

16th July 2014

Chairman, Members

I am pleased to have this opportunity to discuss my Office's report *A Good Death*. Issues around end of life care have featured extensively in my work as an Ombudsman and this report was one which I was very keen to issue. At the outset I want to thank the staff of the office for their work in producing it.

The report itself is unusual and indeed unique for my Office, in that it is not a report on a statutory investigation into maladministration by a public body under Section 4 of the Ombudsman Act 1980. The report does not contain formal recommendations or name individual hospitals in its various case studies. It is instead a look back at a range of end of life care complaints dealt with by my Office in recent years. It does not seek to point the finger of blame at particular professionals or institutions. However, for members of the public and health care workers who read the case studies and the conclusions set out in the report, I hope it provides a good opportunity to encourage learning. The report highlights the mistakes of the past and seeks to apply the lessons learned for the future care of terminally ill people and their families.

Above all, the report aims to tell the stories of people at the end of their lives and their loved ones. Their stories can have a far more powerful impact than a dry policy paper. Many people complaining to my office do so because they want their negative experience to be used as a catalyst to ensure service users in the future don't face the same issues. Reports of this kind are intended to bring about that learning and change.

My Office has a close relationship with the Irish Hospice Foundation (IHF), and central to the reasoning behind the report was to inform and underpin its work. The IHF is a national charity dedicated to improving the quality of care available to people in life limiting circumstances and to the bereaved. The Foundation is working to bring hospice style care to hospital settings through the Hospice Friendly Hospitals Programme. It was appropriate therefore that we recently launched the report along with the IHF. The launch event also included a preview screening of the RTE /Irish Hospice Foundation documentary, *Way To Go: Death and the Irish*, presented by Norah Casey. The documentary features first-hand experiences of healthcare professionals and people who are dying, speaking openly and honestly about going through the last months of their lives. The documentary was screened on RTE television at the beginning of this month.

I don't propose to go over too many of the details of the individual stories in the report in this presentation, but I will offer some reflections on the themes which emerged. In the vast majority of cases, patients and their families and friends receive the professional and humane service that they expect. I recognise this very much and respect the hospitals and the staff that provide a wonderful standard of care. Sadly, as Ombudsman, I see some of the cases where people have received poor treatment. In some cases, the patient was denied the peaceful and dignified death that might have been hoped for. In others, families and friends were traumatised by events surrounding the death of a loved one and have suffered a prolonged and traumatic grieving process as a result.

There is one common thread running throughout the complaints in this report and the many others that we encounter in the Office. **Communication** – good and bad – holds the key to how a patient and family experience the unique process of nearing the end of life and of dying. It's so easy for two people in conversation to take away very different views of what was said. There is often a gap between the message professionals intend to give and the way it is understood. One woman understood that her husband's cancer "was gone" as she put it, following chemotherapy. This was not what was said by the consultant but that's what she believed. In another case a man believed he had hastened his mother's death by agreeing to a *Do Not Resuscitate* order.

It just shows how important it is for medical and nursing staff to make sure that the person understands the exact message that they believe they are communicating. Sometimes the wishes of the patient and those of the family and friends are in conflict, and the clinician face a major challenge trying to make the right decision, respecting rights and wishes as appropriate. Many families believe they have the right to full disclosure of a patient's condition and even the right to advise what should be done. Of course the doctor's responsibility is - first and foremost – to the patient. In some of the cases mentioned here, families complained that they were not fully informed about the patient's condition. What we found when we looked into some of these complaints was that the patient had explicitly wished to keep this information private. The hospital staff did the right thing in respecting these wishes, but families were left very upset and sometimes angry.

Many people would prefer to die at home and their families often want to grant this wish. Sadly, it is sometimes the case that these heroic carers are left without the support they need. One family brought their 85 year old mother home. They were not told how to administer morphine, there was confusion over how it was to be sourced, and they had to call out a GP in the middle of the night to help their mother with her pain. That was a bad experience for the woman and left a crippling memory for her daughters.

Another woman who had experienced problems when she brought her mother home to die pointed out "It takes many years for doctors and nurses to qualify – it is only fair that carers would be offered the relevant information before they are required to manage the final stage of terminal illness and the death of the person they love."

Many people who complain to me make the point that the death of their loved one was a unique event for them, but a routine matter for the staff dealing with them. Staff are busy, but empathy with the patient and family is simply not negotiable. The hurt inflicted by casual or unthinking remarks, or by a failure to attend to the needs of a dying person, can leave a terrible scar with surviving family.

So what are the major lessons to be learned from these cases? We need to talk about death and our own preferences for end of life care and to document these. We need to keep open and clear channels of communication between professionals and patients and between patients and families. We need to be clear about what is happening in these final weeks, days and hours. We need to be clear about the rights of patients and families and the duties / responsibilities of doctors and other caregivers. We need, above all, to aim to make these final precious moments as pain-free, peaceful and dignified as they can be for the dying person and their loved ones.

Thank you and I am happy to take questions.