

Before his death from Alzheimer's on the 12 March 2015, author Terry Pratchett described Dementia in the following way, comparing it to cancer after a discussion he'd had with his father, who was terminal at the time:

"Dementia in its varied forms is not like cancer. Dad saw the cancer in his pancreas as an invader. But Alzheimer's is me, unwinding, losing trust in myself, a butt of my own jokes and on bad days capable of playing hunt the slipper by myself and losing. You can't battle it; you can't be a plucky 'survivor'. It steals you from yourself."

What Terry had described so clearly is the loss of capacity and competence which is the trademark of the cognitive deterioration in Alzheimer's. A person's loss of capacity in Dementia is very often a process of decline into inability where there are lucid periods of knowing that you're no longer able to negotiate your own life. One of the

greatest losses is the inability to take responsibility for yourself, your decisions, and maintain control over your life and choices. The person is often aware they're losing the ability to control their own world, which is both frustrating and terrifying. This loss of power, and the need for other people to both assist—and eventually take over—is where the ethical and legal complications arise.

The first hurdle is that the patient's own autonomy around making decisions is lost over time.

Legal and Ethical Responsibilities in Dementia

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The foundation of consent is autonomy, with people being able to make their own decisions. These are not only in line with a person's needs, wants and beliefs, but also have personal value for them. Medical Practitioner's ethical care of patients hinges on a person being able to make decisions with regard to their own treatment and make informed choices. As this treatment moves towards end of life decisions, this increasingly involves making choices which give meaning to the persons ending of their life's journey. From an ethical standpoint, the person must be assisted to maintain their independence for as long as, and in the most meaningful way possible.

A loss of cognitive ability doesn't happen overnight, and neither does it happen across all domains at the same time. The person also may be able to make less complex decisions for an extended period. There are times when the person will be lucid, and others where they're less or more cognitively able. For example in the early evening, where agitation and confusion increases markedly with relatively lucid periods in the morning. The important thing, is to manage the capacity available at these times to ensure the person gets to participate in their own decision making when they are ablest to do so.

The temptation to take total control of the Dementia patient's life, and make everything work perfectly is overwhelming. This is where another ethical dilemma rests. Family and friends will often, as soon as the patient has been diagnosed, attempt to

organise the person's affairs and finances to ensure that no bad decisions are made or losses incurred. This is done with the best intentions and best interests at heart, but is frequently misguided and occurs too soon. This effectively rips away the person's ability to be independent, even on a limited scale. The ethical way is to involve the person as much as possible in decision making, when and however best they can, for as long as they have capacity to do so.

Capacity is a clinical term which describes the reasoning ability, personal preferences, and emotive mechanisms that allow a physician to enter into a consent contract with a patient, and to ask the patient to make specific decisions with regard to their own care. In general life, it's the ability to be independent and exercise choice. A person's loss of capacity is usually gradual, and there may be many areas in which the person can retain control over their own decisions and independence. This deterioration will continue to a line where the legal definition of not being of sound mind will occur i.e. where the person becomes incompetent.

There will come a time when the Dementia sufferer is impaired to the point where substitute decision making becomes a duty which needs to be undertaken by a responsible person. This is when the legal aspects of care become important, and the person is considered to lack competence. Competence is a legal term which denotes whether a person is able to participate in legal proceedings or can enter into contracts. The person's mental state must be such that they can take responsibility for their actions and decisions. Competence is decision specific.

Making decisions on behalf of an impaired person is done to avoid the person's being discriminated against on the basis of their being unable to make their own decisions. A legal proxy¹ is an individual who is assigned the duty of ensuring that equality and justice are preserved for a cognitively incapacitated person. This individual doesn't need to be a

