Hopes and fears in palliative care: talking about dying is everyone's responsibility

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One could be forgiven for assuming that improving palliative care is solely the job of the NHS, hospices and appropriately trained health and care professionals. It is of course true that we – as a society – have entrusted certain professionals and organisations with the responsibility for thinking creatively about how their expertise can best serve those experiencing the common conclusion to each person's pilgrimage through the suffering human condition.

However, there are downsides to the assumption that improving palliative care is the responsibility solely of 'the professionals'. These relate predominantly to the responsibility we all have as individuals in families and communities, to reflect on and talk about our own dying and to support others as they do the same.[1]

That there is an inchoate sense of shared, non-professional or 'civic' responsibility for how we die is attested by the remarkable levels of voluntary commitment that many communities show to the hospices that serve their area. The fundraising energy which has typically surrounded the care of the dying is, of course, not a constant. More would always be welcome. However, unlike other health charities which focus on conditions which affect specific sub-populations, palliative care organisations do reach the heart of most people, at the level of our affections or emotions. Why?

Fear and hope

Well, in part at least, it's to do with fear and hope. What I'll suggest here is that examining our own fears and hopes about dying and death – culturally and in families as well as individually – would go a good way to improving palliative care.

What do we fear about dying? Many things. Some fear loneliness and disregard; the lurking suspicion that this final, momentous event in our lives – my death – will be treated as unimportant, as a mere statistic; or even embarrassing, as a kind of failure – a fight lost, a treatment ineffective. Others fear the loss of the dream of healthy aging, a descent from a healthy 'Third Age' into a 'Fourth Age' of decrepitude, multiple co-morbidities and rapidly approaching death. We all probably recoil from leaving those we love, especially those who depend on us.

As one writer suggests, we tend to manage the fear – even terror – of death 'by constructing a cultural worldview, in which everything that reminds us of deep old age at the threshold of death is kept far away.'[2] For this reason, the 'Fourth Age is an embarrassing … shadowland of diminishment and the portal to death, the result of our inability to eliminate the impairments at the end of life and to push the vital and healthy Third Age until the very moment of death.'[3]

If our fears are like this, for what do we hope? As we die, we hope both for the kindness of those we love and the kindness of strangers, typically health professionals. We hope for the presence of others in our dying, people who will wait with us, hold our hands, listen to us if we can still speak and maybe have something helpful to say to us if we can still hear. And when the hour of our death has been and gone, we hope that those that remain will remember us lovingly – even mercifully – after we have departed.

In these and many other ways, fear and hope can shape the experience of all involved in palliative care, whether patients, friends, families or professionals. Voluntary financial support alone for hospices is vital but is not enough. All of us need to improve our talking about dying and death with one another, and especially with those we love. We need to do this so that fear can be alleviated, where possible, through the renewal of well-grounded hope. Such talk is a deep and practical form of the compassion which can sustain us when hard-pressed, whether as individuals, families, institutions or at a societal level.[4]

Through such compassionate conversations people find that facing up to death is a universal problem and that others have both the same and different fears. We can acknowledge that no one knows for certain what, if anything, lies ahead. But there is a power in sharing which helps get our thoughts in order.

Everyone has responsibilities

In talking like this, we take up a key aspect of individual, familial and civic responsibility. Why? Talking about death and dying has the potential to be a profoundly hopeful activity. Hope is vital to families, healthcare institutions and societies amidst the phenomena of dying. Hope gives purpose for it entails that the experience someone is

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going through can be different and better. Hope can take various forms. There is the hope that I will be able to fight through my sickness and recover. There is the hope that I will be reconciled before I die with those with whom I am at odds. There is the hope of a 'good' death when the time comes. For many, both in the UK and around the world, there is the hope of continuing life after death, whether through bodily resurrection or in some other way.

