Supporting Families at End of Life

Family is who the patient says it is

Fundamental to good end of life care is the support we give to the family of the person we are caring for before, during and after death. While we always need to keep the patient at the centre of care, patient care includes family care. Family-inclusive end of life care should aim to identify the unique needs and abilities of families and to open the lines of communication between family members. We can enhance family support by good communication. Families usually provide the primary support for the person and may also act as mutual support for each other. Support given to families should encompass the domains of care depicted below while recognising social and cultural difference, and diverse family situations and make-up.

When a Relative is Near End of Life—Key Points when Supporting Families

- ‘Family’ can be defined as ‘those closest to the patient in knowledge, care and affection’. This broad definition includes the natural or biological family, the family of acquisition (related by marriage, civil, same sex and de facto partners or adoption), and the family of choice and friends.
- Communication is key: listening, asking, telling.
- Families need time, space, privacy and compassion.
- Families need support with both the practical and with the emotional aspects of the anticipated loss of someone close and when the person has died.
- It is important to be mindful of the issues that may arise within different death scenarios—for example, expected death, sudden death, the death of a child, miscarriage, intrauterine death, stillbirth, neonatal death.

Differential Domains of Care—Differential Aspects of Family Involvement

Kindness

Compassion

Emotional/Practical

Communication

Preparation

Spiritual

Social/Cultural

Physical/Environmental

Information

Continuity of Care

Inclusion

Privacy

Time

Some of the Things Families Have Said Make a Difference*

- The care and attention received was excellent, considered, respectful and dignified
- To be told we could visit any time and to be asked if we would like to stay overnight. I would have stayed with my husband if someone told me I could.
- More communication between medical staff and family
- We needed to be told she was dying so we could plan our last days with her
- A member of staff could bring family members to the morgue. My family and I were alone and very upset.
- My relative’s spiritual needs were fully met
- We were often left in the dark about what was happening and were left on our own mostly
- No children were ever allowed to visit and my mother loved her grandchildren and great-granddaughter so much
- Pain management and palliative care should have been available

(*Responses received from family members in Audit and Review of End of Life Care meetings, Hospice friendly Hospitals, 2013)

This leaflet is part of a larger collection of good practice resource leaflets (TOOLBOX TALKS) available from the HSE:
http://www.hse.ie/eng/about/Who/qualityandpatientsafety/Local_Quality_and_Patient_Safety_Offices/QPS_DNE/Tool-box_Talks/
How to support family members

WAYS YOU CAN HELP

1. Involve family members at the level of involvement that they want to have.
2. Provide information and enable family involvement in care.
3. Recognise and allow for the different coping styles of different family members.

We would like to be involved, but our mother’s wishes are paramount.”

“We weren’t told that she was going to die. We should have been told. We didn’t realise that her death was so close – it came as a shock”.

COMMUNICATION

- All communication between health care staff and family should be governed by the expressed wishes of the patient and, where these are not known, by the best interests of the patient.
- Clear decision-making processes should be in place and adopted by all staff. These processes should also cover circumstances where a patient does not have mental capacity.
- Information should be given sensitively and in a planned way to ensure time and privacy. Language should be clear and understandable, avoiding jargon. Written information may be given to family to take away.
- Try to support individual family members in their communication with their relative. Each person may need time on his/her own with the patient but they may not feel they can ask for this.
- Communicate regularly with the family members about the care being provided, and about any changes in the condition of the patient and about the dying process.
- Prepare families, especially when death is imminent. If families are not aware of what is happening, they may miss the chance to say what they need to say to their dying relative.

IN VolvEMENT IN CARE

- With the consent of the patient, families should be offered the choice to be involved in all aspects of care. However, it is important to involve family members at the level they wish to have—some may prefer to have a hands-on involvement, others may be happier staying further back.
- Family members may come to you to talk or ask about different care or treatment options. If/when they do, remember that they are simply advocating for the patient.
- Family members should be encouraged to voice any worries or concerns they may have.
- Family members can play an important role both in assisting with communication with the patient and in assisting with providing personal care to the patient (if they wish).
- In keeping with the wishes of the patient, flexible visiting arrangements should be in place. Family members may wish to be present with their relative as much as possible, including staying overnight.

For further information:

- Quality Standards for End of Life Care (Hospice Friendly Hospitals, IHF)
- National Consent Policy (HSE, 2013)
- http://hospicefoundation.ie/education-training/

When facilitating family meetings, it is useful to be aware of the fact that each family member is an individual with his/her own needs and coping skills/styles. Also, it is important to be alert to the possibility of family conflicts (old or newly-arising) and to ensure a safe place for people to express concerns.

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