

# Update

## Medical aspects of end of life care

Patient care at the end of life (EOL) is an important part of comprehensive medical care. Care at the end of life takes place in a different context to care that is directed at prolonging survival by controlling disease or improving patient well-being by treating symptoms such as pain. Care at the EOL is a very personal and intimate time for patients, their family and loved ones and this should be reflected in the environment in which it takes place. For example, personal items such as photographs have a place at the bedside and family and close friends should have access to their loved ones around the clock, without disturbing others. There are also particular biological, psychosocial and spiritual considerations during EOL care.

### Biological considerations

#### Symptoms – pain and weakness

Patients and their families may fear that pain may worsen at the EOL. It does not – there is no increase in pain with dying. However, if pain is present, it needs to be diagnosed and distinguished from terminal delirium, which is a type of neurological agitation that is discussed below. Indicators that pain may be present in an unconscious patient are the presence of sustained facial tension and grimaces. A short-lived grimace, however, is not significant. Another indication that pain may be present is an increase in the heart rate. Sometimes, if one is not certain, an analgesic or pain killer can be given and the effect monitored.

If pain is diagnosed, it is managed in a different way from the usual pain management. Conventionally, analgesics are given at regular time intervals (usually 4 hourly) to control pain when it starts. However, at the EOL, there is low urine output and so it is necessary to reduce the dose of analgesics or stop routine dosing. Analgesics are metabolised, and the products may also have an analgesic effect. It may be useful to use analgesics without active metabolites, such as fentanyl. It is important to give pain killers using the least invasive route. Avoid injection and give medication either orally or by absorption through the lining of the mouth.

Conventionally, when a patient is weak and in bed, he/she is encouraged to be

mobile to avoid medical complications such as deep venous thrombosis, which result from lack of movement. However, weakness is an irreversible situation at the EOL and patients should not be forced to be mobile.

A consequence of being weak is joint position fatigue. This is pain that can occur in the joints because of lack of movement and so passive movement, such as gently moving the limbs, will be helpful. Also, in the presence of weakness take care to look after the skin and check that there are no pressure points. Pressure against a particular area of skin increases the risk of producing ulcers. Pressure bandages, a sheepskin or an air bed could be used to distribute the pressure points and the patient needs to be turned over regularly. In addition, it is often comforting for the patients to have their skin massaged. Oedema can be massaged away and discomfort reduced.

#### Food and fluid intake

There is a decreased intake of food and the family may be concerned that this is a sign that the patient is starving and that the medical team is 'giving in'. It is helpful to understand the underlying biology at EOL. Patients are not hungry and food may, in fact, cause nausea. Food that the patient may not want can also cause abdominal discomfort and bloating, because the food is not digested. Moreover, medical studies have shown that the weight loss that occurs at the EOL is independent of the intake of food. The family can be directed to alternative ways to care for the patient, for example by maintaining physical contact and massaging the skin.

One of the consequences of decreasing intake of food is loss of fat. A characteristic would be a loss of a fat pad which sits behind the eyes – the eyes then tend to fall back in the sockets and there is insufficient eyelid length to cover the eye fully. The eyes therefore may remain open. Exposure of the mucous membranes covering the eye needs attention. There is an increased risk of dryness, and miniaturisation of the eye must be maintained.

There is also a decreased intake of fluids at the EOL and the family may fear dehydration and thirst. Dehydration in itself does not cause distress. However, it is better to avoid the experience of thirst. There are receptors that are sensitive to fluids within the mouth and simply

providing one or two mouthfuls of fluid can often relieve the sense of thirst.

Giving fluids intravenously is not usually helpful, even in the presence of a degree of dehydration. The cardiovascular system cannot handle the additional fluids and so-called 'fluid overload' may develop. Fluids leak into the lung and cause cough and secretions.

However, decreased hydration means that the mucous membranes need to receive careful attention and may need to be moisturised. Biological effects may be a lowering of blood pressure and possibly diminished urine output. The ends of limbs may become cool and bluish in colour.

#### Neurological changes

Death follows after a progressive loss of consciousness and cessation of neurological function. There are two recognised roads to death. Patients following the usual road become progressively more sleepy, lethargic and comatose before dying. A useful way of monitoring the degree of loss of consciousness is the eyelash reflex, which is the reflex blink when the eyelash is stroked. This is a gentle test and does not disturb the patient.

However, patients may, much less commonly, follow the difficult road called terminal delirium. Patients may become restless and confused and may have jerks and even seizures. This is a result of uncoordinated neurone behaviour in the presence of progressive loss of consciousness. Patients with terminal delirium require medical management, usually with tranquillisers, for example benzodiazepines, chlorpromazine or haloperidol. If patients have seizures they need to be treated with anti-epileptics. It is important that the family understands this process and that the associated agitation they see is not a reflection of the degree of discomfort that their loved one is experiencing. It is also, however, important that it is rapidly treated.

