



## dementia and dying

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**Dementia** is the progressive deterioration of a person's functioning with Alzheimer's being the most common and best-known form of the disease. Dementia has often been called 'the long goodbye'. This is because from diagnosis to death can often be many years. Over that time the person's cognitive and physical functioning will decline and the loved one who you once knew will gradually change and diminish.

**Every case is different:** but there are some stark similarities in all cases – all forms of dementia are progressively degenerative, there is no cure and there are no survivors. Dementia is usually associated with ageing but not all elderly people contract it and there are many cases of people who are diagnosed with some form of dementia in middle age.

**After the diagnosis:** There is often a sense of confusion and a mix of emotional messages. There is no outward sign of the condition and your loved one is not in pain. Yet the physician can offer no treatment or intervention that gives hope.

**In the time you have left:** If there are opportunities to enjoy life with your spouse, your partner, your parent or sibling, seize them and prepare for what lies ahead. How does your loved one want to live out his or her days? What pleasures can still be enjoyed now and what plans are to be made for when dementia takes away their ability to think and make decisions for themselves?

**When your loved one can no longer decide:** It is essential to put plans in place *before* this happens. Is Enduring Power of Attorney and Guardianship in place? Has a will been updated? Does the person want to make an Advance Directive that gives a clear message on how he or she wants to live out their days when they can no longer communicate their desires?

**Being a good carer means:** Seeking support and not trying to do it all alone. Family, friends, community and professional care should be accessed if possible. Caring for a dementia sufferer is generally a marathon that is run over several years. You can't be a good carer if you allow your own physical and mental health to deteriorate. Know when you need help and know when you need respite.

**A changed persona can be heart-breaking:** Dementia patients can go through strange and inexplicable personality changes. They can become aggressive, anti-social, non-communicative and irrational. There will be a time when they no longer recognise family or friends. Try to remember them as they once were and to understand that their 'new persona' is a result of dementia taking hold of their mind.

**The long goodbye:** As your loved one diminishes in mind and spirit, your grief will inevitably grow and envelope you. Many people feel that their grieving has been done when their loved one dies. This is rarely true; grief can and does stay with you for long after the death of the dementia patient.

**Tom Valenta** is an Australian author and former journalist and public relations consultant. His book, **Remember me, Mrs V? Caring for my wife: her Alzheimer's and others' stories** is a memoir. His first wife, Marie, was diagnosed with Alzheimer's at age fifty-four and died at sixty-one.