

A Public Interest Perspective

Address by the Ombudsman,

Ms Emily O'Reilly

***End of Life Care:- From the Margins to
the Mainstream***

A National Conference to reflect on the first
National Audit of End of Life Care in Irish
Hospitals

Clontarf Castle, 19 May 2010

In the last seven years of my life, I have learned much, as citizen and as Ombudsman, about death and dying. In so doing I hope that I have gained an insight into the issues around this time in a person's life, be they simple or complex, and the diverse range of needs that the dying person and his or her loved ones can have.

I now more fully appreciate the challenge that healthcare providers face in meeting the needs of dying persons and their families, and indeed of their own staff. That challenge however, is made easier by the visionary, professional and successful work of the Irish Hospice Foundation and I most sincerely congratulate them for raising consciousness about End of Life care, for the development of *Quality Standards for End of Life Care in Hospitals* and for this latest achievement, the *National Audit of End of Life Care*.

If we had a choice, most of us would prefer to die at home surrounded by our family, yet if current trends continue, half of us here today will die in an acute hospital. That isn't how it should be so it is vital that Hospitals continue to engage with the Hospice Friendly Hospitals Programme to facilitate “good deaths” in hospital and that services are developed in the community to allow more people to die at home.

This *National Audit of End of Life Care* has demonstrated that the Quality of Life Care for people who die in an Irish hospital compares favourably to Hospitals in the UK, France and US, but it also demonstrates significant weaknesses at each stage of the patient’s journey, from admission to death, and these are areas that must urgently be addressed. Twenty two percent of relatives believed that the quality of care provided was neither good, nor very good so it is clear that there is room for improvement. Just as our tolerance for poor hygiene in Hospitals has shrunk, so too must our acceptance of regimes that militate against a peaceful, dignified death. Our intolerance should focus on poor physical environments, insufficient human resources,

inadequate skills and unacceptable attitudes in the care of the dying. It is vital that Government and society acknowledge care of the dying as the most basic of our obligations as human beings.

Last year my Office was asked to make a submission to the End of Life Forum. To make that submission we did our own informal audit of complaints that we had received in the health and social care area. We found, unsurprisingly, that most of the health care complaints related in some way to experiences at the end of life. In our submission, we identified the following as the main areas of complaint with poor communications outstripping everything else. Some people were given a devastating diagnosis in the most merciless and insensitive way. There were failures around the consideration of a person's right to know about their illness versus a family member's wishes in relation to how much they should be told; there were failures in the documentation of important interventions and conversations that allegedly occurred; there was the absence of clear policy, information or communication on important care decisions such as resuscitation, or the withdrawal of active treatment measures; there were failures to talk to the dying person or their loved ones about the fact that they were dying, and to include them in planning their care.

The admission to hospital of terminally ill people through Emergency Departments was another common source of complaints. Some people, admitted in this chaotic manner, were forced as a consequence to spend some of their final precious hours, stripped of dignity, in physical and

emotional pain and in discomfort with strangers. A common theme related to the indignity of dying in a crowded and busy ward; televisions playing in the background, conversations and laughter to be heard; life continuing for everyone else while, for this person and their family, life has stopped.

Family members told of having to muffle their sobs or hide in a toilet so as not to disturb other patients; no space, no peace, no dignity. A number of people have approached my Office in recent years about the absence of information regarding post-mortems; a failure to educate families about Coroner versus Hospital post-mortems, the logistics and arrangements that were required, the questions that a post-mortem might answer. Families regularly complain about the absence of any support to them after a death. The support does not always have to be provided by a Social Worker or Counsellor necessarily, but nurses and doctors that were involved in the care of their loved one could take time to sit for a few minutes, to remember the person, to answer questions, to acknowledge the loss for the family. Frequently, my Office is told that insult was added to injury when families complained to the hospital about their loved one's experience and their complaint was ignored, belittled or they were patronised with a meaningless response and an insincere apology.

Many stories have lodged in my memory over the years.