There are important principles regarding communication in the presence of a patient with loss of consciousness. Assume that the patient hears everything and include them in conversations. This way the patient is assured of the presence of people around him or her and that they are in a safe environment. It is also time to give the patient permission to be restful and to maintain contact by means of touch.

## Update

There are other features that go along with a decrease in neurological function. There will be changes in respiration, so that the breathing pattern alters. The depth of breathing may grow less and breathing may be intermittent. Oxygen is not helpful in this situation and the mask or tubes with which it is administered result in an unnecessary barrier between the patient and his/her environment.

There is also loss of the ability to swallow and this can result in the build-up of saliva and secretions with gurgling. Medication to dry these secretions should be administered and the patient turned on the side to assist in the drainage. Suctioning deep within the trachea is not helpful.

Another phenomenon that may occur is the loss of control of sphincters. This may result in incontinence of urine and stool, and care must be taken with cleaning and skin care. At times a urinary catheter may be used but this is not always necessary for the decreasing urine output, and absorbent pads can be sufficient.

The signs that death has actually occurred are the absence of the heartbeat and breathing, the pupils become fixed and there may be a change in the body colour and temperature. Other phenomena that may occur follow from the relaxation of muscles and sphincters. The eyes can remain open and these should be closed out of respect. The jaw may open and this, too, can be closed. The loss of the sphincters within the gut may mean that fluids trickle internally and this may be audible to those around the bedside.

### Psychosocial-spiritual considerations

A number of lay and professional people will contribute to the care of the patient. A fuller discussion of this is beyond the scope of this article, but a few points of particular medical relevance are described.

When patients or family request information on EOL care, they can be counselled that death is usually a restful process, that they will be in a safe environment and that they will be respectfully cared for. During EOL care,

it is appropriate to monitor and discuss the state of the patient with the family and loved ones in terms of the events of the dying process.

It is also a time for empathy with the family. This involves telling them that it is appreciated that this is a difficult time for them. Health professionals are aware of the importance of cultural, religious and ritual considerations, as well as the involvement of other caregivers and counsellors.

After death the care will often shift to the family and close friends. They should have access to the bedside and a doctor in the background could monitor and be aware of any acute grief reactions. Other medical caregivers need to be notified. Bereavement care for the family will often take place through the family's personal or community support systems. This requires follow-up and is associated with practical matters such as the redeeming of insurance and arrangements for the will, meeting financial obligations and estate closure.

### The doctor-patient relationship

The doctor-patient relationship will have a significant bearing on EOL care. The conditions of any significant relationship include openness, responsiveness and fidelity. Openness and responsiveness involve a meeting, an appreciation of and a response to each patient's individuality in terms of their perspectives, their values and also the contributions they have to make towards their health care and the doctor-patient relationship. Fidelity touches on the justified expectations that are part of a relationship. Patients will expect that doctors are committed to restoring them to good health, in addition to being skilful. It includes the anticipation that doctors will stand by them in difficult times.

There is greater scope for the expression of and a response to emotions within a relationship. Emotions are part of our integrated response to the world around us. We can recognise and respond sympathetically to patients as angry, sad or indeed happy and give them the opportunity to work through their feelings.

Serious illness is a time when patients may confront and think deeply about illness and death and put themselves into a larger framework of spiritual issues. Spirituality is about moving beyond immediate realities and the purely biological or functional model of health care, where the focus is on the patient's cells, organs and reflexive emotional responses.

Spirituality concerns deeper values and issues such as meaning and purpose – be they from a religious or non-religious viewpoint. It embraces a unitary perspective of life, which includes health and illness. For many people, spirituality is closely linked with their sense of community and this would include the medical personnel with whom they have a relationship. Within a relationship, there are mutual opportunities to develop and grow. Both patient and doctors can learn about the appreciation of life, about equanimity and calmness and about caring for others. Some people are able to show leadership by example. They create new possibilities and enlighten those around them.

### Conclusion

End-of-life care is part of comprehensive care and requires a multidisciplinary approach. The medical aspects require knowledge of the biological considerations of care. It is a great privilege to care for patients with serious illnesses, whatever the outcome.

### Further reading

Abratt RP. A 'good death' revisited in the context of doctor-patient relationships. *J Clin Oncol* 2001; 19: 3999.

Doyle D, Hanks G, Cherny N, Calman K, eds. *Oxford Textbook in Palliative Medicine*. Oxford: Oxford University Press, 2005.

Education in Palliative & End of Life Care (EPEC) Curriculum. <http://www.epec.net>

End of Life Physician Education Resource Center. <http://www.eperc.mcw.edu>

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