

End of life problems: Group workshop (tables 9 & 10)

Instructions

Outcome - **Tables 9 & 10 consider what happens when with end of life issues in the elderly. What do you do?**

Table 9 – **Margaret with no relatives** (discuss for 15 minutes)

Table 10 – **Consider the Question – Why aren't we allowed to die naturally anymore?**(discuss for 15 minutes)

The two groups then combine and collaborate to compare notes in order to do a (not longer than) 5-minute presentation at the end on how doctors and patients deal with end of life issues in the elderly and what it means to you.

This isn't about right or wrong answers in terms of management, much more about the patient's family's and your attitudes and feelings.

The presentation can involve all or just a few of you – can just be a summary of your discussion or innovative and entertaining. The Aim is to educate the rest of the audience quickly

(If you have time to spare and you will have a total of an hour in total – go back into groups and discuss the other cases).

The material is on subsequent pages but don't feel you have to include this, think globally, think about your own families, young and old. Think about your own experiences and stories too.

Table 9. material

Margaret is a 92-year-old widow with no children and no surviving relatives. She was a music teacher and a very accomplished pianist. She lives alone, but is becoming increasingly frail and experiencing progressive short-term memory loss. She manages to remain in her home only through the intensive support of a number of good friends. She has made a will, has a prepaid funeral plan and appointed a friend some years ago with enduring power of attorney (EPA).

Her GP has asked her if she would like to make an advance statement of wishes, but she has declined, preferring not to talk about it and saying: 'I am sure you will do the best for me when the time comes.'

If her dementia becomes advanced and decisions have to be made about her treatment or place of residence what will you do to manage her condition?

How will you manage decisions regarding resuscitation if she deteriorates at home?

How would your decision differ should she be in a nursing or residential home?

(Note: it may be necessary to appoint an independent mental capacity advocate, because her EPA does not have authority to make such decisions. If Margaret needs to move to residential care, this would be a good opportunity to try to establish a formal plan for her care, while she still has the capacity to do so.)

Table 10. material

Consider the Question – Why aren't we allowed to die naturally anymore?

You might find the material below of interest.

Memento Mori: Iona Heath – Past president of RCGP 2012

How is it that at the beginning of the 21st century, we have forgotten how to die and have even forgotten that death is itself a gift? The art and literature of previous generations was steeped in the tradition of *memento mori* designed to make humanity explicitly aware of the brevity of life and of the urgent need to use the short time to its limits. Today, we who live in the richer countries of the world have the unprecedented good fortune of a gratifyingly extended expectation of life but, apparently still dissatisfied with this, we seem to want to push it further and pretend that life can be indefinitely extended. Public rhetoric now attaches more value to the length of life than to its intensity—and the whole of health and social policy seems to be predicated on the belief that everyone wants to live forever. There is no allowance in this view for those whose lives are full of doubt and desperation and a recurring uncertainty as to whether life is worth living at all; no room whatsoever for an understanding of suicide. And yet, as Primo Levi reminded his readers, the gift of death is that while it places finite limits on the possibility of infinite happiness, at the same time and in precisely the same way, it curtails the possibility of infinite suffering and infinite despair.

Today, of course, we remain aware of death but in an unacknowledged, almost furtive way, and as an undercurrent of fear. It has become an imperative of social responsibility to minimize exposure to risk and the enthusiasm with which we do this insidiously undermines our enjoyment of the excitement and thrill of living. A whole generation of children has been deprived of the delights of playing outside without adult supervision because of a distorted perception of risk. This cossetting of children in the richer countries contrasts all too starkly with the experience of children who have the simple misfortune to be born on the losing side of the equation.

The denial of death within contemporary Western society means that everyone is obliged to stay alive and to struggle for life to the limits of endurance. Patients and relatives ask for more and more treatment and this general expectation makes it very difficult for an individual to choose the different path of letting nature take its course during a final illness. For reasons that are not entirely clear to me, religion too often allies itself with medical science to deny nature. In Italy, this found extreme expression in the case of Eluana Englaro. This 38 year old spent almost half her life in a persistent vegetative state, kept alive by medical technology after a tragic accident in 1992. Her father struggled through every layer of the Italian courts seeking permission to have artificial feeding stopped so that she could be allowed to die. Eventually, in 2008, permission was granted but within

weeks and at the last moment, the Vatican questioned the morality of the decision and caused a further delay. Finally, on 9 February 2009, Eluana died, 4 days after her feeding tubes had been removed, and yet the political, judicial and religious wrangling has continued.

