

Peter Phillips reflects on appropriate care of frail patients



WITHDRAWING & WITHHOLDING CARE

key points

Withholding or withdrawing care not in a patient's best interests is different from acting to end a life.

Diagnosis of terminal illness needs careful scrutiny and discussion with experienced colleagues since recognising the dying patient may prove difficult for less experienced doctors.

The peace of mind of relatives has to be satisfied.

This is a very emotive topic for healthcare professionals, patients and their families taking place against the backdrop of the debate on assisted dying. However, I hope to demonstrate that withholding or withdrawing care which is no longer in the patient's best interests¹ is quite a different scenario from a deliberate act to end life.

As Christian doctors and healthcare workers, we seek to provide the best possible care for our patients following the principle taught by Jesus Christ of loving our neighbour as our self. This love, and faith in God's ability to heal, is combined with evidence-based medical and surgical treatments.

However, those patients who are terminally ill, frail, disabled or without mental capacity are the most vulnerable and require the most scrupulous care to ensure that we are acting in their best interests rather than the interests of the family or healthcare providers. Any decision on best interests should be inspired by Christ's love for us all and our love for each other.

I start from a position of opposing any deliberate act to end or shorten a patient's life, that is assisted dying or euthanasia, on the basis that this is contrary to the sixth commandment '*Thou shalt not kill*'. In a secular society we have also to argue that assisting another person to die is wrong for a number of reasons:

- None of us is autonomous and the act of assisted dying will adversely affect other people drawn in to the act.
- Assisting mentally competent people to die is one end of a slippery slope which threatens vulnerable, mentally incompetent individuals.
- A cultural shift in favour of euthanasia would leave disabled and vulnerable people feeling that they are a burden and should be expected to volunteer for euthanasia.

Having dismissed euthanasia as an unacceptable practice, the next question is how far we should go along the spectrum of diagnostic and therapeutic interventions in each case. This ranges from 'pulling out all the stops' for a patient with an acute,

Best Interests Principle:

Featured in the Mental Capacity Act (MCA) and promulgated by the GMC to provide guidance on what can be reasonably considered to be in a patient's best interest where the person lacks the capacity to provide informed consent to undergo or refuse to undergo a procedure. Decisions should take account of:

- Options for treatment which are clinically indicated
- Any evidence of previously expressed preferences
- The doctor's own and the healthcare team's knowledge of the patient's background
- Views about the patient's preferences from a relevant third party (eg spouse or family)
- Which option least restricts the patient's future choices where more than one option (including non-treatment) seems reasonable

potentially reversible medical problem on the one hand and, on the other hand, limiting that intervention for another patient with terminal illness because of very low probability of benefit. Whether or not an intervention is offered will depend on the potential benefits for the patient in terms of quality and quantity of life as agreed between the healthcare team and the patient and family.

For example, in the case of a frail elderly patient with multiple comorbidities, undergoing active medical treatment after a stroke, myocardial infarction or pneumonia, it may be considered that, in the event of cardiac arrest, attempted cardio pulmonary resuscitation would be unlikely to produce survival or benefit for the patient. Such a decision should not be made without obtaining the approval of the patient, if mentally capable, and family. In cases such as this there is usually agreement that we should not embark on an intervention which would simply 'prolong the dying process'. Of course, patients agreed to be not for attempted resuscitation are not to be abandoned by their medical and nursing attendants. They continue to be treated actively in the hope of some improvement while every attempt is made to maintain comfort and dignity.

We are left with the scenario of the dying patient, with no prospect of recovery in the opinion of the medical team. This may be due to uncontrolled malignancy, or irreversible failure of multiple organs eg heart, lungs, kidney, brain, liver, bone marrow etc. The diagnosis of terminal illness should always be scrutinised and discussed with experienced practitioners as less experienced doctors may have difficulty recognising the dying patient. If in doubt, a further medical opinion should be obtained. When the diagnosis of terminal illness has been agreed, we should review the appropriateness of certain diagnostic or therapeutic interventions and aim mainly at improving quality of life rather than quantity of life. This scenario should always be discussed with the patient if possible and family members, especially those with Lasting Power of

Attorney.² Provided all are in agreement, a referral for palliative care may be the best way to demonstrate to all concerned that the care plan has changed from active treatment to palliation. If a patient is assessed to be imminently dying, within hours or the next few days, offer of the Liverpool Care Pathway³ or equivalent may be appropriate.

Within the context of end of life care, the question of withholding or withdrawing care usually applies to medication or food and fluids. There is a view that, as long as the doctor offers every possible intervention, including medication, food and fluids, he or she cannot be accused of negligence. However I would suggest that such defensive medicine is not necessarily in the patient's best interests. Instead we should be doing our best to discern what is most likely to keep the dying patient comfortable. Palliating may include relief of pain and other distressing symptoms and offering food and fluids by mouth according to the patient's willingness or ability to accept them. However this may not extend to tube feeding, intravenous or subcutaneous fluids, which are artificial medical interventions, unless it can be demonstrated that these will make the patient more comfortable. Sometimes it is the relatives' peace of mind which has to be satisfied by giving parenteral fluids even though there may be no benefit to the patient. However this would not normally extend to feeding by nasogastric or gastrostomy tube unless there was clear benefit to the patient. The experience of gastrostomy feeding in patients with severe dementia or very severe disability from stroke, for example, has not shown benefits in terms of quality or quantity of life.⁴ There is no evidence that parenteral fluids improve the biochemical status of dying patients.⁵

With this in mind, it is possible to understand scenarios when it may be appropriate to withhold or withdraw *artificially* administered food or fluids towards the end of life. However, oral food and fluids should *always* be offered provided the patient is conscious, willing and able to accept them. More rigorous testing of swallowing ability may sometimes be relaxed in the context of palliative care.

So what may appear to the layman as a callous neglect of the patient's needs may, in fact, be an act of Christian love on realising that artificial medical interventions are no longer of benefit. They may amount to a futile prolongation of the dying process. This should be sensitively explained to colleagues, relatives and carers with time given for reflection and further discussion among the family before the decision to withhold or withdraw medical treatment is made.

I would welcome any comments or reflections from personal experience to further explore this important question which faces many of us in daily practice.

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Lasting Power of Attorney

A means under the MCA where someone, unable to make decisions, can appoint a person or persons to make these on their behalf. There are two types of LPA and a person may invoke one or both:

- health and welfare
- property and financial affairs

In the fields of health and welfare, persons appointed under a Lasting Power of Attorney can make decisions about:

- the daily care routine (eg eating and clothing)
- medical care
- moving into a care home
- refusing life-sustaining treatment

What may appear to the layman as a callous neglect of the patient's needs may, in fact, be an act of Christian love

references

1. GMC. <http://bit.ly/VHsv0k>
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4. Sanders DS *et al*. Survival analysis in percutaneous endoscopic gastrostomy feeding: a worse outcome in patients with dementia. *American Journal of Gastroenterology* 2000; 95: 1472-1475
5. Stewart TL. Intravenous fluids in end of life care. *Journal of Palliative Medicine* 2006; 9(5): 1230-1231