



# Family Caregivers in Cancer

**Dr. Gary Mumaugh – Bethel University**

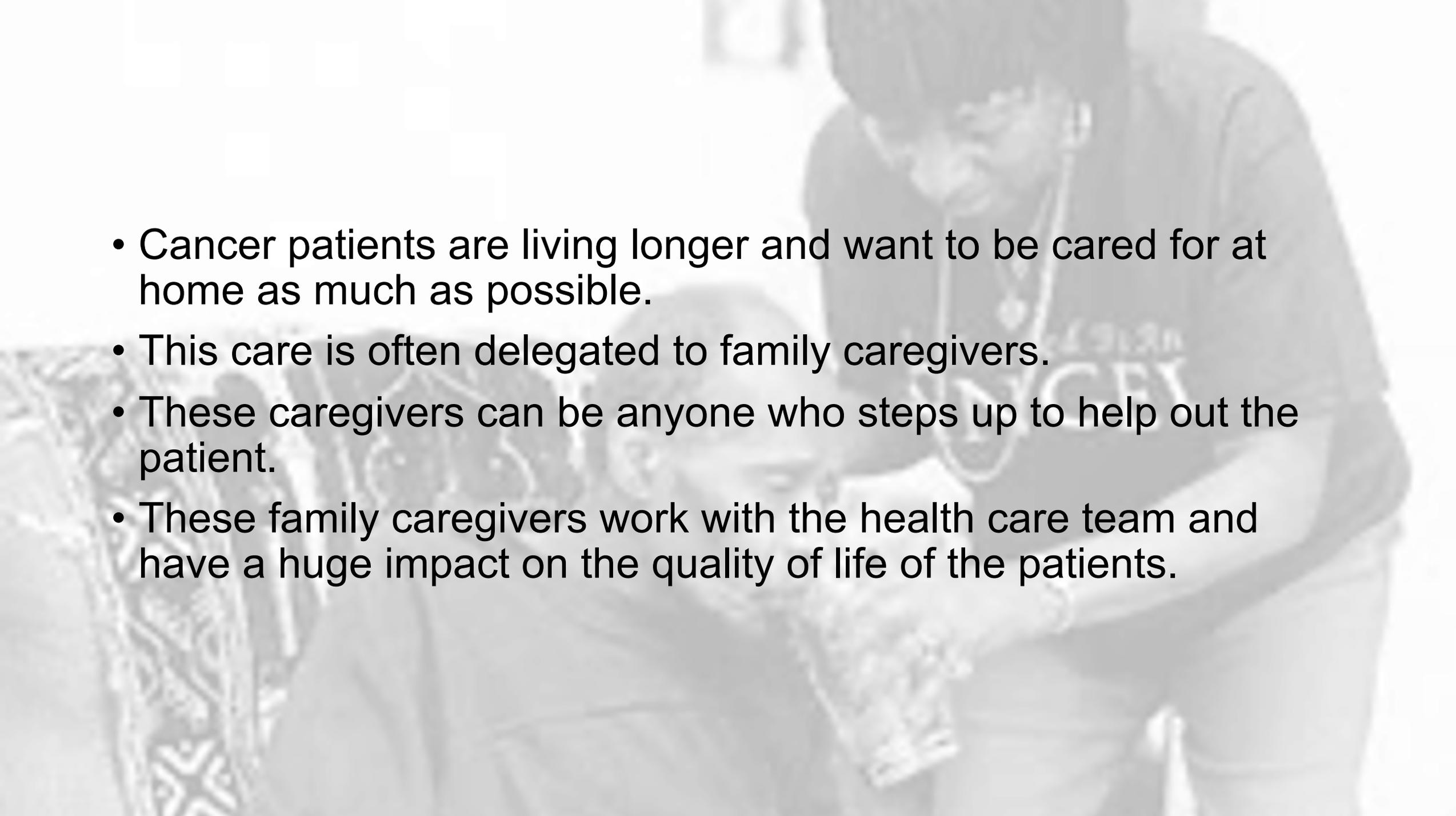
# Overview

- Every year 1.6 million new cancer cases are newly diagnosed in the USA.
- Most patients will require some care at home from a family member or friend.
- Actually family caregivers form the foundation of current cancer care trends.