At 8.08 on a Sunday morning a family rang the hospital to enquire about their father. They were told to ring back as the nurses were changing shift. 12 minutes later they

received a call from the hospital to say that their father was very ill and to ask them to come straight away. On arrival they were told that their father had been found at 7.50 in a collapsed state (this was 18 minutes before they had phoned the ward). When the rest of the family arrived they were then brought into the ward to see their father. The curtains were pulled around but he was unshaven. The family asked if Last Rites had been administered but their question was met with shrugs and what they perceived as apathy. The nurses checked the book and told the family that he had not. The family arranged it themselves. No member of staff offered condolences. No member of the medical team offered to meet with them. When they left the ward shortly afterwards they were asked to take their father's belongings which had been bundled into three black bags and left insensitively under the Christmas tree in the ward.

A woman told me about how her husband had been admitted to a hospital with a serious illness but he was not dying. One night he had a heart attack and she and her son were called. They were asked to sit outside and they did so for thirty minutes. A nurse came and told them that her husband had had no pulse for twenty minutes and that they needed to decide whether he should be resuscitated. They agreed that he should not and that he should be let go peacefully. The nurse said that perhaps they would like to spend his last few breaths with him. They of course said yes, and the nurse left them for a moment only to return to say that it was too late; he had passed away. They asked for a priest and he came up and together they all said a few

prayers. The staff asked them to wait outside again for a few minutes. After an hour or more had passed the son asked what was taking so long and could he be with his father, he was told that the staff could not find the matches to light the candle....The woman told me how distressing this was; her beloved husband had died without her being present and she just wanted to be with him in those moments afterwards. Why could this fundamental need not have been acknowledged and facilitated? The hospital had treated her and her husband, in this regard, with little sensitivity or respect.

This woman complained to the HSE and eventually to my Office, but she did so reluctantly. She said in her letter to me:-

I find this letter hard to write. I am not satisfied with how the hospital dealt with my complaint. I am not looking for any monetary gain or anyone's head on a plate, but I would like someone to tell me what actually happened and why my husband deteriorated so quickly. I know his cancer was not curable, but it was treatable and was not in fact the cause of his death.

Another family, on a similar note, told me about their experience:-

We are a small family who have been treated badly. We are seeking only explanations and apologies for the manner in which our father was treated. It was very hard to see our father die, but to see him suffer so much unnecessary pain and anguish, which was completely due to the failures, both

personal and systemic, in this hospital, is something we will never forget. Even at the end, some of the family were not with him due to such failure. We accept that he was a very sick man, but he was treated very badly and that is very hard for us to now live with.

The woman told me how she had received a call from the hospital in the middle of the night to say that her father had deteriorated and a bed in ICU was being sought. She said she would come in immediately, but the nurse advised her not to. She and her mother went to the hospital anyway. They were left for an hour sitting across the corridor from where her father was. A nurse came out and said she was getting the chaplain; with shock and worry they asked if her father was that bad. The nurse responded that it was merely standard practice. Somewhat relieved they continued to wait, only to be then told that her father had died. This woman was extremely upset and indeed angry that she was not made aware that her father was dying, that the rest of the family were not notified and that no effort was made to allow them to say goodbye.

Thankfully, the work of the Irish Hospice Foundation, the bravery and commitment of families who make complaints after a loved one has died and the commitment and vision of some healthcare professionals and managers has helped to make these experiences occur less and less. I am aware of many developments in the last number of years to improve the comfort of patients who are dying. Only recently the Mater Hospital informed one of my complainants that they have committed to developing a dedicated unit for patients who have entered the end of life

stage. The Unit will be underpinned by the principles set out in the Hospice Friendly Hospital Programme. The Unit will dedicate itself to providing a respectful, dignified and compassionate environment for dying persons and their families.

Many Hospitals have reviewed how they communicate with patients and their families and have developed policies on how good communication should take place. They provide training on a regular basis to medical and nursing staff. Other Hospitals have developed policies on Resuscitation where they can share information with patients and families in an easily understandable and sensitive manner.

My job is to investigate complaints, to determine what happened, to ensure that the truth is found, to seek an apology where the hospital has failed and assurances that measures will be put in place to prevent another patient and family suffering. As well as investigating the family members experience, I investigate what they understood was the patient's experience. I note from the audit being launched today that hospitals are better sometimes at having and at recording conversations with families than they are perhaps at having and recording discussions with the patients themselves and I think there is a concern that because of complaints and litigation, hospitals almost prioritise their communication efforts with family rather than the patient. If this is the case, it is simply wrong; I do not think communication should be an either / or situation.

