

Sub# 8

It Is Not Easy To Die! July 2012

It is not something one wants to do alone after spending years of socialising with others.

So why is so little mention made in the public media about the process – of how to handle it well for oneself and family and friends?

Is it because we live in a Capitalist society – so business and Government is well aware that one is no longer consuming – one is not going to be a customer in the near future?

What is futile or inappropriate care?

Is it based on expense for someone about to leave the consumer society?

Is it about prolonging life or about prolonging death?

From the moment we receive a terminal prognosis do we live a posthumous life (as Keats described)? Just waiting for the physical death.

There can be no path that suits everyone. However one's approach to death should be humane, with quality of life, dignity and fulfilment.

Some die quickly as in an accident – but others may be given months, even years to live. These are months of life – not death. Opportunities to say goodbye to friends and family; to sort out old problems and perhaps to enjoy again places one has loved.

Treatments that will enhance this are not futile. Treatments that leave one weakened and without quality of life are certainly futile however not treating medical problems that can still be eased so that one can live life to the full would be unethical and cruel.

Maybe it is cost effective not to treat medical problems for the terminally ill? Why not just leave us to die as quickly as possible – pat our hands and tell us that the pain is something to be expected. Much unspecialised hospice care is of this sort, and they are probably doing all they know how to do. However is this what we want to happen at the end of our lives?

In my own case I had an unexpected Stage 4 prognosis of cancer last December. I was given an outside chance of lasting 3-18 months but the doctors warned that I would probably not make it alive to my daughter's wedding in the coming May.

I had indicated that I was not interested in experimental Chemo trials ( even though there are oncologists who always suggest they can extend your life but without thinking of what the quality of that life may be). I worked with Palliative Care and Palliative Oncology from then on.

I had chest infections I could not clear because of the tumour in the way. Antibiotics made a huge difference to my quality of life. Only because my partner wanted me to try some palliative chemo to see if it could make my tumour less aggressive I agreed. After several days of side effects which I hated I discovered I had 5 weeks of reduced symptoms – less pain and coughing.

So we work on the plan that while an occasional treatment can still stop my tumour (which I call Fujin and my partner calls Gollum) giving me pain and coughing at the rate it did previously, it is



worth a few days of side effects. There is no set time scale to the treatment – while I feel good I stay away. When my coughing and pain increases again I go for another treatment – we work together to try to ensure we do not have any chemical in it that will knock the rest of my body too badly. A 5 mg steroid in the morning gives me a bit more energy without noticeable side effects.

I found I could start doing pottery, art, walking, gardening again. I can no longer do aerobics, go up steep hills, lift heavy objects and stay up late – but that leaves a lot that I can do. I have met up with valued friends, participated in valued events.

I do have difficulties in that I am in a 'no man's land'. Society does not really want to know about the terminally ill.

I was warned that I would lose some friends who would find the idea of death too uncomfortable to be around. This did not stop me from being quite open about where I was up to – and sorting out my affairs. I did lose one or two acquaintances but I found far more of them to be relieved that I did not mind talking about death. Some had questions.

I realise how fortunate I am that I live in a main population centre where I can access specialist palliative care. In most parts of Queensland this would not be possible. I would assume from how ill I was at the time of my prognosis that I would have been dead by May. So far my treatment is not futile or inappropriate. When I cannot hold back the tumour's effects then the chemo should stop. I can see that day is not far off perhaps as the relief is no longer as complete. When I reach the stage of not being able to look after myself I would like to be pain free and not a nuisance.

I do not want to be at home as it would force someone else to be there looking after me and we have no one at home usually except me. I hope the time I may spend in final terminal care (probably in a palliative care ward in hospital) is not long – I have already asked about what happens if I do not eat or drink at that stage – and it does not sound too bad. Who knows what I will think when I am actually there though? I am not afraid of death – well after death particularly – I am worried about the actual process – that it not be too painful. But with appropriate specialist palliative care I know that I should neither be in pain nor knocked out with pain killers more than I need to be until the time comes. Perhaps I will find that looking out of the window at clouds is rewarding, perhaps I will be able to make up poetry into a bedside recorder?

The main thing is that at all stages we deserve the autonomy we have enjoyed during our lives to make treatment decisions on life and death. We have been part of life's community and remain so even as we die. Life can still be enjoyed after we have received a terminal prognosis. Dying should not be an embarrassment; it could be an accepted part of our life journey which could help others with knowledge of their own final path.... without fear.

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