mrs Doyle was an older woman living in a nursing home when she became ill and was transferred to hospital. Her condition deteriorated and she died several days later. When she died her son complained about the treatment provided to his mother in her final days and he looked for her medical records.

He was clear that he and his family had agreed to a 'Do Not Resuscitate' notice on his mother's file. However, he insisted that phrases on her medical file such as 'for comfort measures only' and 'for peaceful measures only' were never explained to him.

He believed in hindsight that by agreeing to the DNR he had also agreed to the withdrawal of medication. This upset him greatly as he felt that this had hastened his mother's death. He was of the view that he had the right to request that certain treatments be made available to his mother. He was not aware of any duty on the part of the doctor to make clinical decisions in the patient's best interest.

The Ombudsman found that the experience highlighted the need for a more rigorous or formal procedure for making, recording and communicating about a DNR decision. Patients and their families or next of kin, need to understand what such a decision entails and who holds responsibility. There is a need to ensure that families or next of kin are consulted in a clear and unambiguous way about the treatment that is likely to be provided or ceased, where the decision has been made to adopt a DNR status. Next of kin should be able to talk to a doctor and be given information which explains the implications of the decision for care and treatment. Nationally agreed policy should inform each hospital's policy and clarify the duty of the medical team in the decision making process.

What can we learn?

Poor communication is a feature of almost every complaint sent to the Ombudsman. There is often a gap between the message professionals intended to give and what the relatives and friends understood. Sometimes the language used is overly technical or complicated. Sometimes the manner in which information is given distorts its true meaning. Sometimes the message is rushed and basic information is omitted. More often it is the case that the information is so overwhelming that it needs repeating and summarising, and it requires time at the end for discussion to ensure it has been properly understood.

Patients and families often do not understand terminology that is routine to staff. Sometimes a professional's effort to be kind and sensitive results in vagueness and confusion. Families sometimes have the experience of clinicians communicating with them in ways that seem defensive, arrogant, uncaring or aloof.

Cultural diversity and language differences may also give rise to difficulties for staff, patients and relatives. While respecting cultural difference, the patient and the loved ones remain at the heart of care. Every effort must be made to ensure that information is communicated in a clear and respectful manner to them. Medical staff need to carefully document discussions they have with patients and relatives about diagnosis and prognosis.

There can sometimes be confusion about the rights of next of kin. This happens particularly in relation to "Do Not Resuscitate" orders or "Comfort Only" measures orders either placed on a patient's record, or conveyed by a consultant to a team, without communicating this to the family. The bedside of a dying loved one is no place to engage in conflict about these matters.

Patient Autonomy

Daughter not told of father's deteriorating condition, at his request

A Patient's wishes

Mr Mooney, an older man, was receiving treatment for a range of chronic conditions in an acute hospital. His condition became more serious overnight and the staff on duty wished to contact the family. However, when the staff suggested this to him he said that his daughter should not be contacted as she was not well herself and he did not want to worry her. As Mr Mooney's condition had improved somewhat and the staff knew that his daughter was due to visit, they decided to respect his wishes.

Unfortunately, no member of staff spoke with Ms Mooney before she reached her father's bedside and his worsened condition was a great shock to her. Ms Mooney believed that she should have been informed of the deterioration before meeting him.

The Ombudsman found that the hospital had respected the patient's wishes and had documented them clearly. But the case highlighted the need for good communication and for staff to be vigilant and empathetic to family members' anxieties and concerns. While staff may have been too busy to notice the daughter arriving into the ward, a few kind words with her at some point during her visit could have resolved the matter locally and prevented weeks and months of distress as the complaint escalated eventually to the Ombudsman.



Patient told of terminal illness without offering to have family member or support staff present

A Family's wishes versus the Patient's wishes

Mrs Wilson was 87 years of age and a patient in an acute hospital. Her doctor told her that her illness was terminal. Mrs Wilson's daughter was extremely upset about this and said that she had made it clear in advance that her mother was not to be told about her condition.

The daughter claimed that the hospital had breached its own guidelines on breaking bad news by not having a family member or staff member present when the news was given to her mother. Ms Wilson said that the experience had distressed her mother deeply and made her last weeks miserable.

Ms Wilson had initially found out about her mother's condition when talking to a hospital Registrar. She said that she told the Registrar at that point that her mother was not to be told how ill she was. She could not identify the person with whom she had spoken and there was no record in the patient's notes documenting the discussion.

