

Communication Challenges at the End of Life

“Nature gave us one tongue and two ears so we could hear twice as much as we speak.”

– Epictetus (55AD to 135 AD)

The professional health care staff in a long term care home are often faced with the challenge of discussing end of life care issues with residents and/or residents’ representatives. This discussion may preclude or follow a physician’s visit or evaluation. Due to their day-to-day interactions with residents, residents and/or their families may seek out long term care staff for guidance and greater clarification.

As with all communication regarding diagnosis and prognosis, the physician needs to take the lead in providing the information. It is the responsibility and privilege of other health care professionals to reinforce and restate the information as the resident requests and desires. Not all residents have the need or desire to know what is ‘going to happen’ as their health declines. Some residents do not want to discuss death with anyone. The role of the professional or volunteer is to practice the art of listening in a non-judgmental way and, when questions are asked, be prepared to respond in the appropriate manner.

Health care providers at all levels find it a difficult task to break the news of a life-limiting or a terminal illness. Talking about

death is usually complex. To communicate effectively is at the heart of all resident care. Often, apprehension over what to say and how to say it feeds our fears and can lead us to avoid dying residents just when they may need interaction and our human spirit the very most.

To communicate effectively with residents, we must have a clear understanding of the sensory losses that can occur normally with aging or disease. Age-related changes that can interfere with communication include diminished vision, hearing loss or distortion and changes in speech.

Residents or family members may ask the same questions over and over again. Emotional and physical barriers may interfere with their ability to absorb this information. It is important to communicate with patience, sincerity and empathy.

Based on the expectations expressed by residents and families who are experiencing life-limiting diseases, it is important to communicate the following:

- You will be honest and truthful.
- You will not abandon them.
- You will elicit and request their values and goals and will help as much as is possible to achieve these.
- You will assist them to explore their realistic options.
- You will work with the entire interdisciplinary team and see that they understand the care plan, that they communicate the goals of care to one another and that they contribute to the development of the care plan.

Setting the stage

The environment in which communication takes place can affect one’s ability to lead or sustain a conversation. However, during a time of an illness that weakens the defences and control of the resident, the ability to direct or lead conversation is diminished.

Recognizing this fact, it is essential for each person, regardless of age or illness, to maintain his or her identity. Allowing residents a choice of environments for conversation demonstrates your respect for their autonomy in making choices, even if they are small ones. Choosing a place that has limited background noise, minimal interruptions and privacy allows for focused communication.

Ensure residents are comfortable in the chair, bed or recliner that they choose. Offer a drink if their throat is dry. If they appear to be hot or cold, attend to their needs by asking what you can do to make them more comfortable. Ideally, a family member or significant individual of the resident’s choosing will have been invited to attend and to witness the conversation, either in person or by remote access.

Communication skills

The success of communication will depend on your interpretation of both verbal and non-verbal behaviour. Most people are not aware of their own body language or the tone or pitch of their voice. In fact, when people listen to a tape-recording of themselves, they usually criticize the sound of their voice as it is played back. It is imperative that the words chosen are understandable, decipherable and delivered in lay terminology, and that you are aware that the same words may have several different meanings.

A display of sincerity and compassion in voice and action goes a long way to setting the stage for effective communication. Allowing the resident and family adequate time to react to spoken comments—purposefully pausing to allow time for absorption, followed by an invitation to ask questions and then give responses that are concise, timely and honest—elicits trust and confidence.

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by Lores Vlamincck

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The palliative response: sharing bad news

First step in planning care

- Helps to develop the therapeutic relationship.
- Discuss the agenda of the resident/family first.
- Let physician priorities flow naturally from the resident/family (e.g., discussion of resuscitation and other advance directives).

Discussion agenda

- Physical care—setting and level of residential care.
- Social care—family and financial issues (e.g., dependence/disability).
- Emotional care—sources of support.
- Spiritual care—sources of meaning.

Physician role

- Do not delegate sharing bad news. Sharing bad news is the physician's role.
- The physician is best prepared to interpret news and to offer advice.
- Residents often accept bad news only from the physician.

Physician preparation

- Confirm medical facts; plan presentation.
- Make only one or two main points; use simple, lay language.

Setting the stage

- Choose an appropriate, private environment (neither the hallway nor a curtain provides privacy).
- Have tissues available.
- Allot sufficient time (20 to 30 minutes minimum with documentation).
- Determine who should be present.
- Turn beeper to vibrate (this avoids interruptions and demonstrates full attention).
- Shake hands with the resident first.
- Introduce yourself to everyone in the room.
- Always sit (do not stand) at eye level with the resident at a distance of 50 to 75 cm.
- Ask permission before sitting on the edge of the bed.
- Arrange seating for everyone present if possible (this helps put the resident at ease and prevents him or her from hurrying).

Starting the conversation

- Ask if the resident/family understand what is happening. What have others told them?
- Wait 15 to 30 seconds to give them an opportunity to respond.
- Listen for responses, which may vary from "I think I am dying" to "I don't understand what is happening."

How much does the resident want to know?

- Ask the resident if he or she wants to know the prognosis.
- The resident may decline conversation and designate a spokesperson.

When the family wants to 'protect' the resident

- Honour the resident's autonomy.
- Meet legal obligations for consent and privacy.
- Promote family alliance and support for the resident.
- Ask family members what they are afraid will happen.
- With the resident's permission, offer to have the family present when you speak to the resident (so they can hear the resident's wishes about knowing status/prognosis).

