



Seven ways you can help a person to die well

I once nursed a young woman who had a stroke causing ‘locked in syndrome’ – the complete paralysis of her voluntary muscles. She was dying very slowly and doctors had discussed her prognosis with her. Her husband came into the hospital every day and sat with her. He found it difficult to speak to her. He knew she could hear and understand, but her inability to respond to him made communication challenging. Each night he left the unit stooped and weighted by the burden of grief. I would go in to see his wife and she would be distraught, crying without tears due to the locked in syndrome. Her end of life journey was distressing to watch. This experience demonstrated to me that a good death is not just about pain relief and symptom control. There are things we can do that facilitate a person’s good death. Here are seven things I have learned:

- 1. Do talk about the life-limiting diagnosis.** Talk with the person about the life-limiting diagnosis even if it is uncomfortable. We may be scared of saying ‘the wrong thing’ and end up saying nothing! Professor Robinson (2013) a respiratory consultant physician at Sir Charles Gairdner Hospital in Perth, notes that family and friends of newly diagnosed cancer patients often provide information about “new” and “alternative” treatments in an effort to be positive and hopeful. He notes this can bring short-term comfort, but it may increase anxiety and a sense of failure when the person’s health continues to deteriorate.
- 2. Provide appropriate and wanted support.** I have heard the comment “Let me know if there is anything I can do to help” so many times, and while I am sure the sentiment is well intentioned, it seldom results in supportive action for the dying person. The intention may be good, but not many people will ring you and ask for assistance! It is more useful to say “I would really like to support you. How can I be most helpful to you at this time?” It may even be appropriate to take the initiative and suggest how you can help, if there are things you can see that will be helpful. If it is not invading the person/family’s privacy, you go ahead and proactively provide an act of kindness. E.g. shopping, house-help, mending, gardening, transport, meal, relieve the family carer, pay for the carer to have a massage etc. Finally, if you say you will do something - make sure you do it, and ensure that it doesn’t add to the family’s pressures!
- 3. Keep your conversations broad.** Do talk about the diagnosis and the prognosis, but remember not to focus entirely on the person’s health condition. This is true for all people living with chronic conditions and deteriorating health. The person is more than their diagnosis and we want them to live well until they die, so talk about family, current affairs, work, clubs, sport... anything you would normally have spoken about. Remember the good times you have had together and the adventures you have shared.



- 4. Thank the person for who they are.** As death becomes imminent it is helpful to thank the person for the things they have done for you, your church, and your community. Saying thank you lets the person know that their life matters to you and others. Tell them about the things for which you are grateful and the personal qualities you admire in them. It can help to have similar discussions with the family, so they have the pleasure of reminiscing about their loved one's life journey. It will help them to see that others have also experienced good things with their family member.
- 5. Encourage the person to write letters of love.** Professor Robinson (2013) gives every patient diagnosed with cancer in his care this advice "*Plan for the worst but hope for the best.*" He encourages people to do the things they want to do, such as visit special places and people.

An approach like this enables people to do things like write a memoir, write letters to their children and even letters to grandchildren to open on their 21st birthday which explaining their love for their grandchild. Doing this will bring tears of sadness to the person as they write their letter, but it helps to achieve a good death.

If the person cannot write for any reason, you may scribe it for them while they dictate the content. Alternatively, they may speak their letter as a voice or video recording.

My father spoke his final goodbyes to us on audio-tape and was a treasured gift that helped me cope with my grief.

Encourage the person to write the letters while they can, because life-limiting disease can cause fatigue, and as it progresses the person may become affected by medication and/or physical symptoms that render them unable to write the letters. Letters are a gift that enables a person to die well. They also a blessing to the grieving family and close friends which have the ability to bring hope and direction to the family of the person after the death. Robinson (2013) says "...in some curious way, the lives of the family of the person who has died, are enriched by having had that intensely personal and open, caring experience of an open expression of love".

- 6. Keep up your connections.** Over years of nursing and pastoral care I have seen the dying person get a rush of people visiting them and their family in the few weeks after diagnosis/illness. However, as illness proceeds the supportive connections drop off, until few people connect at all. Be willing and available to spend time with the person and walk alongside the family for the long haul.

I have found it helpful to set a reminder in my diary because my life gets busy, but for the person who is housebound the days can be long. Setting a reminder helps me to make sure I don't forget the person in my own busy family/ministry/work schedule.



I also find that at the end of life it is better to keep your visits frequent but short (unless you feel an issue requires more time). Most people at the end of life only have enough energy for loved ones and immediate family. [If they don't have family there ensure your presence increases]. Know when it is time to move to very short visits and increase your care focus to the family via text message and phone call of support.

7. **Share conversations about faith.** Listen for cues about what they want to talk about regarding faith. Keep encouraging them to draw strength from their faith. I have a list of Bible verses in my diary and in my phone that I find encouraging and I use them when visiting people. The most important thing is not to push anyone into talking if they are not ready. Just make sure they know you are willing to listen if and when the time is right.

I always pray before I go in to a visit for the Holy Spirit's leading and wisdom. I offer to pray with the person, if they would like me to. I have never had any person refuse the offer. I ask if there are specific things for which they want prayer. I use the time of prayer to thank God for the person and their family, to reiterate his promises and then ask for the things we have discussed.

Reference

Robinson B. (2013). Dying Well, *The Australian*, 27 September 2013, <http://www.theaustralian.com.au/news/inquirer/dying-well/news-story/0952cc4d92360489522e928f89b66e26>

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