The patient is, and should be, the hospital's primary concern, and the hospital must ensure that the dying person's needs - physically, emotionally or spiritually- are addressed, but the family's needs must also be considered. And, any important intervention or interaction, whether with the patient or the family, must be documented, as much to ensure that the entire team are aware of what has or has not been done, as to provide a record for quality improvement and audit reasons later on, or indeed for personal reasons.

While sometimes my Office will be critical of healthcare or management personnel, we also acknowledge the great work that is being done on a constant basis and the difficult circumstances in which people work. We are all aware of the physical environments which restrict best care at the time of death and the limited resources with which staff have to try and meet challenging needs, but I am also struck by attitudes and behaviours, by the culture in this regard. Do hospitals, senior healthcare professionals and managers, and Medical and Nursing Schools to name but a few, have to re-examine their philosophy towards death and the priority given, or not given as the case may be, to enabling *good deaths*? Sometimes a good death is not about having a better physical environment and staff having more time, it is about staff's ability to understand the patient's needs, their ability to relate to the patient's experience and communicate with them.

Pauline W Chen is an American Surgeon who has written a book, *Final Exam: A Surgeons Reflections on Mortality*.

Twenty years ago when I applied to medical school, I believed I was going to save lives. Like the heroic doctors of my imagination, I would spend my days in triumphant face-offs with death and watch the parade of saved patients return to my office full of life, smiles and back-slapping gratitude. In a profession made attractive by the power to cure, it is rare to find the young medical student who dreams of caring for terminal patients. Most patients and their families fully expect physicians to be able to comfort and provide support... Unfortunately few doctors are up to the task.

She described how... I learned from my teachers and colleagues to suspend or suppress any shared human feelings for my dying patients, as if doing so would make me a better doctor.

After many years of being a doctor she finally got an insight into how my own fears and trained responses had, in the end, incapacitated me. Amid the pain of losing patients, I learned that I might be able to do something greater than cure. I could provide comfort to my patients and their families and in turn open myself to receive some of their greatest lessons.

She talks in her book about always wishing she could do “more”, always wishing she could cure, but eventually she realised that that sometimes doing more might be about doing less, making sure the patient is comfortable, talking to them, listening to them, talking to their loved ones, that might in fact be “more”.

Irish hospitals are extremely busy places, admitting patients, assessing them, ordering tests, performing tests, reading results, administering drugs, performing surgery, emptying beds, stopping the spread of infection. Would anyone choose to die in that environment? Some do, because they believe that their dying at home would be too burdensome on their family and that the hospital will be able to relieve their pain and care for them better. Many do not get to make the choice. Regardless, a hospital must seek to mirror their home environment, no matter how challenging that might be.

I recently spoke to a woman who told me about her mother's death. She told me that despite the terrible loss of her mother, to whom she was very close, she and her family were "lucky" to experience things as they did. She shared with me her thoughts about being "lucky". I will call her mother *Mrs. Daly*.

Mrs. Daly had been ill for only a few months with a form of cancer. She was being cared for at home by her four daughters. Four weeks after the completion of a course of radium treatment, which, it had been hoped, would reduce the tumour, she had a major incident and was rushed to hospital in the early hours. When she left A&E, she was brought to a private room in the hospital which had become available - she was not a public patient. The doctors did not expect her to die; her prognosis was bad, but they did not expect her to deteriorate quickly. They continued to assess and treat her, unable to identify when the tumour would develop further to cause death.

Mrs Daly's family had been watching her very closely during the months since her diagnosis. Prior to this incident, they felt strongly that their mother was deteriorating rapidly. When they tried to bring this to the attention of her doctors, they were told that she was fine and was proceeding as they anticipated; the doctors needed to wait until the effects of the radium had "settled down" and there was no immediate cause for alarm. However, now, in the hospital, the family were convinced that they were right. One of the daughters was an experienced nurse and between the four of them they had read a lot of the recent research and medical literature. They spoke to the doctors at length about what they had observed in their mother's condition and how her symptoms, as observed by them day by day, actually fitted with a different picture to the prognosis they had been given. After one week, the doctors, having reviewed all of the tests, scans etc. and having done a complete medical work-up themselves, agreed and accepted that, in accordance with Mrs. Daly's wishes, she would be provided with palliative care and all active treatment would be stopped.

