SUBMISSIONS ON END OF LIFE CARE
Wed 6th May 2009

IDEAL SITUATION

Given a choice, I would imagine that most people would choose to die at home, being cared for by qualified nurses, surrounded by their families and close friends.

However, this option is not always possible due to lack of nurses and homehelp or a patient's condition dictates that full time hospital care is required.

The current system of Palliative Care provided to those with terminal cancer should be extended to include all those dying with chronic conditions.

CARE in the HOME

This would need to include the following:-
Home Help –Practical household support for the patient's family, to enable them to spend quality time with the family member.

Home Care – Provided by qualified care assistants trained in Palliative care to work in conjunction with and supervised by the Palliative Care Team.
This has been done successfully in the Milford Care Centre, Limerick.

Home Nursing – Provided by the Palliative Care Team in conjunction with the Public Health Nursing Service and the patient's GP.
The GP can also help prepare the family for what to expect following the patient's death – post mortem, body bag requirements.

Social Worker – Providing ongoing support to the patient's family both during the illness and following the death to talk about their feelings, in addition to making practical arrangements.

CARE in HOSPITAL

I believe that this is actually the most challenging aspect of End of Life Care. While Hospice Care is not available to everyone, acute general hospitals can learn from what works best.
Currently, hospitals generally aim to cure the patient. When this option is not the expected outcome, it can pose challenges for both the hospital and the health care professionals.

Pain Management – Effective pain relief and symptom management is extremely important for the terminally ill person. This requires the expertise of the Hospice team. Many acute hospitals now have pain specialists who need to be involved early on to advise the patient's Consultant on best practice.

Comfort - The need to feel special – the patient's physical surroundings are important, while cleanliness is essential, clinical surroundings are not always conducive to comfort and ease especially in the terminal stages.

A large single room with an en-suite is ideal, which has the space for a fold-up bed for relatives. If possible, the patient could have their own special things from home with them: photos, music, bed covers.

Relatives need to be encouraged to sit with the patient who may want to reminisce or listen to calming music. Whatever the person's religious beliefs, the attention to detail can help to normalise the whole experience, helping the person to let go and even help people see it as a celebration of the person's life.

CARE of the DECEASED

Universal Precautions and Body Bags – When people die with infectious diseases, this can be a nightmare for the family. There were 259 of our members infected with HIV and/or Hep C viruses by factor used to treat their bleeding disorder.

Currently, here in Ireland we do not have regulations which care for the public health, while being sensitive to the needs of the family.

The use of Body Bags remains a live issue for the Irish Haemophilia Society. When someone dies with an infectious disease, the body is placed in a black body bag.
In the past, this was then sealed on the hospital ward and it could not be opened by the Undertakers to enable the body be viewed by relatives.

Throughout the years when many members died with HIV and/or Hep C, the Society had to provide an 'End of Life Care' which enabled their families bring them home from hospital to die. The Society provided nursing care and worked with the Undertakers to ensure that the family could wake the body at home and have an open coffin.

Today, this is still a concern when a member dies. Some hospitals are very sensitive when dealing with the regulations and the family. However, this is not always the case.

What has worked in some areas, is the use of a body bag to transport the remains from the ward to the mortuary and then to the person's home. With the Undertakers permission, this can be opened down out of view to enable the family to pay their last respect. After the wake, the bag can be zipped up and the coffin closed.

Sensitive Legislation – We need sensitive legislation which takes into account the needs of the family and the needs to protect public health. Currently there is no national policy.

Different hospitals have different policies and each hospital works within their own guidelines. Internationally there is no agreement on guidelines on which to base national guidelines.

The Health Protection Surveillance Centre had established a sub-committee chaired by Dr Elizabeth Keane, to develop National Guidelines on the Management of Death from all infectious diseases (MoDI). This Sub-Committee includes Clinicians, Microbiologists, Funeral Directors, Morticians and Pathologists. They are now reviewing responses received during the consultation process which ended on 31st March 2009.

Post Mortem – When there is a need for a post mortem, I suggest that it is important that the family are informed of this in advance, by the patient's Consultant. At any time this can be difficult for the family to accept, however, if it comes from the patient's Consultant it can be easier to understand and therefore accept.

CONCLUSION

Need for Creative Thinking – Given the current financial situation, there is a definite need for us all to think creatively in order to develop a sustainable system which meets the needs of our dying members.

We need to heighten our awareness of what Dignity and Sensitivity means when it comes to end of life care.

Challenges for Health Care Team – Old ways of thinking need to be challenged. We have to open up our minds to new ideas and be willing to change.

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20th April 2009
IRISH HAEMOPHILIA SOCIETY