



PATIENT SAFETY TOOL BOX TALKS®

EFFECTIVE CARE & SUPPORT

END OF LIFE CARE SUPPORTING FAMILIES v1.0



Family is who the patient says it is

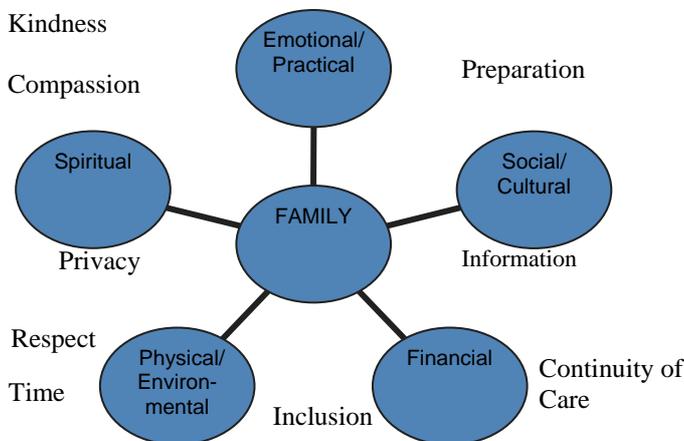
Key points to remember in supporting families:

- ◆ Family can be defined as 'those closest to the patient in knowledge, care and affection'. This includes the biological family, the family of acquisition (related by marriage, civil, same sex and de facto partners or adoption), and family of choice and friends
- ◆ Communication is key
- ◆ Families need time, space privacy and compassion
- ◆ Families need support with both the practical and 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 – expected, sudden, the death of a child, miscarriage, intra-uterine death, stillbirth, neonatal death.

What can I do?

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

Fundamental to good end of life care is the support we give to the family of the patient 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. What do we as a team need to do to meet these needs?



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

My relatives spiritual needs were fully met

We were mostly left in the dark about what was happening and were left on our own mostly.

We needed to be told she was dying so we could plan our last days with her

No children were ever allowed to visit and my mother loved her grandchildren and great-granddaughter so much

Pain management and palliative care should be available

A member of staff could bring family members to the morgue. My family and I were alone and very upset.

How can we support 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 it was so close—came as a shock".

For further information:

-Quality Standards for End of Life Care

-National Consent Policy

www.irishhospicefoundation.ie/education/information/training

Communication

- ◆ All communication between healthcare staff and family should be governed by the expressed wishes of the patient and where these are not known, by the best interest of the patient.
- ◆ Clear decision making processes should be in place and adopted by all staff, including situations where medical decisions must be made and the patient does not have capacity (see Adv Care disc and CPR/DNAR ?)
- ◆ Information should be given sensitively in a planned way to ensure time and privacy. Language should be clear and understandable, avoiding jargon (see Dealing with Bad News). Written information may be given to family to take away.
- ◆ Support individual family members in their communication with their relative. Each person may need time on his/her own but may not feel they can ask for this.
- ◆ Communicate regularly with family members about the care being provided, changes in condition of the patient and about the dying process.
- ◆ Prepare families. If families are not aware of what is happening they may miss the chance to say what they need



Involvement in Care

- ◆ With the consent of the patient, families should be offered the choice to be involved in all aspects of care. Involve families at the level of involvement they wish to have
- ◆ Family should be acknowledged as advocates for the patient
- ◆ Families should be encouraged to voice any worries or concerns they may have
- ◆ Family should be seen as playing an important role in assisting with communication with the patient and assisting with their personal care needs if they wish.
- ◆ In keeping with the patients wishes flexible visiting arrangements should be in place. While it may be difficult for families they may wish to be there as much as possible, including overnight.



Facilitating family meetings

Family meetings can provide the opportunity to

- ◆ Create a partnership / shared care approach
- ◆ Listen to family members and clarify their understanding of their relative's prognosis
- ◆ Anticipate their needs in terms of supports. What are they struggling with most at the moment?
- ◆ Enable their involvement in care. Including symptom management, communication and assisting with the physical care needs of the patient if they wish
- ◆ Explore how the death of the patient may impact upon the physical and emotional health of family members
- ◆ Be aware of the fact that each family member is an individual with his/her own coping skills and needs
- ◆ Be aware of the possibility of family conflicts and ensure a safe place for people to express concerns.