Sharing bad news

- Give a warning to allow people to prepare.
- Briefly state only one or two key points.
- Use simple language.
- Stop.
- Ask questions to assess understanding.
- Do not minimize the severity of the news.

Response to emotions of resident, family and staff

- Be prepared for a range of emotions.
- Allow time for responses.
- Communicate non-verbally as well as verbally (it is usually acceptable to touch the resident's arm).

Suggest a brief plan

- Have a medical plan (e.g., control dyspnea, control pain).
- Suggest ancillary support (e.g., social work visits, pastoral care visits).
- Introduce advance care planning—"Sometimes when people die, doctors try to bring them back to life. Have you considered whether you would want this?"
- Ask the resident if he or she would like to discuss timelines.

Offer a follow-up meeting

- When? Usually within 24 hours.
- Who? For the resident and current and additional family members.
- Why? To repeat portions of the news.
- How? Offer to contact absent family members. Get permission to share news if necessary.
- Plan the next meeting, talk about upcoming decisions and suggest a flexible timeline.

Ending the meeting

- Ask "Do you have any questions?"
- Wait.
- Answer.
- Stand (an effective way to end the conversation).

Detrimental to a resident is the statement, "There is nothing more we can do for you." It can portray abandonment and failure and engender hopelessness. While there may not be a medical or surgical cure for the terminal illness, there are many measures of care and comfort that can be offered to the resident and family that promote hope and demonstrate kindness.

It may be beneficial to ask residents if they wish to meet with the social worker, chaplain, counsellor or other professional staff member of a hospice. It is important that each team member recognizes his or her level of comfort and expertise. One of the benefits of an interdisciplinary team is that another team member may be able to offer information and possess experience

that enhances communication and understanding and provides the peace of mind and comfort the resident is seeking.

Communication with family members

There may be times when the resident has reached a level of peace and understanding,

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but his or her loved ones are struggling. Informing and encouraging family members to discuss and share their feelings provides an opportunity for growth, understanding and acceptance of the resident's change in health status or impending death.

Protecting residents from their loved ones' anger, anxiety or fear is a normal response, but hiding or ignoring emotions does not allow for positive healing and growth. Open communication is needed on all levels to resolve issues as residents and their families work through their fears and concerns.

In studies, residents have related that a high percentage of their unmet needs are due to poor communication. One approach is to routinely ask residents what they want to know. As their illness changes, their need for information may increase or decrease.

When difficult or complex decisions need to be made, a communication session should be planned in advance to allow family members or loved ones to be present. It is

important that health care staff listen to the information as it is presented. Following the discussion, they should encourage residents and their family members to share concerns and ask for clarification.

The information needs of most families are similar to the resident's needs concerning diagnosis, prognosis and treatment. Research demonstrates that although families may

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spend hours visiting the resident in the long term care home, little time is spent discussing the illness. It is best not to assume that family members are receiving information from residents about their ill health. Children and siblings need to be informed (if the resident is capable of making decisions and has given explicit permission). Pertinent

to these discussions is also the identification of family roles in determining communication patterns and responsibilities.

Family conferences

Scheduling a family conference brings attention to the needs at hand and provides an opportunity for discussion and information so that all family members are on the same page. Family members are encouraged to come prepared with a list of questions, concerns or discussion points. Each staff and volunteer member in attendance should be encouraged to participate to ensure the multi-disciplinary approach.

Families may display emotions and behaviours that are not typical for them in this time of crisis. They need to be free to 'feel what they feel' without concern that they will be judged or criticized. Obviously, any destructive comment or behaviour that risks the safety of the resident, family, staff or volunteers needs to be reported to

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supervisory staff immediately.

The amount of information required differs for each resident and each family and from day to day as the illness progresses. Residents may tell the team they 'do not want to know anything' about their disease early in the process. As bodily changes and symptoms occur, however, they may want to know more so they can prepare for the next step.

Effective team communication

The communication of pertinent information to team members for the purposes of accuracy and the timely acquisition and dissemination is critical. Residents' trust in the health care 'system' and the staff increases when they sense that staff have assumed accountability for their personal needs and care. Ongoing communication of the physical, emotional, spiritual, psychological and financial needs of the resident and family are necessary to develop an individualized care plan that meets the

resident's and/or the family's stated end of life care goals.

An essential mechanism for communication between all team members is documentation in the medical record. Written communication should demonstrate the team members' roles and goals for each resident. Regular team meetings are an effective tool for communicating and revisiting the resident's goals of living and goals of care.

Conflict resolution

Conflict may occur between the resident and family and/or between staff. Conscious efforts must be made to recognize the conflict and to take a step back to allow each party space and time. Identification of one's own emotions by describing them—rather than displaying them—offers an effective opportunity for resolution.

Identification of the area(s) of conflict, probable cause and the articulation of differing opinions offers a constructive and objec-

tive method for dealing with problems. Debriefing with a trusted colleague encourages objectivity, disclosure and the deconstruction of perceived or real barriers to communication. Conflict resolution may take on one of many forms, including an agreement to disagree, negotiated compromise, transfer and discharge—but never abandonment. Opportunities for negotiation and resolution should be explored. Modelling unconditional acceptance of the emotions of the resident and the family enhances communication and diffuses anger and frustration.

Advocating for the resident

Communication is complex in the best of circumstances, but it can be very challenging when working with residents with advanced disease and their families. While emotions may be expressed as fear, joy, anger, frustration or apathy, the role of the health care team is to advocate for residents' best interests. **LTC**