



Facing the End

Text by Dr Yang Sze Yee

Quality of life for patients with advanced illnesses includes emotional, spiritual and social well-being. Patients and their family have informational needs that vary at different stages of their illnesses. There are opportunities for counselling throughout the illness. In cancer cases, psychological/spiritual distress peaks at diagnosis, disease recurrence and the terminal phase of the illness. Most patients/families would like to receive information regarding the illness, prognosis and future symptoms, and any information that will aid decision-making regarding treatment options at each particular stage of illness. The topics, especially prognosis, should be broached in a sensitive manner. Patients' and caregivers' informational needs should be

assessed individually. As the illnesses progress, caregivers need more information especially with regard to the dying process, possibly so that they can be mentally prepared and to feel more confident in providing the required physical and emotional support. Meanwhile, patients may prefer less detailed information about prognosis or other end-of-life issues.

Understanding their needs

Illness trajectories provide a framework for physicians to address patient and family expectations with regard to anticipated progression in advanced disease. The disease trajectories in patients with advanced illnesses differ broadly between three different illness groups. Patients with cancer,

especially those with solid tumours, maintain their function till several months before death when they experience a steep decline. Patients with dementia/frailty experience a gradual deterioration of cognitive and physical disability over several years. In organ failure, most typically represented by late stage heart, respiratory or renal failure, there are episodes of exacerbations that may result in death. If the patient survives the episode, his/her health and functional status may have deteriorated.

Recognising family dynamics and addressing family members' emotions is crucial in assisting the integration of advanced illness into family dynamics. There should be preparation for any discussion, including negotiating who should be present during family meetings.

As perspectives may differ from member to member in the same family, it is important for the physician to use open-ended questions to elicit views from the family and to listen carefully in order to understand the different views. Each individual's informational needs and level of understanding should be clarified in order to tailor the informational content. Checking the individual's understanding of the health condition and goals is an ongoing process as the situation may change during the course of the illness. Patients and their caregivers should be given the option of not hearing the prognosis.

Addressing their needs

Advance Care Planning is an opportunity to engage both the patient and his/her family and should be performed early. It includes discussing preferences, values and contingencies at the end of life. As the illness progresses, changes in the patient's and family's preferences in response to the situation should be acknowledged and plans should be modified. In patients lacking mental capacity, the physician can encourage family members to think about what the patient would want for himself/herself, based on the patient's values and beliefs.

Strong emotions such as anger, sadness and fear in response to a deteriorating health condition are common in patients. Family caregiving can also strain family bonds and affect personal well-being. Counselling skills support patients/families in finding solutions to their problems, and build a trusting relationship between the physician and the patient/family. These include 1) recognising and validating common feelings to let people

know that they are heard; 2) normalising feelings to ensure that patients/families know that their feelings are common and they are not alone; 3) reframing perspectives – helping patients/families see their situation from a different and more helpful perspective; and 4) educating by providing factual information which helps give patients/families some control over their situation. Other communication strategies include summarising what has been said to capture the essential meaning and emotion, making concrete plans when needed and offering follow-up.

Home is the preferred place of care for most palliative patients as there is a degree of autonomy and dignity that is not easily reproduced in an institution. The caregiver plays a central role in providing medical/nursing assessment and services. This can be an overwhelming responsibility for a caregiver with no healthcare training. Specific information such as the following are required: 1) expected natural history of the patient's illness; 2) emergencies that may occur; 3) present and future care needs; 4) options for alternative care arrangements; 5) administration of medications; and 6) indications and process of accessing professional advice 24 hours a day. Training in nursing care is also essential. The success of the home care plan depends on the relationship established between the healthcare team and the patient's caregiving network.

When a loved one is dying, the family would like to know about the dying process so they can be prepared. There is a common pathway regardless of the underlying cause. It is normal

for the patient to be less concerned about his/her surroundings. There is a decreased need for food and drink. The patient will also spend more time sleeping. Physical changes in skin colour, body temperature, consciousness, breathing pattern and respiratory secretions may occur. Families would also like to know the signs indicating death and the procedures required after death, including issuance of the death certification. Once the patient has lost mental capacity, the physician plays a proactive role in providing medical guidance to the family.

A trusted healthcare professional who shows empathy will clarify each individual's informational needs and level of understanding in the discussions, and also encourage questions that are most valued by patients/family members. Referrals are indicated when the physical and psychosocial needs of patients/families exceed the level of current care being provided. The options include the hospital palliative care team, inpatient hospice or the community hospice team, depending on the most appropriate site of care. ♦

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