When questioned by the Ombudsman's office, the Consultant said that his patient had full capacity. He was unaware that Ms Wilson had strong views about the news to be given to her mother as this was not documented. He had exercised his clinical judgement in discussing her condition with his patient first, while offering to have a family meeting following that. There was no record to indicate if the patient had been asked if she wished to have someone present with her when news of her condition was broken to her.

The hospital's guidelines on breaking bad news outlined a number of rights including the following:

- 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 (i.e. family members including children and /or significant others).

The guidelines also recommend that other members of the multi-disciplinary team, such as a nurse, social worker or a pastoral care team member, should be present when the news is being communicated and during ongoing consultations.

Situations like this are not “win win” for anyone. Respecting the patient’s rights must be, first and foremost, the clinician’s concern. However, it is important that clinicians break such news extremely sensitively and that they be informed of any requests or dynamics that might inform their decision. Health care teams must communicate very well with each other and document all key developments in the medical chart. Good guidance to staff on such sensitive issues as breaking bad news is critical, and should be followed by all staff.

Results of scan not disclosed

Respecting the patient’s wishes

Mrs McLoughlin was receiving outpatient treatment for cancer for more than a year at an acute hospital. Her condition worsened suddenly and she was admitted to hospital to manage her pain. She returned to her home and died several weeks later.

Mrs McLoughlin’s son complained that his mother’s scan results were not discussed with the family in a timely way. Because of this, there was a delay in referring his mother for specialist palliative care and her pain was not adequately controlled for a period of 2 months. Mr McLoughlin said that his mother and the family were deeply and unnecessarily distressed by this.

When the medical and nursing files were examined, it emerged that Mrs McLoughlin held a very strong view that her medical condition was private to her. It was documented that she did not wish to have this discussed with her family without her knowledge. Furthermore, she had told her Consultant that she did not want to have a discussion about her scan results until a family event, due to take place shortly, was over. As that event was postponed, so too was the discussion of the scan results, but this was as Mrs McLoughlin had chosen.

The Consultant believed that if he were to refer his patient to specialist palliative care in advance of discussing the results, this would mean in effect that he was letting her know the results. He believed that to do this would have been in breach of his ethical obligation to abide by his patient’s wishes not to be told of the results until the date of her choosing. The downside of this was that the specialist palliative care team was not involved in her care and her pain control was not as it should have been.

When Mrs McLoughlin’s condition worsened before the agreed date for discussion of the scan, she was admitted to hospital for pain control and agreed to accept home care management. She was nursed at home by her family with the support of the team. However, the family contended that her final weeks were haunted by fear of pain and believed that this experience could have been avoided.

What can we learn?

Patient autonomy means that the patient is at the centre of decisions about his or her care. This includes communication of information about his or her condition as appropriate. The purpose is to respect patients' wishes. Where their wishes are not known, the health care team must endeavour to communicate effectively with next of kin to ensure that the correct decision is made in the patient's best interest. Sometimes the rights of patients and the wishes of families are in conflict and it can be a struggle to balance these. However, to avoid long term distress, it is best to try and settle these conflicts as early as possible through open and sensitive communication.

“Every patient has the right to be fully informed about their health status, including the medical facts about their condition Information should be withheld from patients only exceptionally, when there is good reason to believe that this information would, without any expectation of obvious positive effects, cause them serious harm.”

(Ombudsman's Statement of Good Practice for the Public Health Service in Dealing with Patients)

Patients with capacity will be informed directly of their condition by a doctor unless there is good reason not to do this. Patients who wish to follow a different path need to have their wishes documented.

Families are sometimes unaware of where or how they can fit into the care of a loved one. They sometimes believe, mistakenly, that they have a right to full information about their loved one as well as the right to make decisions on behalf of the person who is ill. Staff should ensure that a patient's wishes regarding disclosure of a condition are documented. Staff also need to be clear about the rights of families and friends to information, particularly where the condition of the patient may be deteriorating. Where conflict arises, open dialogue and early resolution is the better outcome for all concerned.

Specialist Palliative Care

Specialist Palliative Care Team not contacted over a weekend period for advice

“The Staff in the coronary care unit were so kind to us and our father and made sure his final journey was a peaceful and dignified one.”

“Words cannot express how grateful we are to her for the care she gave to our father.”

[A remark about a care attendant]

“I nursed my mother at home for 14 days with the support of the palliative care team. Throughout those two weeks the fear and worry my mother expressed was due to pain.”

“All I wanted was for people to listen so my mother would get the quality of care that she rightly deserved.”



Keeping in touch with the Specialist Palliative Care Team

“My mum was in agony on the Friday until the Tuesday. She never, to the best of my knowledge, received any palliative care over that weekend. That angers me greatly.”