The hospital had a palliative care team to whom Mrs Daly's care was assigned. It was agreed that if a bed became available in the hospice she would move there. She was made very comfortable and her family brought in photographs from home and put them around the room. They brought her own throw for her bed to make her feel "at home" and a CD player so that she could listen to her favourite music. Hospital staff commented when they came into the room that it "was not like a room in the hospital at

all" the atmosphere was so calm. Her family visited, including her grandchildren and because they were in a single room and not disturbing other patients, there were few restrictions.

Only once did the strong medical imperative to treat Mrs Daly break through. The most senior doctor in the Department decided to review her - he had never seen her before, nor had he been involved in her care. He decided that perhaps there was more could be done and ordered a rather intrusive test of one hour's duration. The family did not agree that more could be done but were distressed by the apparent change of mind by the medics - they did not like the idea that they might be refusing something that might be useful to their mother. They agreed to the test. The test was stressful for Mrs Daly and actually had to be stopped prematurely because of this. It resulted in no change to her diagnosis or prognosis.

For the next few days the family enjoyed precious family time together - including delicious ice-creams from the hospital shop, for all three generation present, ice-cream being a particular penchant of Mrs Daly which she had passed on to her grandchildren and which in her last few days gave her and them great pleasure.

Mrs Daly's family felt very lucky that their mother had had such wonderful care. The two weeks in that room were valued by them and they felt that they were allowed to look after their mother in a very personalised way. Everyone they spoke to told them how lucky they were that she did

not die in the middle of a busy ward, how lucky she was that she got a private room in the hospital, how lucky they all were that they were able to spend so much time together, how lucky to be allowed to stay with her constantly in the last few days and to be with her when she died.

The family knew they were fortunate to have had those very precious two weeks together, to have been able to behave as if they were in their mother's bedroom at home and not on a hospital ward. They knew that the ward manager was exceptionally good, and that they were blessed that the bed which became available that night, when they were in A&E, was on her ward.

But why should they feel that this was so “lucky”? As we know, huge numbers of people die every day in hospital. We should not be made to feel “lucky” because our loved ones are afforded the dignity of a single room in which to die in the company of their families. The experience which this family had should be the norm, it should be the experience which all families have if their loved one happens to die in hospital - or, indeed, if we ourselves do. We all deserve such dignity of treatment - it should not be a matter of luck.

I welcome the cooperation of so many hospitals with the Irish Hospice Foundation's initiatives and the National Audit of End of Life Care in Hospitals. I respect these Hospitals for exposing themselves to the scrutiny the Audit

brought with it, and for opening themselves up to addressing necessary improvements.

Death may happen by accident, but improving the experience of people who die in hospitals will not happen in the same way. Everyone must ask themselves how important the care of dying people really is, and everyone must commit to playing their part to make better care and better experiences a reality for every person dying in an Irish hospital and not just for the “lucky” ones.

The Audit talks about hospitals as places of hospitality. Ireland is credited internationally for its hospitality, *a nation of a thousand welcomes*. As well as its welcomes, Ireland is also famous for its farewells. The Irish *wake* is talked about far and wide as a wonderful *send-off*, a personal and community tribute to, and celebration of, a person’s life; a way of family and friends sharing the person’s death with a mixture of sorrow and jollity. The wake is an important part of the grieving process as family, friends and neighbours gather to comfort each other in their loss and support the immediate family of the deceased in coming to terms with their grief.

This Audit has identified 18 ways to improve hospital care at the end of life. These 18 areas correlate with the complaints my Office has received over its 26 year of existence. I am sure that the Irish Hospice Foundation and the HSE will ensure that these 18 areas become the subject of targeted effort and resource.

If half of us will die in what can be a foreign and clinical acute hospital environment, and I hope we won’t, wouldn’t

it be great if even the unlucky amongst us could be guaranteed to experience, along with our families, a quiet and private space, dignity, caring, kindness and attentiveness; and a *send-off* that we might even design ourselves if we had the chance.

To conclude, I thank the Hospice Foundation for inviting me here today, I thank them for including my Office's observations in their work, and I thank them for the valuable insights they have afforded to me and to my staff over the last number of years.