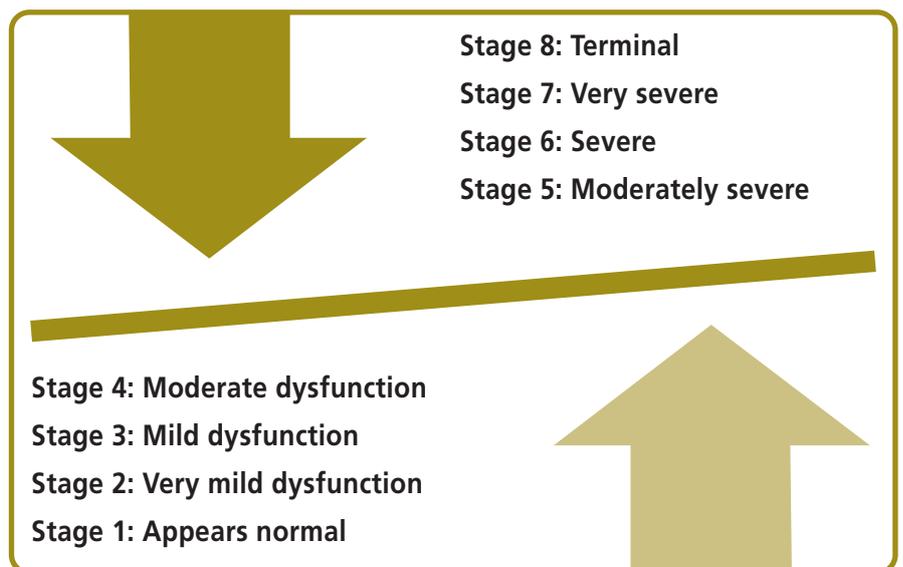
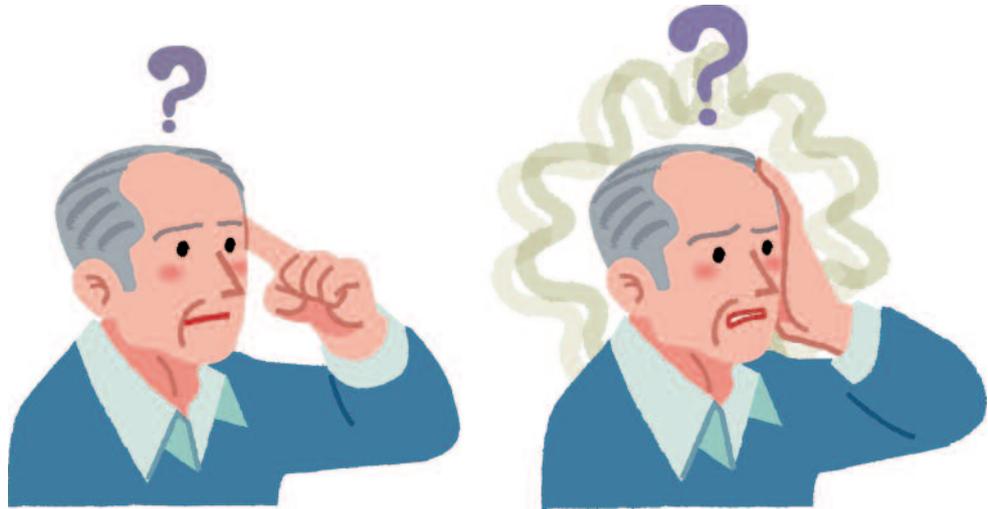


Figure 1: From stage 1 to 4 there are a number of clinical strategies which can be employed to assist the person with management of their illness and worsening symptoms. A person may be able to maintain their own independence, to a more or less degree, with assistance. From State 5 to 8 is when assistance has little value, and the person's ability to manage their independence has shifted to the point where a legal proxy is required.

family member, and in many cases when difficult choices need to be made, ought not to be. Interestingly, research done with older patients showed that most people were more comfortable with their doctor making treatment and end of life decisions for them than their family members. This is why it's important for people to plan ahead for a time when they may need a substitute decision maker they trust to make appropriate decisions for them, and to be comfortable that the person will make decisions reflecting their own wants and needs.

Obviously the ideal situation would be that every person with Dementia would have had the foresight to sit down with their families long before the disease was even suspected, and would have planned and completed an Advance Directive² (sometimes called a Living Will, although this is incorrect). This is a document that lays out all of the person's wishes and preferences, and allows them to choose the care they will receive, by whom, and, in the case of the end of their life, how they will be treated so they can be the most comfortable. This could be anything from choosing not to receive nutrition but to receive fluids, to insisting that



every effort should be made to resuscitate them—just in case, or simply to name a trusted Medical Practitioner to assume their care. It can include funeral arrangements, organ donation instructions – in fact, it will give clarity and guidance to family members and friends who might not be clear what the person's preferences are.

In most cases, we as people just never get around to planning for eventualities that make us uncomfortable, and for this there are legal acts which provide assistance as to who can make decisions for a person who does not have a legal proxy. In cases of medical emergencies, the National Health Act allows for certain family members to make decisions, but makes it clear that a legal proxy should be put in place. The Mental Health Care Act provides for a process where a person can have an Administrator assume control to administer a mentally ill person's affairs.

While there are steps which can be taken to ensure the person retains their ability to have decisions made for them that prevent discrimination and potential harm, we would all choose to speak for ourselves. For this reason alone, it's important that we take the bull by the horns, and put our own processes in place, so that we can guide others to make the most ethical decisions on our behalf.

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References

1. Who could be in the form of a curator bonis, administrator, power of attorney, or legal guardian.
2. To request a copy of a really comprehensive Advance Directive which anyone can use, contact the author.

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