Mrs Brady was receiving treatment for cancer in hospital. Her son complained about her treatment over a particular weekend shortly before her death. He said that the hospital had failed to manage her symptoms adequately. He believed that his mother had been in great distress and pain over the weekend. He complained that the hospital had not called in the on-call Specialist Palliative Care Service at this time to provide the appropriate care and relieve her pain.

The hospital explained that his mother was constantly monitored by nursing staff and was reviewed by medical staff during the time in question. The woman was receiving a combination of pain relieving medication as advised for her by the Specialist Palliative Care Team. Additional medication was also administered to deal with the agitation and confusion she suffered as a consequence of her illness. The hospital said that when she did complain specifically of pain, additional pain relief was provided.

As the decision to maintain a certain medication regime was a clinical one, the Ombudsman could not investigate this or come to any conclusion about whether or not this was appropriate. However, the hospital conceded that, in hindsight, it would have been advisable to have contacted the Specialist Palliative Care Team over the weekend. This would have had the benefit of assuring the hospital staff and the family that the appropriate care was being provided and that all alternative measures to alleviate her distress had been considered.

The hospital said that it had learned from this experience and that staff will bring the learning to bear on their decision making in similar cases in the future and contact the on-call Palliative Care Team for guidance, at weekends.

“Pain relief depends on the knowledge, skills and attitudes of staff. Remember – the pain is the patient’s pain”

Prof. Patrick Plunkett to Oireachtas Committee on Health and Children.

Preparing for a hospital discharge and problems accessing morphine for a patient at home

Home support

Mrs Whelan was an 85 year old woman who had a number of serious conditions including cardiac problems and cancer. She was discharged to her home from an acute hospital and was cared for by her daughters until she died six days later.

Her daughter complained that although her mother was seriously ill, the Public Health Nurse did not come to visit her following her discharge from hospital until the day before she died. The family also complained that the hospital had failed to ensure that medication for pain relief was provided.

The hospital admitted that although a referral to the Public Health Nurse was recorded, she had not in fact been contacted by the hospital and was unaware of the patient's needs. The actual referral was not made until a date following the patient's death. The visit that took place only happened because of local contacts made with the nurse. The hospital apologised to the family for the delay and associated distress that this caused.

When their mother was discharged for the last time before her death, the family received a prescription that afternoon which included morphine. The family received no advice on how to administer it and had to ask the pharmacist about it. They had been promised by a member of the medical staff that they would receive a two day supply of medication to tide them over, but this was subsequently refused by the staff on the ward who told them it wasn't hospital policy. In the event, the pharmacy did not have morphine in stock and the patient and family had to wait until the next day for it. That night the family had to call out a doctor to administer an injection to their mother for severe pain. The family felt that the hospital could have issued the prescription earlier in the day to allow them to source the medication in a timely way, or, that it should have made contact with the pharmacy in advance to ensure that it had a stock of morphine available.

The hospital had told the family when they made their complaint that it was not policy to contact pharmacies to ensure that morphine was in stock and said that the pharmacy should have been able to source the morphine from another source.

What can we learn?

The quality rather than the length of life is more important to most people with a life-limiting condition. Research by the Irish Hospice Foundation confirms this. The patient's priority is that pain will be managed and that he or she will be pain free.

Unfortunately it may not be possible to meet that expectation in every circumstance. Cases put to the Ombudsman show that a peaceful, comfortable death helps both patient and relatives. In contrast, the experience of real or apparent discomfort suffered by a patient can haunt the relatives and prolong the grieving process for them.

It is crucial for patients and families to know that they will receive palliative care if they choose it and that pain will be controlled to the greatest extent possible. Families talking to the Ombudsman cannot understand how a patient in a hospital might not have immediate access to effective relief. The question of what might constitute appropriate pain relief is very much a clinical one and the Ombudsman is unable to comment on this, other than to say that the patient's voice should be heard.

The patient should always be at the centre of care. No one should be discharged from a hospital without arrangements being in place to ensure that their immediate and longer term care needs, including pain control, will be met. While every patient's discharge must be planned extremely well, this is critically important in the case of a person who is terminally ill. Again, these are vital moments for the patient and their family. The family, often without formal qualifications in the delivery of care, really want to do their best for their loved one and give that person a comfortable and dignified death. A rushed or unplanned discharge is unacceptable in those circumstances.