In a similar way, but with people who are mostly of a very different age, it has become standard to use feeding tubes when those who have suffered severe strokes or dementia are no longer able to swallow. All this achieves is to close off one of the routes that nature has provided to allow the body to die. Someone suffering from advanced dementia could be said to be meant to develop swallowing problems which lead to pneumonia and so to the escape of death. Nature provides its own exit strategies. So why are we so unwilling to allow nature to take its course; why do we expect doctors to push the boundaries so far in this direction?

Life can be wonderful and the giving and receiving of love, one of its greatest joys; the losing of life or love is terrible and justly feared. Yet, the finitude and the fragility of both life and love are essential constituents of the wonder and the joy.

There seems an urgent need to rediscover traditions of resignation, stoicism and courage in the face of death on the part of both the dying and those who love and care for them. We need better ways of coping with the pain that comes with the loss of life and love. We have allowed long traditions of ritual to wither away but, at the same time, we have lost the framework of behaviour that ritual provided and the comfort and security that this can bring. People feel adrift and uncertain and have little idea what is expected of them. Fewer and fewer people have witnessed others dying. Priests have lost their role and doctors who were the other traditional familiars of death are too busy trying to keep the dying alive.

Yet, in the care of all patients, science takes a doctor a long way but not far enough—and when a doctor looks after a patient who is dying, science becomes even more inadequate. Death occurs at the limits of medicine and doctors have consistent trouble in acknowledging or even recognizing these limits. As a direct result, quite unintentionally but much too often, medicine is used, within contemporary society, to torture the dying. Scott Murray *et al.* interviewed dying patients in both Kenya and Scotland. The Kenyan patients described wanting to die because the pain and the other symptoms of their disease were so awful; patients in Scotland described wanting to die because the side effects of their medical treatment were unbearable. In the United States, a

study of the care of patients with either disseminated cancer or advanced dementia, dying in an acute hospital, showed that, for nearly a quarter of both groups, cardiopulmonary resuscitation was attempted and more than half of those with advanced dementia died with a feeding tube in place. Where does this sort of care leave dignity and the possibility of peace? It seems to me to amount to a terrible indictment of the role of medicine in the care of the dying.

In my more than 30 years as a family doctor, I have tried to make sense of this situation by seeking both solace and inspiration in literature. The task of finding meaning in the finite limits of life and in its inevitable losses is common to all humanity and neither the specialist knowledge of doctors nor even their familiarity with death gives them any particular aptitude for this most fundamental of existential tasks. And all of this is perhaps even more difficult for younger doctors who mostly have fewer reasons or opportunities to contemplate their own mortality. Further, with the power of modern medicine, it is all too easy for doctors of all ages to sidestep these issues by giving more treatments and more drugs while avoiding the gaze of the dying person. The effect is to treat the dying person almost as an object in need of a technical fix and this consigns the dying to death rather than to life and treats the dying person as if they were already dead. It is infinitely more difficult for the doctor to remain fully present for the dying person and so to acknowledge the importance of the relationship between two mortal human subjects facing the same existential challenges, albeit across a different timescale.

Writers and perhaps particularly poets face these issues both more obliquely and more directly. The key is that they use words with care, thought and deliberation to approach a truth which is recognized by others with an immediacy that makes them feel less alone because aspects of their experience of life and the world have been acknowledged and described. The greatest poets reveal truths that we, as readers, already know but with a new clarity and a new depth that enriches and extends our experience. As the Nobel Laureate Seamus Heaney wrote 'The world is different after it has been read by a Shakespeare or an Emily Dickinson or a Samuel Beckett because it has been augmented by their reading of it.'

Dr Iona Heath
General practitioner, London
E-mail: iona.heath@dsl.pipex.com

If we are to have any hope of forging a more humane contract between science and nature in the care of the dying, we will need all the help we can get from all the different dimensions of human wisdom that are explored within literature and the other humanist disciplines—and perhaps particularly within poetry.

REFERENCES AND FURTHER INFORMATION

- Ahronheim, J.C., Morrison, R.S., Baskin, S.A., Morris, J., Meier, D.E. Treatment of the dying in the acute care hospital. Advanced dementia and metastatic cancer. *Archives of Internal Medicine* (1996) 156: p. 2094–100
- Ariès, P. *The hour of our death* (1977) Harmondsworth: Peregrine Books: 1983, p. 330
- Barnard, D. Love and death: existential dimensions of physicians' difficulties with moral problems. *Journal of Medicine and Philosophy* (1988) 13: p. 393–409
- Crimp, M. Advice to Iraqi women. *The Guardian* April 10 (2003) Accessed via www.guardian.co.uk/stage/2003/apr/10/theatre.artsfeatures1 [date last accessed 04.03.2009]
- Heaney, S. *The redress of poetry* (1995) London: Faber and Faber Limited, p. 159
- Levi, P. *If this is a man* (1958) London: Sphere Books, 1987, p. 23
- Murray, S.A., Grant, E., Grant, A., Kendall, M. Dying from cancer in developed and developing countries: lessons from two qualitative interview studies of patients and their carers. *British Medical Journal* (2003) 326: p. 368–71
- Top Italian court clears way for death of Eluana Englaro *Times Online* November 13 (2008) Accessed via www.timesonline.co.uk/tol/news/world/europe/article5150260.ece [date last accessed 04.03.2009]
- Walter, T. Historical and cultural variants on the good death. *British Medical Journal* (2003) 327: p. 218–20

AND (“Allow natural death”)—could it make a difference?

