When is a Life Complete?

It is a truism that all human life must eventually end. Yet thinking about how we approach the closing phase of our life is a subject that has traditionally not been discussed, though thankfully this is now changing. Many people still prefer to avoid all thought and discussion of the issues, or feel they want to make little contribution to the decision process and "let nature take its course". Other people, perhaps having witnessed the final years of relatives and close friends, find themselves contemplating their own demise, thinking that they do not wish to go through what they have seen their loved ones suffer. The intervention of modern medicine means that very few of us actually leave things to "nature". Modern medicine seems focussed on increasing **quantity** of life, without fully taking into account the individual's wishes regarding the **quality** of any extended life they may be given. This, to some extent, creates the necessity for public debate of these issues.

Our genetics, upbringing, and many other factors contribute to the life we have led. Some look back with satisfaction at a long, fulfilling and happy life, while others have been less fortunate. Regardless of this, there comes a point in the lives of some people when they feel that life no longer has the pleasure or value that it once did, especially for reasons stemming from incurable, deteriorating medical conditions. The future is not something they can face optimistically, based on their realistic assessment of their worsening symptoms. They reach a point where they feel that they would prefer to go to sleep one night and never wake up. The feeling can be persistent, and not the result of a treatable depression. In MDMD we refer to this state as feeling that one has a "**completed life**".

This document does not provide a prescriptive "tick list" set of criteria for a completed life, but instead identifies some factors that people may find helpful to consider in making their own personal decisions, in their own circumstances. Everyone's situation is different. In MDMD we respect the diverse range of opinions that people hold, both within MDMD and outside. The document draws on the experience and opinions of many MDMD members, in the hope that sharing their collective ideas will facilitate a more open discussion in the wider society. The following working definition for **a completed life** is useful and generally agreed on within MDMD:

"Elderly, mentally competent individuals may consider that their lives are complete when they have a chronic health problem (or a combination of more than one condition) which is causing them increasingly unbearable, irreversible suffering, with the additional loss of independence, purpose and meaning in their lives, so that they would now prefer to die rather than stay alive, especially as they dread what the future will soon bring."

It is instructive to consider this definition more closely:

Elderly: How old is "old"? The term "old old" has been used to refer to those over 85. Actually one's health and mental ability are likely to have much more practical significance than any specified number of years. A 70 year old suffering from a severe, debilitating, incurable disease is, in a very important sense, "older" than a 90 year old who takes a daily walk, enjoys reading a newspaper, talking to her neighbours, and is able to largely take care of herself. Some people in their 90's refuse to feel "old"! However, at some point every human life has to end. Some older people will come to terms with approaching that point, giving rise to a feeling that their life is complete. We contrast this with younger people who, due to an incurable medical complaint, no longer wish to continue living, despite their aspirations being unfulfilled and being unable to complete their life as they might wish. It is more useful to think of these younger lives as being "cut short prematurely", against their will, rather than "complete".

Mentally Competent: A decision that one's life is complete, which can be accepted by others, requires the individual to be able to comprehend the nature of their medical conditions, and the likely progress of those conditions over time. Inevitably some people will find the gradual loss of mental and physical ability that comes with ageing to be depressing. It is important to distinguish

this understandable sense of personal and permanent diminution, from other forms of depression which may be treatable. For a medical professional to consider assisting a patient to end their life, the professional must be convinced that the patient has fully understood and carefully considered: the facts of their condition; the likely future progress; and all alternative options, including palliative care. Their decision needs to be settled over time. This requires a level of mental competence.

Chronic health problem(s): These may be physical or mental, such as when a deterioration of memory and mental capability makes life intolerable, or will do soon. For a completed life it is the individual's health problems that are the root cause of their diminishing quality of life.

Increasingly unbearable, irreversible suffering: Ultimately this is for individuals themselves to decide. Suffering can be physical, mental or emotional. While much physical suffering can be alleviated by appropriate painkillers and palliative care, mental and emotional suffering may not be so readily eased. It depends on the individual's personality and experience, and they alone can judge. How much suffering someone can tolerate is never really known until the situation presents itself. Experience of the Death with Dignity Law in Oregon suggests that some people, when they know they have a dignified exit strategy available if/when they need it, choose to tolerate a lower quality of life for longer. In other jurisdictions like in the UK, without such an option, some people choose to take pre-emptive action earlier, while they still can, to avoid future unbearable suffering.