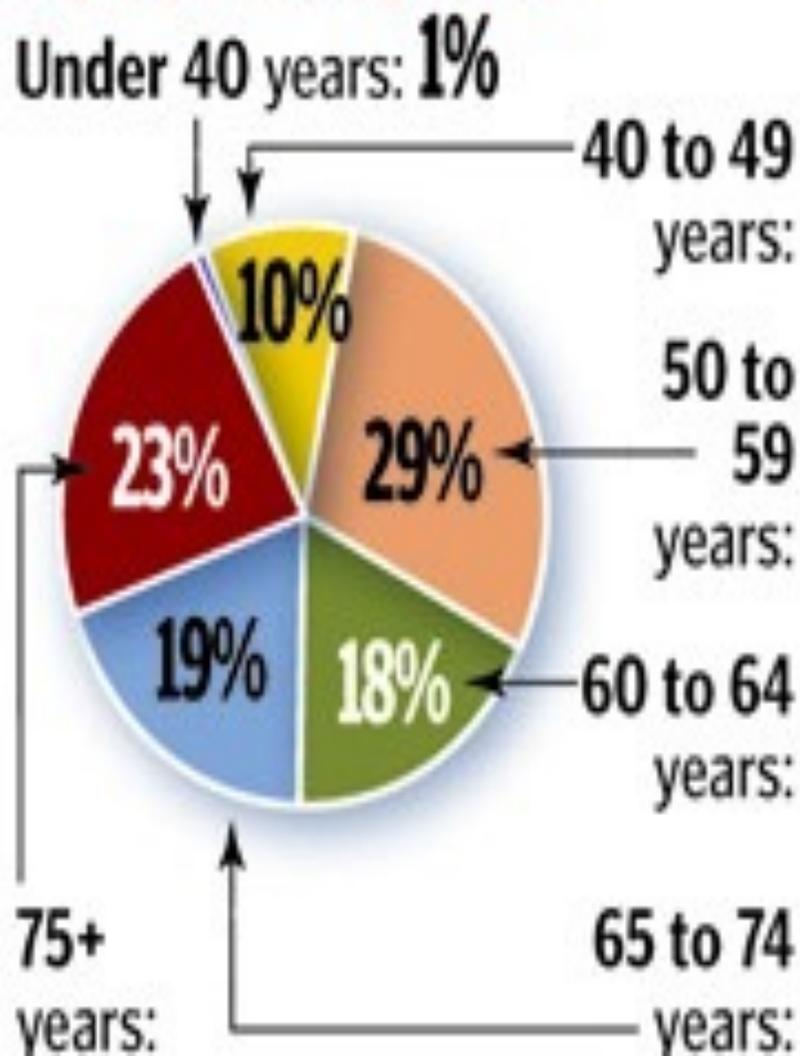
# Who is a Caregiver?

- They are also referred to as informal caregivers.
- Family caregivers may be spouses, partners, children, relatives or friends who help with the patient with daily activities and home health care needs.
- Generally speaking, more women than men become caregivers.
- Most caregivers are related to the patient and most caregivers are over 55.
- Many cancer patients receive care at home. Hospital stays are much shorter and most treatments are given as an outpatient, not requiring a hospital stay.