Patients and carers at home face a range of challenges usually of a type never faced by them before. They are dependent on their GP, Public Health Nurse and the palliative care team where available to support and guide them through this experience. Careful pre-planning and formal cooperation between health care professionals is required if there is to be 'joined up thinking' and appropriate support for the patient and carers.

We need to avoid the situation where an already stressed carer is made to believe that it is his or her fault that their loved one is in pain. We need to avoid situations where a traumatised family is forced to call out a doctor in the middle of the night to administer pain relief that should have been available all along.

Support for Families and Friends

Family not contacted to say mother was dying

Timely warning

Mrs Cummins, who was 79 years old, was a patient in an acute hospital. She rang her son from the hospital one morning and told him that she was dying. Later that evening Mrs Cummins passed away.

Her son said that when his mother rang, he immediately went to the hospital to see her. He complained that he was not told by the hospital for a further four hours after his arrival of the seriousness of her condition. Mr Cummins said that as a result of the hospital's failure to speak to him directly, other members of his family who lived a distance away did not have time to travel home to be with their mother when she died.

The hospital admitted that there had been a failure to contact the next of kin in a situation where there was clear consent to do so and clear evidence of a deteriorating condition. As a result of the experience in this case, the hospital put in place a written policy on contacting next of kin, to make sure that this would not happen again.

Sister told to “stop hyperventilating – she was not helping anyone”

Breaking News of a Death

Mr O'Rourke, a young man, was seriously ill in the Intensive Care Unit of a hospital, following a head injury. Ten days later he was transferred to a different hospital where he died.



Family room in Nenagh Hospital Pic: Kieran Clancy

Ms O'Rourke was recorded as the next of kin on her brother's records and she expected that any serious communication would be made directly to her. On the day of her brother's death, her parents were visiting the hospital when their son died. Unaware that her brother had just died, Ms O'Rourke arrived in the ICU and overheard two nurses speaking of her brother's death. She began to hyperventilate with shock and says she was told by a nurse very abruptly to 'stay calm as you are not helping anyone'. She was very upset to find out about her brother's death in this casual way and also complained that the nurses were not supportive of her when she became upset.

The hospital in question is participating in the Hospice Friendly Hospitals Programme. The hospital apologised for what happened on this occasion and said that it hoped that participation in the HFHP would encourage a better understanding by the staff of how to communicate sensitively with families around the time of death.

Lack of privacy when patient died

Privacy

Mr Devitt was 61 years old when he was admitted to hospital following a stroke. He was transferred to a high dependency ward and died several days later.

Mr Devitt's daughter made a number of complaints about her late father's care at the end of life. The family was especially upset because there was no single room available and hence their father died on a busy ward. When he died, the only privacy available to the family was the curtain around his bed. The family was grieving for their father while normal activities such as meals and television continued around them. At one point, a member of support staff had pulled the curtain back to ask their father if he needed dinner.

The family also complained that they were asked to leave at a certain time even though the remains were left on the ward for several hours before being moved to the mortuary. They were upset by what they saw as a lack of respect for their father.

“I attended the bedside of a friend who was dying in a Dublin hospital. She lived her last hours in a public ward with a television blaring out a football match, all but drowning our final conversation. I have since come to believe that in hospital, aesthetics are as important as function, and that an aesthetic environment automatically leads to good practice and better care.”

Actor Gabriel Byrne

Treatment of the remains after death

Dignity after death

“This was my father; he was a unique human being. After helping to save three other lives, it seems to us he was simply put to one side and given no more thought.”

Mr Byrne was admitted to hospital following a fall. He had suffered irreversible brain injury and the medical team discussed organ donation with the family. As their father had been an enthusiastic supporter of organ donation, the family agreed to this. Mr Byrne was pronounced dead in accordance with the appropriate procedures.

While the care provided up to this point was unquestioned, from the time that the family agreed to the organ harvesting procedure, things went wrong. The hospital failed to contact the Coroner in a timely way to enable an identification to take place when Mr Byrne was pronounced dead. The family understood that the hospital would get in touch with them as soon as the organ harvesting procedure was over, but this did not happen.

When the family themselves contacted the hospital a day later they were eventually told that the procedure was completed and that they would now need to undertake a Garda ID of the remains. They made their way to the hospital to do this. The family describe a lengthy walk in and out of corridors, out through an open space strewn with rubbish and debris, until they eventually were brought by a back door into what they believed was the mortuary.

