

Living with dying

When someone we love has a terminal illness (or even if we are that person), we must find a way to live with dying.

Living with dying is a complicated combination of emotions, decisions and actions.

Emotions

More than two decades ago, University of Chicago psychiatrist Elisabeth Kübler-Ross, MD, identified various stages that people who are dying may experience. Their families quite often experience the same emotions. The stages do not necessarily progress in the order listed. Furthermore, the dying person, and those who love him or her, may go back and forth among some or all of these stages. Knowledge of these stages may help us understand the dying person's reactions — and our own.

- **Denial:** “I want a second opinion.”
- **Anger:** “Why didn't the doctor spot it sooner?”
- **Bargaining:** “Please just give me enough time to see my daughter get married.”
- **Depression:** Depression over things we will never do again and things we will never get to do at all.
- **Acceptance:** Acceptance is not a happy time or a sad time. It just is.

Sometimes we can see a loss coming before it happens. Perhaps a friend or family member is suffering from a terminal illness, in which case we might start the grieving process while they're still alive. In a way, we're grieving the expectation of death. This is known as anticipatory grief.

Decisions

- For the person with the illness, one of the most important facets of living with dying is securing peace of mind about their end-of-life care. This is called Advance Care Planning, and it is the process of ensuring their health care wishes are honored if they no longer have the ability to articulate them themselves.
- They need to decide on the specific type of end-of-life care they want (or don't want) and decide who they trust to carry out their wishes.



Actions

It is important for those decisions to be documented. These documents are known as Advance Directives. They are a combination of a living will (which is different from a last will and testament) and a health care proxy.

Another important action to consider is using the services of a hospice during the last six months of life. According to the Hospice Foundation of America, hospice is:

- Medical care to help someone with a terminal illness live as well as possible for as long as possible, increasing quality of life
- An interdisciplinary team of professionals who address physical, psychosocial and spiritual distress focused on both the dying person and their entire family
- Care that addresses symptom management, coordination of care, communication and decision making, clarification of goals, and quality of life

In many cases, hospice care is provided at the person's residence, and as mentioned above, it covers the patient and the entire family unit. Attempts to provide a cure are replaced by palliative care which is focused on the reduction of pain and other symptoms of the specific illness or condition. Patients can choose to use as many or as few of the hospice services as they see fit. Your doctor can recommend a program in your area.

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Critical support when you need it

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