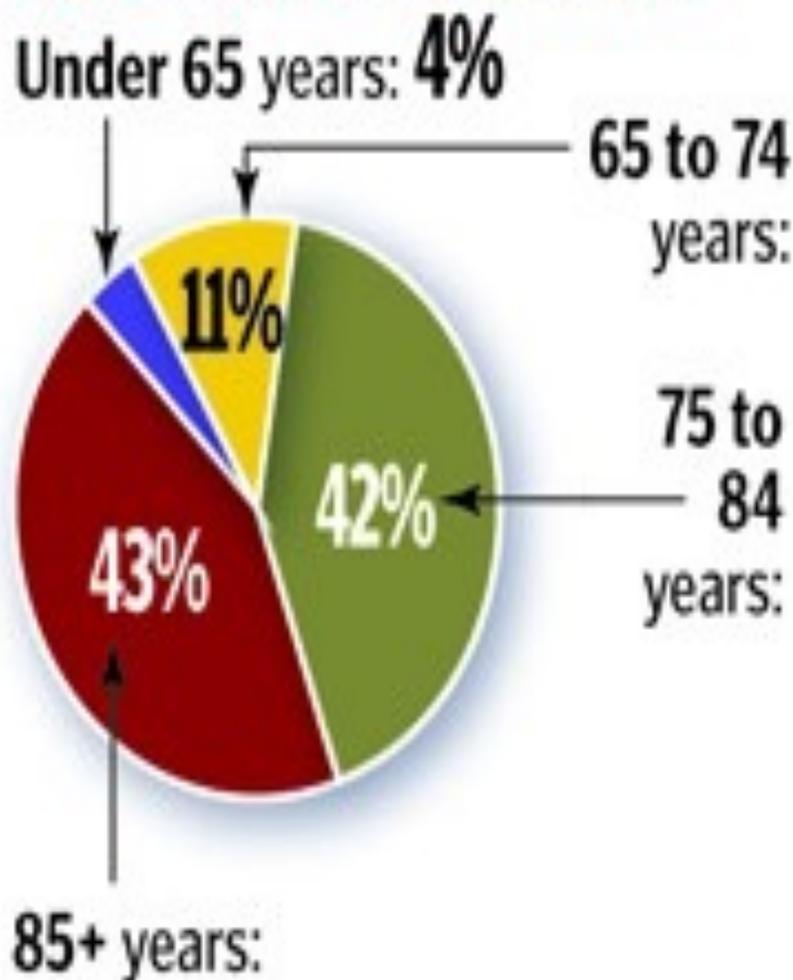
- 
- Cancer patients are living longer and want to be cared for at home as much as possible.
  - This care is often delegated to family caregivers.
  - These caregivers can be anyone who steps up to help out the patient.
  - These family caregivers work with the health care team and have a huge impact on the quality of life of the patients.

More than 80 percent of long-term care is provided by family, friends or neighbors. These informal caregivers spend many hours tending to a loved one, and many have to balance their own family and work life.