PERSONAL VIEW Rachel McCoubrie

Throughout our medical careers most of us will be involved in DNAR (“Do not attempt resuscitation”) discussions with patients and their families. Last year I found myself, for the first time, on the other side of the discussion. My father had longstanding polycythaemia, which transformed into myelofibrosis. In the last month of his life he was admitted to hospital with epistaxis then again, a week later, with deep vein thrombosis and pulmonary embolus. His physician, faced with the dilemma of how to manage a patient with low platelets, proved thromboses, and daily nose bleeds, decided, in discussion with my father and us, on treatment with low dose, low molecular weight heparin.

Two weeks later he was admitted with a massive retroperitoneal bleed. He was not fit for surgery, and admission to a high dependency unit was judged to be inappropriate. He was managed with blood and platelet transfusions, fresh frozen plasma, and Gelofusine to try to normalise his blood pressure. However, he remained hypotensive and became anuric, and his oxygen saturations dropped as he became progressively more fluid overloaded.

It was at that point that the registrar discussed DNAR with my mother, my non-medical sister, and me. She started well, explaining past events and the current

We would not offer a surgical procedure or drug treatment to a patient if we did not expect it to work. The same applies to CPR

problem of not being able to maintain his blood pressure, then asked my mother what she wanted them to do about resuscitation. My mother was clear: she would want him to be resuscitated. She was told that it would be a medical decision, so she asked why she had been consulted in the first place if she had no choice. My sister felt that he should be given “every chance”



and asked what difference DNAR would make. I explained that the difference would be that we would be able to sit with him and hold his hand as he was dying, rather than having to leave the room while the team carried out chest compressions to try to restart his heart and breathing. Eventually we all agreed that he should not be resuscitated.

The wording of the statement “Do not resuscitate” is in itself negative. To patients and their relatives it can sound as though we are denying patients something that rightfully should be theirs. Doctors, whether junior or senior, sometimes struggle with DNAR decisions. The 2007 revised guidelines from the BMA, the Royal College of Nursing, and the UK Resuscitation Council helped to clarify some of the problem areas, but many doctors still lack confidence in handling DNAR discussions, remain uncertain as to exactly who should make the decision, and are uncomfortable signing a DNAR form.

Many think that the patient has the ultimate choice. This may indeed be the case if there is a chance of cardiopulmonary resuscitation (CPR) working. However, the guidelines are clear that if the medical team judges that CPR would not be successful then it should not be considered, and DNAR can be documented without explicit discussion with the patient. This is because a futile treatment should not be offered. We would not offer a surgical procedure or drug treatment to a patient if we did not expect

it to work. The same applies to CPR. Moreover, in weighing up the potential benefits and harms, it might be thought that attempting CPR in the final stages of an incurable illness is subjecting patients to an undignified death.

Some still believe that relatives have a choice. They do not, and they should never be put in the difficult situation of being asked to decide on resuscitation of their loved one. That is not to say that we should not be talking to the family; but our aim should be to discover what the incompetent patient’s wishes would have been, not what the family wishes us to do.

If the medical team believes that a patient is dying, it is crucial that the patient and their family are aware of this, so that the patient can have a chance to put their affairs in order and that their wishes concerning place of care and place of death can be ascertained. DNAR will be implicit in discussions about changing the focus of care from active treatment to comfort care and palliation of symptoms. Equally, when planning a patient’s discharge home or to a hospice or nursing home to die, the medical team does not need to raise DNAR as a separate issue.

If we do not attempt CPR when a patient’s heart and breathing have stopped, we are simply allowing the patient to die naturally without medical interference. CPR was never intended for patients dying at the end stage of an incurable illness. If broaching the topic of DNAR is difficult for doctors, and upsetting for patients and their families, is it time for a major change? Why not change the way we handle this important and difficult issue by, as the ethicist Daniel Sokol argued in a recent *BMJ* column (*BMJ* 2009;338:b1723), simply changing the terminology to the more positive, and perhaps more comforting, “Allow a natural death”?

Rachel McCoubrie is consultant in palliative medicine, Bristol Haematology and Oncology Centre
Rachel.mccoubrie@uhbristol.nhs.uk

Cite this as: *BMJ* 2009;339:b2762