They described finding their father’s body on a slab ‘with nothing more than a sheet thrown over him’. They spoke of the ongoing trauma of reliving this scene. Although the hospital said that the remains were gowned, the family stated that his shoulders were bare and they believed their father to be naked. The hospital in this case acknowledged that mistakes were made and apologised to the family for the distress caused. The hospital also recommended that the End of Life Committee in the hospital produce an action plan to avoid a recurrence of the problems that arose.

Poor communication with bereaved family

Sudden death

Mr Donohoe had a number of diagnostic procedures as an inpatient. Eventually a diagnosis of pancreatic cancer was made. Mr Donohoe remained in hospital while palliative care options were being discussed. His condition deteriorated suddenly one night and he died an hour later.

Mr Donohoe's daughter had several complaints about her late father's end of life care, including the way in which news of his terminal condition was eventually communicated to him, his hygiene and grooming care, and the management of his pain. She said that the most distressing issue for the family was the failure to alert them when Mr Donohoe became seriously ill. By the time the hospital contacted the family, Mr Donohoe had already died.

Mr Donohoe's daughter said that when her family arrived at the hospital they were brought to view their father's remains in a public ward. This was during the night. The family became upset and were asked to leave as they were disturbing other patients. They said that no one sympathised with them or offered to explain what had happened to their father.

Family had to ask for Last Rites

Respect for religious beliefs

Mr Brennan was being treated for cancer. He had been ill for some time and his condition was terminal, but when his death occurred it was unexpected.

Mrs Brennan made a number of complaints about her husband's end of life care. One of the issues raised was that there was a delay in arranging to have the priest called to administer the Last Rites. She herself had to request that this be done. The priest was eventually called, but it was an hour before he could attend and the family was very upset by the delay.

The hospital agreed that the complaint highlighted weaknesses within the hospital in relation to the quality of standards around end of life care. The hospital accepted that, although staffs were aware of the protocol, there was delay in contacting the priest as they were busy at the time attending to the needs of other sick patients.

The hospital apologised to the family for the distress caused and told the Ombudsman that it was working in conjunction with the Hospice Friendly Hospitals Programme to make good end of life care central to the work of the hospital. Since dealing with this complaint, the hospital has provided leaflets to bereaved families, providing useful information and contact details.

Educating the Carer

Ensuring that the Carer knows what to expect

“I didn’t know what questions to ask – I only found out what I needed to ask as I went through the experience of caring for my mother.”

Mrs Brown had pancreatic cancer. Following reviews by the Specialist Palliative Care Team Mrs Brown was discharged home into her daughter’s care. Mrs Brown was reluctant to consider the involvement of the Hospice at that point and it was her wish to die at home when the time came.

On the day of her death, Mrs Brown became unwell and experienced some breathing difficulties. Her daughter was unsure whether her mother needed to be readmitted to hospital and she sought assistance from her GP. However, the GP only managed to call out to her home later that evening which meant that Mrs Brown was without medical assistance throughout the afternoon.

The GP diagnosed septicaemia but advised against moving Mrs Brown to hospital. The emergency services attended Mrs Brown and provided oxygen to relieve her breathing distress. However, the emergency services could not provide the drip treatment which she would have needed to help treat her condition. The hospice nurse attended shortly afterwards and Mrs Brown later died as she had wished, in her own home.

After her death, Mrs Brown’s daughter made the point that carers should be properly briefed so that they are as well equipped as possible to meet the needs of the dying patient. Her daughter said that it would have been beneficial for her had a formal “hand over meeting” taken place, attended by both the oncology team and the palliative care team, so that all relevant information could have been provided to her.

She said that this should be standard practice in hospitals. “It takes many years for doctors and nurses to qualify - it is only fair therefore that the carer(s) would be offered this opportunity before they are required to manage the final stage of terminal illness and the death of the person they love”.

She told the Ombudsman that she simply did not know what questions to ask at the time and only realised what she needed to know as she went through the experience of caring for her dying mother. She considered that had some printed information and advice been available to her with regard to what she could expect, this would have been most useful. While such information is available to staff, there is no literature currently available to carers or relatives who are looking after terminally ill patients at home.

What can we learn?

Families have certain needs when dealing with the end of life care and death of their loved one. Every death is unique and for families, every death, even when it is expected, is deeply emotional. In some cases it may be the family's first experience of death and they may be completely unsure of what to expect and what must be done. 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.

Good communication is at the core of these needs. For example, families need practical and comprehensive information on what to expect and how to cope when a patient is discharged home. Families will depend on the hospital to have alerted community services to their urgent need in the home. They will expect the experts to forewarn them of likely difficulties and to offer advice and assistance on how these will be managed.

