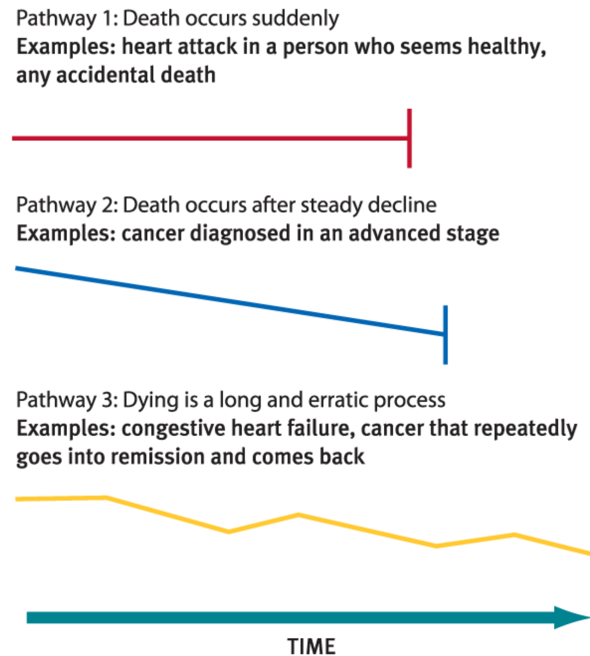
Figure 15.1: Three pathways to Death



The prolonged, erratic pattern of death (the yellow line) is the most common pattern dying in affluent countries. This is likely due to medical advances that can avoid death by "natural" means that have killed people in the past.

How we experience and deal with death cannot be examined without looking at the culture in which a person lives in.

Advance Care Planning

Advance care planning refers to the process of patients thinking about and communicating their preferences for end-of-life care.

What kind of care do you want if you are unable to communicate it to family members or a doctor?

A living will is a legal document that reflects a patient's advance care planning (think you are living and what is your desire? It isn't a will regarding inheritance). A study of older adults (most end of life research is done with older adults and not younger adults) found that advance care planning, such as a living will, was associated with improved quality of care at the end of life, including less in-hospital death, and more hospice care.

While 90% of patients reported that it is important to discuss health-care wishes, only 60% had done so and only 15% of patients 18 years or older had a living will (Santrock, p. 425).

Better Care of Dying Individuals

One recent direction of health care is the care of dying individuals.

Medical advances have delayed dying. Even though pain killers are available, one study found 61% of dying patients were in pain in the last year of life and about 1/3 had symptoms of depression and confusion prior to death. Death in the United States is often lonely, prolonged and painful.

Care providers are increasingly interested in helping patients experience “a good death” that involves physical comfort, support from loved ones, acceptance and appropriate medical care (Santrock, p. 426).

In Search of a Good Death

For some individuals, a good death involves accepting one's impending death and not feeling like a burden to others. Three frequent themes on a good death involve

(1) focusing on the dying process,
(2) pain-free status, and
(3) emotional well-being

Critiques of a good death also needs to shift away from death being a single point in time to a process that occurs over time that can be as long as 10 years (see figure 15.1) (Santrock, page 227) and focus on making their live better during this prolonged time.

In Search of a Good Death

Many religions agree that death should be celebrated after a long life. Death should be peaceful, which explains why violent deaths, like suicide or murders, are especially anxiety provoking. Death is "best" when it occurs in the "homeland" (not far away), accounting for why—around the globe—people prefer to die surrounded by loved ones and dislike the impersonal dying that takes place in intensive care (page 445).

It is suggested that a good death have the following characteristics:

1. We want to minimize our physical distress, to be free as possible from debilitating pain
2. We want to maximize our psychological security, reduce fear and anxiety, and feel in control of how we die.
3. We want to enhance our relationships and be close emotionally to the people we care about
4. We want to foster our spirituality and believe there was integrity and purpose to our lives.

One study suggests having a sense of purpose in life was related to feeling comfortable about dying.

Factors that Hinder Dealing with Death

Culturally:
Broadly speaking, American culture avoids talking about death and engages in death denial. This denial can take several forms such as:

1. The tendency of the funeral industry to gloss over death and fashion lifelike qualities of the dead.
2. The persistent search for a "fountain of youth".
3. The rejection and isolation of the aged, why may remind us of death.
4. The medical community's emphasis on prolonging biological death rather than on diminishing human suffering.

<u>Historically:</u>

- During the Middle Ages, death was an expected presence throughout the lifespan. People died, as they lived, in the view of the community and were buried in the churchyard in the center of town (page 440).
- During the 18th and 19th century, because of the fear about disease, villagers relocated burial sites to cemeteries outside of town (cities, due to the high likelihood of contact with other people, increases the risk of spread of disease).
- In the 20th century, when medical science reduced the risk of death due to disease, death became less common in the early ages of the lifespan and more common at the end of the lifespan. In addition, death shifted from the home to hospitals and nursing homes. Death was disconnected from life.