Loss of independence: The degree to which an individual is prepared to accept help is highly variable. Some people do not want to be “looked after” by others on anything other than a temporary basis while they recover from a treatable illness. Linked with this may be a strong reluctance to give up control, for example over decisions concerning their future care. They may dread being treated in a way that suits “the system” rather than the individual.

Loss of purpose and meaning: What gives an individual purpose in their life is, of course, highly personal. It changes through life as the individual experiences different roles in work, parenthood, grandparenting and retirement. Elderly people may find purpose and meaning in seeing younger relatives, playing games, conversations with friends or simply watching birds in a garden. When chronic health problems mean that the things that previously filled their time are no longer possible, and new pleasures in life cannot be found, an individual may understandably be left feeling that there is nothing left that they want, or are able, to do.

Dread what the future will soon bring: The actual dying process – deteriorating gradually until the body gives up – can be a very unpleasant, drawn out, and undignified process. Many people do not want to have to suffer this, nor wish their relatives and close friends to remember them this way. Witnessing loved ones dying unpleasantly may have informed their 'end of life' wishes.

There are several other factors which can contribute to a feeling of having a completed life, in addition to those covered by the definition above.

Bodily decline: Even if these have not been diagnosed as chronic health problems, things like poorer mobility, stiffer joints, poorer vision and hearing loss can all contribute to an enforced withdrawal from normal life, and thus an impairment of quality of life.

Loss of identity: When an individual becomes less able to remember events and people from their life there is a sense in which they cease to be the person they were. Self-awareness that this is happening can give a sense of one's personality irretrievably decaying.

Loss of personal dignity and self-esteem: This can come as a symptom of many chronic health problems. Incontinence is a clear example which can severely impact an individual's perceived quality of life.

Declining social network: When an individual's partner and close friends have died or are no longer able to communicate effectively, the elderly person can be left feeling isolated. When an

individual no longer feels connected to others they may well feel that their life is complete. Some may continue to find positive ways to relate to others – even if it is just smiling at someone to help brighten their day – but for others such opportunities may be insufficient.

Feeling a burden: Some people, knowing they are approaching the end of life, do not want to feel a burden – on their relatives, on the NHS, or on social services. We should respect and accept this as an understandable part of their caring, considerate, personality, but equally accept that others have no such qualms about dependency. The feeling of being a drain on others may be in terms of time, money, resources, emotion, or some combination of these. It may simply be that they would prefer their life savings to be spent on their beneficiaries (including charities), rather than their continued daily care in a life they would prefer not to be living.

It is important to distinguish between genuine altruism, and elderly people being made to feel they have a duty to die, against their will, by uncaring relatives, carers, doctors, or society. One way to tell the difference between these two is if someone has repeatedly recorded their desire not to continue living when their quality of life has irreversibly diminished below the level when they become heavily dependent on others. This statement could be made as part of an extended advance decision. If this record is initiated and witnessed at a time when the person was clearly mentally competent and not acting under pressure of others, there would be no doubt about the person's independent wishes for their end of life care.

For some people, who have decided that for them, their life is complete, the next logical step is a medically assisted suicide. This is already legally possible in Belgium, The Netherlands and Switzerland. Not everyone shares this view and we respect everyone's personal opinion. Within MDMD we aim, eventually, for a law change which will provide medically assisted suicide as an option for those who feel their life is complete, within careful safeguards, and with professional counselling for the person considering this option. Although we believe that a completed life should be a **sufficient** condition for some people to be granted a medically assisted suicide, if that is their persistent wish, we do not believe it is a **necessary** condition. We recognise that some people seeking assisted suicide do not feel their life is complete, but instead that it is cut short by an incurable illness or condition that has permanently reduced their quality of life to a level which for them is unacceptable.

People concluding that their lives are complete is a growing issue. The European Court of Human Rights recognised this in their statement on April 29, 2002 as part of their judgement in the case of Diane Pretty, from the UK, who was slowly dying due to MND "In an era of growing medical sophistication, combined with longer life expectancies, many people are concerned that they should not be forced to linger on in old age or in states of advanced physical or mental decrepitude which conflict with strongly held ideas of self and personal identity". Advances in medical science have cured many early killers such as heart disease and some cancers. This leaves a much larger proportion of people than in previous generations who die with degenerative diseases like dementia, or who simply get gradually weaker and weaker as a result of the ageing process until they succumb to an infection which kills them. In the course of their gradual deterioration, some people may quite rationally conclude that their lives are complete long before they actually die.

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www.mydeath-mydecision.org.uk

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