Families need support and compassion, regardless of whether death is expected or occurs suddenly. Families will differ in their response to the death of a loved one. Some family members will need to leave the scene and seek space on their own for a time; others will want to spend time with the remains. In many unfortunate instances, death occurs suddenly before a family can reach the bedside of the dying person and the immediate reality of the death strikes home only when they see the remains. This has to be expected and the proper facilities should be available.

Whatever the circumstances of a death, it is the experience of the Ombudsman that where and how the family spend their final moments with their loved one, before and after death, is very significant. A traumatic experience can have significant consequences for the grieving process. The opportunity for next of kin to view, or spend time with, their loved one after death is precious. In ideal circumstances this will take place in a dedicated private space, sensitively decorated and appropriately lit and the family will have as much time as they need. The family will have been told in advance what to expect in terms of the condition of the dying person or the remains to minimise any shock.

All hospitals should have clear internal communications procedures for communicating with patients and families. The hospital system, as distinct from individual departments or sections, should ensure that all foreseeable instances are planned for and staff know what they should do. When a death has occurred, staff should sensitively extend their condolences to all relevant family members and friends.

Post-Mortem Examination

No information about the family's right to ask for a post-mortem examination

Explaining Options for a Post-Mortem

Mr Brennan had been ill for some time when his cardiac function deteriorated rapidly and he died suddenly in hospital. Mr Brennan's wife wanted to find out exactly what the cause of death was, because her husband had died unexpectedly. She was upset that no post-mortem was carried out to establish this.

The hospital explained that the man's death did not fit the criteria for a Coroners' post-mortem but apologised to the woman for the fact that the option of a hospital post-mortem had not been discussed with the family at the time. The medical team could have decided to do a post-mortem themselves, even if the Coroner did not require one, but they had not considered this necessary and were not aware that the family would have valued the information it might have given.

As a result of the woman's complaint, the hospital undertook to review and amend its guidelines following the death of a patient to include discussion with the family about a post-mortem where relevant.



Refurbished Mortuary, Mercy Hospital Cork Pic: GMC Photography

Hospital did not perform post-mortem following patient's fall

Providing explanations

Mr Devitt was receiving treatment in hospital following a stroke. He had at least one fall while a patient, this being quite a severe one where he broke a tooth and suffered a serious laceration to his head. His family were very shocked by his death a couple of days after this fall. His daughter complained that the hospital had delayed in informing the Coroner of her father's death and had not carried out a post-mortem. As a result, the family did not know whether their father had died of the admitting cause, a stroke, or as a result of the fall and injury to his head.

Following the Ombudsman's intervention the hospital apologised unreservedly to the family for the distress caused and undertook a range of initiatives to prevent this happening again.

Failure to arrange post-mortem examination

Timely arrangements

Mrs Fleming was 82 years old and living in a residential care setting for older people. Mrs Fleming suffered from Alzheimer's disease and had been assessed as being at high risk of falls. She died eighteen months after going to live in the facility.

Mrs Fleming's family had a number of complaints about their mother's care and death. One of the complaints concerned the family's wish to donate their mother's brain to a neurological research facility at a local hospital, an idea that had been proposed to them by one of the medical staff caring for their mother, and how this wish was frustrated. The family also requested a post-mortem to determine the cause of death as their mother had a number of traumatic falls in the days preceding her death. The family believed the post-mortem had been agreed to by the medical consultant.

The family assumed that their mother's body would be transferred to the hospital on the day that she died and that the post-mortem and donation of tissue would take place the following day. Instead they discovered that her body had remained in the nursing home mortuary and that no arrangements had been made for the post-mortem. The family was greatly distressed by the situation. Ultimately, after much delay and confusion, they decided to withdraw the request for a post-mortem and the offer to donate their mother's brain for research.

The Ombudsman investigation found that the absence of appropriate protocols between the facility and the hospital delayed the transfer of the body to the hospital. The investigation found that there had been a complete breakdown in communication between staff in the nursing home, staff in the hospital and the family.

Family could not view loved one in public mortuary

Death in a Public Place

Mr Fitzgerald was hill walking when he became ill suddenly and died. The Ambulance service and the Gardai attended at the scene. Mr Fitzgerald was unresponsive to intervention by the Ambulance crew and the crew decided that there was no point in bringing him to the hospital. It was decided to remove his body to a local undertaker / funeral home. From there his body was removed to a public mortuary at the request of the Gardai, as a post-mortem was required.

When the family arrived at the mortuary some time later, they were told that they could not visit Mr Fitzgerald's remains. They understood that this was because his death had not yet been formally certified by a doctor, but were very distressed and clearly wanted to spend time with him.