  Because hospitals were “sold” as places of recovery, death became an indication of the failure of science. When people died, health-care workers removed all signs of death’s presence—they shroud the body and shipped it to a funeral home. By the mid-twentieth century, death had become disgusting, abnormal, and never discussed (page 440).
- Doctors shifted directions from avoiding telling people of a cancer diagnosis to being more open and direct about it and start re-acknowledging that people do die, and perhaps it isn’t a failure of the medical system.

The Dying Person: Kübler-Ross's Stages of Dying

Many people are familiar with Kübler-Ross's Stages of Dying. It was originally proposed that we progress through five emotions in coming to terms with death:

1. denial,
2. anger,
3. bargaining,
4. depression, and
5. acceptance.

She deserves credit for looking at the emotions that people have toward death, however, she was not quite correct. People deal with death in different ways.

At the hospital, Homer sits on an examining table in his underwear, and Dr. Hibbert and Marge come in. Homer takes a look at Marge's sad demeanor and concludes, "Ooh! It's good news, isn't it!" But it isn't.

Dr. H.: You have twenty-four hours to live.
Homer: Twenty-four hours!
Dr. H.: Well, twenty-two. I'm sorry I kept you waiting so long.

Homer embraces Marge.

Dr. H.: Well, if there's one consolation, it's that you will feel no pain at all until some time tomorrow evening, when your heart suddenly explodes. Now, a little death anxiety is normal. You can expect to go through five stages. The first is denial.
Homer: No way! Because I'm not dying! (He hugs Marge.)
Dr. H: The second is anger.
Homer: Why you little! (He steps towards Dr. H.)
Dr. H: After that comes fear*.
Homer: What's after fear? What's after fear? (He cringes.)
Dr. H: Bargaining.
Homer: Doc, you gotta get me out of this! I'll make it worth your while!
Dr. H: Finally, acceptance.
Homer: Well, we all gotta go sometime.
Dr. H: Mr. Simpson, your progress astounds me.

He leaves Homer a pamphlet, "So You 're Going to Die."

*Kubler-Ross's stages are denial, anger, bargain, depression, and acceptance

The Dying Person

Terminally ill patients often don't want to fully discuss their situation

- Both loved ones and patients do have qualms about discussing the possibility of death. Dealing with death in the abstract is easier, specific plans may be more difficult.
- Some people avoid the discussion of death to protect themselves and/or give them hope.
- Some people avoid the discussion of death to protect loved ones.

The discussion of death is difficult when people are trying to protect one's emotions (whatever emotions they happen to be—fear, anxiety, etc.) and their relationship with others. This makes navigating the discussions both within the family and discussing it with a family difficult and the need to pay attention to subtle cues and context of family relationships.

Terminally ill patients may not want to know "The full truth"

Some patients do want to know want full disclosure of what is going to happen, while others do not. Sensitive caregivers need to pick up on the direct and indirect messages, and perhaps ask for clarifying questions directly and indirectly and keep in mind their assumption whether they want to know what is happening is correct or not.

<u>People do not pass through stages in adjusting to death</u>

People facing death do not progress emotionally stage-to-stage as she originally suggests. A problem with Kübler-Ross's stages is that it encourages us to distance ourselves from dying loved ones by incorrectly labeling real emotions from real circumstances and events as a "phase".

One emotion that people do experience is hope. Some may hope for a cure, some may hope that they live to reach a short-term event or goal (e.g. seeing the birth of their grandchild, attending graduation, etc.). People can understand that they are dying and still have future goals and plans (page 444).

Mourning a Child

A child's death can be more upsetting than any other loss and may evoke powerful feelings of survivor guilt.

- If the death occurred suddenly due to an accident, there is the possible guilt at having failed as a parent.
- If the death was expected (e.g. due to cancer or a known disease), parents must cope with their anger that an innocent child had to suffer and unfairly robbed of life.

The problem is that a child's death can never be really "good," because the death of a child is inconsistent with the world view that the universe is predictable and fair.

Researchers find that parents are more likely to get partial closure if they discuss what is happening with their child during the final weeks—but only if their child is old enough to understand death and dying.

Avoiding the topic of death and dying, increases the risk of feelings of regret (page 448). In addition, advising parents to "move on" does not help.

Mourning a Child

Successful psychological adjustment focuses on how we feel. Keeping their memory of their child alive, helps parents cope. Recovering from a terribly unfair death depends on finding new meaning in the death to restore a deep belief that that the universe is predictable and fair.

- Some families find solace in donating their child's organs to help another live.
- Others may adopt that child's life passions.
- Others may work suicide hotlines or advocate for gun control or substance abuse education.

Engagement in the world is the main predictor of good psychological adjustment for grieving parents. Whether it is a tragic death or not, social support—having someone who understands how you feel helps people cope.

The case against dying at home
1. No worries about family members not being able to control your pain.
2. No fear of burdening your family with your care.
3. Privacy to vent your feelings, without family members around.
4. Avoiding the embarrassment of depending on loved ones for help with your intimate body functions.
The case in favor of dying at home
1. Avoiding having life-prolonging machines used on you.
2. Spending your final days surrounded by the people you care about most.
3. Spending your final days in the physical setting you love best.
Given these considerations, would you prefer to meet death at home?