We need to improve our talking about each of these kinds of hope if palliative care is to be improved and if we are to fulfil our responsibilities to each other. Each of the forms of hope is complexly related to fear. Giving up on life or not living to see key life events (such as the birth of grandchildren) is understandably sorrowful and fearful for some and so the hope of recovery is a powerful driver. Fear of not being at peace with people can darken the experience of dying.

Then there is fear that death, when it comes, will be nasty, painful or lonely. Finally, there may be fear of the nothing which the event of death brings about – of the whole complex span of my life, with all its yearnings and colour, reduced to a dusty zero; and even of not continuing for long in the memories of the living.

Practices which make for peace

What does reckoning with hope and fear mean in practice? There are many things that health professionals can do to reduce fear and encourage hope. Appropriately detailed information on how pain will be alleviated in the final stages of life is one obvious example. But, for our part, when our pilgrimages reach a time of needing palliative care, we will bring with us our fears and hopes which will in some way affect how well that care proceeds. That's why we all have a responsibility to talk about dying earlier, more wisely and with more grounded kinds of hope.

We might do this in families, with friends or, for some, in churches, mosques, temples or other religious communities. This might involve learning to resist familial, cultural, religious and medical pressures to emphasise prolongation of life as the single most important unit of success. This desire to extend is often influenced more by fear than by anything else: fear of having to accept the inevitable; fear of separation; fear of nothingness. Practically speaking, such fear, so focussed on life prolongation, might paralyse people into inaction about making preparations for death.

By contrast, hope can bring a peace that surpasses the understanding of those who do not share in it, even those close to the dying person. And yet that peace which those approaching death feel can come to be shared by their loved ones even in those final hours. In a 2017 public event hosted here in Oxford entitled 'Talking about Dying', it was just that sense of peace and hope which marked the advice of one dying person to the rest of the audience. She spoke movingly of how she was now making everything ready for the day she died, down to the tender details of letters addressed to her young children, giving her a sense of purpose.

How hope and fear affect care is something for which we are all responsible in one way or another. Whereas fear can be a block to talking about practical preparations being made for death, a hope which brings peace can enable a range of preparations which will help all concerned. Advance directives, decisions about life prolongation, powers of attorney, family reconciliation, funeral arrangements or anything else: all these can improve the quality of palliative care so that all involved find a measure of peace with the timing and manner of the person's death.[5]

Conclusion

So, what one thing can be done to improve palliative care?

The perspective offered here is that we all need to take responsibility to explore unresolved issues and, as we explore them, alleviate at least some of our fears and find peace through whatever hope we have. Then, if and when we need palliative care, we will be ready to receive such care and to make a good death, whenever it comes, in the company of friends and at peace, perhaps with a God whose love banishes fear, and certainly with those we love, and whose love can then accompany us, holding our hands, to the end of our pilgrimage. ■

References and endnotes

1 See the excellent *Ambitions for palliative and end-of-life care*, National Palliative and End of Life Care Partnership, 2015; especially Ambition 6: 'each community is prepared to help'. Accessible at www.endoflifecareambitions.org.uk.

2 Frits de Lange, *Loving Later Life: An Ethics of Aging*. Eerdmans: Cambridge. 2015. p77.

3 Frits de Lange, *Loving Later Life: An Ethics of Aging*. Eerdmans: Cambridge. 2015. p5.

4 For recent work on compassion, see the following Open Access publications: Joshua Hordern, 'Compassion in Primary and Community Care' in Papanikitas, A and Spicer, J (eds), *Handbook of Primary Care Ethics*, Taylor and Francis (October 2017), 25–33 [Open Access at http://bit.ly/2oCBtXx]. Joshua Hordern, 'Religion and Culture', Medicine, October 2016 44:10:589–592 [Open Access at http://bit.ly/2AQFlWv].

5 For a readable volume which very movingly explores dying in many different circumstances and with wise practical advice see Philip Giddings, Martin Down, Elaine Sugden and Gareth Tuckwell: *Talking about Dying: Help in Facing Dying and Death*. Wilberforce Publications: London. 2017. More details at www.healthcarevalues.ox.ac.uk/talking-about-dying

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