The Coroner later explained to the Ombudsman that the family was unable to view the remains, not because of a problem about the certification, but because the mortuary did not have the facilities or staff to enable this to take place. He said he was sorry for the distress caused to the family and regretted that the situation was not explained to them before they made the journey to the mortuary.

What can we learn?

The Ombudsman has received many complaints over the years relating to post-mortems. Post mortems are rarely something we give much thought to until faced with a traumatic event. 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 cause of death, even if not required by the Coroner, and are often unaware that they may request such a post-mortem. Complaints have also been made about delays in arranging for post-mortems or in having the remains released or available to view.

The death of a loved one, whether anticipated or unexpected, is always traumatic for the relatives. The HSE's Standards and Recommended Practices for Post-Mortem Examination Services recognises how important the post-mortem examination process is for families in providing information and comfort about the care of the loved one. Confusion around the need for, or right to, a post-mortem, can only compound the problems of the bereaved. Yet again, complaints like this show the need for good communication, clear procedures and adherence to procedures.

Returning the Deceased Person's Belongings

Belongings, soiled and clean, returned in plastic bags

Mr Prendergast was a patient for several months in hospital where he was being treated for cancer and eventually died. After his death his partner made several complaints about his treatment and care. One of the many complaints made by her was that her partner's belongings (both soiled and clean) were returned to her in green plastic bags. The soiled clothing was a stark reminder to her of his pain and suffering in his final days. The return of his personal belongings in refuse sacks, so impersonally and insensitively, was far from the dignified approach she felt should have been taken. She saw the hospital's actions as careless, thoughtless and lacking in respect.

What can we learn?

Returning a deceased patient's belongings to his or her family needs to be managed sensitively.

What seems like a simple action can highlight the different attitudes of staff and bereaved relatives. Returning belongings is a routine task for hospital staff. Staff are used to seeing clothing or belongings in a soiled state and of course, they are obliged to return these to the relatives.

To the relative, the return of the belongings is evidence of the loved one's death, and evidence that his or her death may have taken place in unpleasant circumstances. To some people the manner in which the belongings are returned will not matter; to others the use of a plastic bag is disrespectful and it is important that the belongings are presented in a more appropriate way. Some people might prefer not to have soiled or damaged clothing returned to them at all and it might be appropriate to have hospital staff offer the choice of disposing of items.

This issue was initially raised when the Ombudsman conducted a formal investigation into end of life care in one acute hospital. As a result of the investigation, the IHF introduced the concept of the 'Handover Bag', designed to return belongings in a formal and dignified way. It was disappointing to see the same problem occurring in a different hospital.

Managing Complaints

Doctor responds to complaint defensively and insensitively

“It gives me great peace of mind that my letter of complaint has and will continue to lead to a number of changes in practice in the Radiology Department and hopefully deter such poor standards of care occurring again.”

Poor response to complaint

Families are regularly upset by the reaction of hospitals when they complain. Ms O’Rourke wrote a letter to one of the hospitals that had cared for her late brother, setting out her concerns about his treatment.

She received a response from the leading Consultant in which he failed to offer condolences and was critical of her decision to complain to the hospital rather than directly to him. Ms O’Rourke found the tone of his letter defensive, offensive and intimidating. Because she felt so intimidated and upset by the response, Ms O’Rourke could not bring herself to meet with the Consultant and others involved in her brother’s care. This was unfortunate as it prevented her from gaining access to information about her brother’s condition, care and death. This was information that she needed to bring some closure to her and her family’s loss.

The Ombudsman asked that the case be brought to the attention of all Consultants in the hospital so that they would appreciate how a certain approach to a complaint could have such a negative impact on a family, and to show how important it is to communicate non-defensively and sensitively with families, whether verbally or in writing.



What can we learn?

A more consistent, timely and high quality approach is needed to deal with health complaints. An Ombudsman review of complaints handling to identify good practice and failings is currently underway, and will make recommendations designed to secure improvements in the future.

Good complaints management is a key element of good administration and service delivery. Every well run organisation recognises that things will go wrong from time to time. The way to deal with this is to have accessible, open and prompt complaints systems that objectively identify and acknowledge where errors have occurred, that apologize where appropriate and that continuously change systems to improve services and provide reassurance to service users. Defensive, incomplete, superficial or delayed responses on the other hand only go to increase the sense of anger, frustration and disappointment felt by complainants. They also fail to make the most of opportunities to learn from poor service delivery and to stop such failures recurring.

