END OF LIFE CARE: THE LAST DAYS
How can we care for people as they approach the end of their life... and in the days afterwards

KEY MESSAGES
Keep the person at the centre of all conversations
Acknowledge and address the family's concerns
Good end of life care is everybody's job, and it continues after death

MY ROLE: Keep the person at the centre - continue being available to them and communicating with them, break any bad news well, listen to the person's concerns and allow for tears, keep monitoring the person's needs and recognise when the person is dying. Involve the whole team: palliative care, social work, AHPs, pastoral care and HCAs. Mind yourself and look out for your colleagues too (this can be a hard time for staff).

The FAMILY needs... Family members need to have their concerns and fears acknowledged and addressed. They need clear information (given with the patient's permission), including being told clearly when the person is near death/dying. They need to be included in the caring, and linked with support services (such as social work, pastoral care). They need support, including privacy and having individual time with the person for conversations, and time to process what is happening.

The PERSON (PATIENT) needs... to feel like they are still fully respected and at the centre of what is happening to them through being included, having a say in their care, being listened to, being honoured, being supported, and good honest communication and documentation about their needs, concerns and wishes. The person also needs privacy, a chance to get their affairs in order, to have their spiritual needs met, and to be at peace.

CARE AFTER DEATH—WHAT HAPPENS NEXT?

1. Acknowledge loss
   Family given refreshments and privacy, and information about what happens next.

2. End-of-Life Symbol placed on view
   Personal belongings placed in Handover Bag

3. Doctor pronounces death and signs Death Notification Form


5. Last Offices*
   Person's body prepared, ensuring dignity at all times. Appropriate bed drape used.

6. Pastoral /Spiritual Care informed, if appropriate Rituals/Prayers

* Last Offices (known as 'laying out' of the deceased person) refers to the care of a person's body after they have died. Last offices occur when the doctor has certified the person dead and the family have had time to view their deceased loved one.

To cure sometimes, to relieve often, to comfort always.
Anonymous physician, 16th century

“If patients couldn’t control getting cancer or ultimately dying from it, they wanted power over such issues as treatment decisions, family issues, final days of life and control of arrangements after death.”
- Dr. Debbie Volker

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/
KEY POINTS

1. Acknowledge the loss, using simple and direct language, such as “I am sorry [name of person] has died”.

2. Give support as needed but make sure that people have some private time too.

3. Offer practical help and support too, such as refreshments, information, and access to a phone, if necessary.

4. Be available to the family / relatives, etc.

5. Ensure dignity, respect and time.

6. Give people information, in a way and at a pace that they can absorb.

CONTINUING TO CARE FOR THE PERSON AFTER DEATH

- Ensure dignity, respect and privacy for the person.
- Always refer to the deceased person by name. Leave the person’s body undisturbed for an appropriate time.
- Establish the person’s preferences — check any documented notes of their advance care wishes.
- Gather necessary information and contact numbers for family.
- Last Offices, as per policy — invite the family to play a part (e.g. fixing the person’s hair).
- Place patient’s personal belongings (but not food), in the designated Handover Bag.
- When bringing the family back in to view the deceased person, tell them how the person will look now. Approach the body first yourself. Touch the person’s head or hands and again acknowledge the loss. This simple gesture makes it safe for everyone. Stay a little while until family settles and take your leave.

SUPPORT FOR FAMILY / RELATIVES / FRIENDS

Make sure Next of Kin / Significant Other(s) are informed. Once the person has died, confirm the death to the relatives. Acknowledge the loss (see box below on what to say). Remember, even though the death may have been expected, it can still come as a shock to them. Stay with the family until they settle. Then, take your leave, assuring them that you are nearby if they need you. Ensure privacy. Invite people, especially partners/family members, to take five minutes each alone with the person if they want. Inform Pastoral Care, if appropriate. Reassure them that there is no need to rush. Provide refreshments and phone access, if needed, and information on what will happen next. When the family are almost ready to leave, return the person’s belongings in an appropriate handover bag, and give contact numbers and information on mortuary opening hours, how to collect the Death Notification Form, bereavement support, remembrance services, etc.

DO SAY

“I am sorry ..... has died”

“Death is always a shock, even when you expect it.”

“This is hard for you”

“Take your time do not rush arrangements.”

“Would you like some time alone to say good bye”

“I am just outside if you need me”

“Would you like to help us to lay out your loved one?”

“Would you like to bring in the children?”

DON’T SAY

“At least the suffering is over…”

“She is in a better place”

“He is happy now”

“He had a good innings”

“Wasn’t he a great age?”

“You have an angel in heaven”

“He is gone!”

“It could be worse!”

“I know how you feel…”

First published August 2013. Bereavement Education Resource Centre, Irish Hospice Foundation