The recent establishment of hospital groups provides an opportunity for better resourced complaint handling and to share learning from individual complaints.

Conclusions

The complaints set out in this review provide a glimpse into end of life experiences in acute hospitals and show the range of difficulties that can arise. The experience of the Ombudsman is that many problems arise because of poor communication and oversights often caused by resource deficits.

Communication

Almost every case in this review, and most of those that come to the Ombudsman, arise because of poor communication at some level and lack of clarity about the respective duties and rights of doctors, nurses, patients and families or friends.

Health professionals work in a busy and stressful environment. They work with people who have usually not chosen to be in that environment and who may be very ill or distressed. Health professionals and other staff working with dying people must make every effort to provide the space and time to communicate clearly and empathetically with patients and their families. To the patient and his or her family, that skill is integral to the high quality medical and nursing care expected from the hospital.

Good communication depends on more than empathetic communication between individuals. Patients and families need to know that they can rely on an institution to deliver the best care possible. Communication systems within hospital departments, between doctors, between nurses, with the family, with related settings and with services outside the hospital (including General Practitioners and Public Health Nurses), need to be planned, well structured and effective so that patients and families will have proper and timely access to the supports they expect and require.

Families and friends may not be clear about the unique relationship of a patient to a doctor and the rights of the patient over that of the family. This will have implications for the care of a patient and can leave family and friends in the dark as to what is happening to their loved one. Doctors and staff may on occasion be unclear themselves as to how much information they in turn should communicate to family and friends in these circumstances. It is clear too that patients do not always want to communicate openly with their own families and this can lead to dilemmas if the patient's condition deteriorates.

The language and way in which information is communicated is crucial. Information needs to be shared using simple clear language, in a manner that treats the patient and family or friends as equals, facilitating the emergence of the 'expert patient' as envisaged by the Health Service Executive. When patients and relatives express their fears about a diagnosis, a prognosis, or pain control, they need to know that staff will listen to them, take them seriously and respond with the reassurance or action that is needed. Time is often required for good communication, and there is rarely an over-supply of it, but professionals need to be clear on the importance of these conversations at the end of life or after a death. Hospital staff also need to be vigilant in documenting any important actions or discussions.

Resources

Regularly an overburdened staff and lack of physical facilities feature in complaints. Sometimes the defence offered by staff of being very busy and under pressure does not explain or justify the poor and insensitive service. Sometimes management has no choice but to accept the fact that services are unviable unless further investment is provided.

With regard to physical facilities, patients and families want peace and privacy at the end of life. For most people this means access to a private room. Relatives need a private space to spend time with a loved one after death, a space clear of normal hospital routine, where they can grieve without worrying about the needs of other patients, or without being observed by others.

Relatives need to see their loved one cared for in a dignified way after death. For relatives this means that the remains will be dressed or covered appropriately and can be viewed in a clean and calm place.

Pain Management

The question of when, or if, palliative care should be suggested to a patient is a matter of clinical judgment outside the competence of the Ombudsman and is clearly something for clinicians and others to debate. What is clear to the Ombudsman however is that patients want to be as comfortable and pain free as possible and that acute hospitals are expected to rise to the challenge of meeting that expectation, within ethical and medical constraints, and while respecting the wishes of individuals. The hospital has a responsibility to ensure that a patient who has been discharged has been brought to the attention of local services in a timely manner and will have their pain control needs met at home.

The Way Forward

The Forum on End of Life in Ireland has encouraged communities to have a more open attitude to dying and death, and to the broad range of issues that death raises. Using tools such as the citizen-led Think Ahead form, we are encouraged to plan and to have our wishes and preferences recorded and respected. HIQA standards also make provision for such advance care planning and consultation.

It is a matter for individuals to decide whether or not they want to plan ahead to spell out their preferences in the event of a significant health emergency or in the face of a serious prognosis. Certainly such clarity may make life easier for health professionals and may lead to more comfortable experiences for patients and families.

Regardless of individual advance care planning, the onus remains on all those responsible for providing health care to ensure that the service at end of life is completely focussed on the dying person's needs and thereafter their loved ones. Service providers need to continuously improve and learn from mistakes that have occurred.

The Ombudsman will continue to contribute to that process by examining complaints in an independent and impartial manner and by providing feedback to complainants and service providers. The Ombudsman commends the Irish Hospice Foundation, the Hospice Friendly Hospitals Programme, and all other public and voluntary organisations who strive to provide excellent care for people at the end of their lives.



Refurbished Mortuary, Mercy Hospital Cork Pic: GMC Photography



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