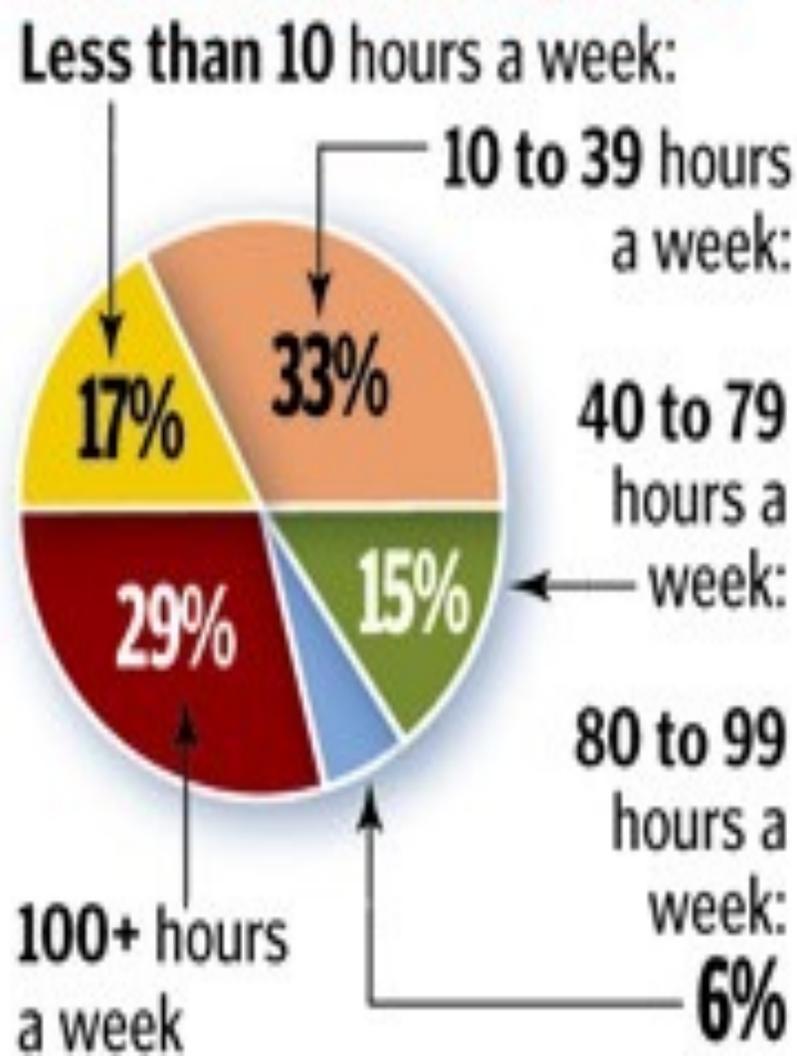
### Age of caregivers



### Age of care receivers



### Time spent caregiving



# Caregiver's Tasks



- Caregiver's are no doing a lot of what use to be performed by health care providers in hospital and clinic settings.
- Tasks are varied but could include helping with medicine, doctors' visits, schedules, and navigating health insurance concerns.
- Care could also include emotional and spiritual support and helping the patient make decisions.

# **It is important that the caregiver be a part of the health care team from the start.**

- The family caregiver has a very important job of watching for changes in the patient's medical condition while also giving long term care.
- Family caregivers can help plan treatment decisions, make decisions, and carry out treatment plans all through the different phases of treatment.



# The Caregiver's Point of View

- Caregivers need help and emotional support.
- Every caregiver responds in his or her own way to the diagnosis and prognosis.
- The caregiver's need for information, help and support is different than what the patient's need.
- The caregiver's role changes as the patient's needs change during and after cancer treatment.
  - At diagnosis / During hospital treatments / During care at home / After treatment ends / At the end of life

# At Diagnosis

- Family caregiver's take an active role that begins when the cancer is diagnosed.
- The caregiver has to learn about the cancer being diagnosed.
- The caregiver has to learn new medical terms.
- The caregiver also goes with the patient to new places for treatment and helps the patient with treatment decisions.

# During Treatment at the Hospital

- The patient may ask the caregiver to be the one to talk to the health care team and make important decisions.
- The relationship between the caregiver and the patient affects how well this works.
  - Disagreements and arguments between the patient and the caregiver can have an effect on treatment choices.
- During the active treatment phase, a caregiver needs to meet the demands of supporting the patient as well as the demands of home, work and family.

# During Care at Home

- The move to the home care setting is pretty stressful.
- The patient would rather be at home in a familiar and comforting place.
- The return home usually means more work for the caregiver.
- The caregiver may also be asked to
  - Take on the patient's household duties.
  - Be a companion to the patient.
  - Take care of medicines and meals.
  - Schedule hospital visits and arrange for transportation.
  - Work through the health care system for the patient.
  - Arrange for home visits of therapists, nurses and other professionals.
  - Handle insurance matters.
  - Deal with medical emergencies.

- Caregivers worry about how they will be able to do all these tasks and take care of themselves.
- Often, the caregiver gives up social activities and misses work.
- This can be challenging and emotionally and financially draining.



# After Treatment Ends

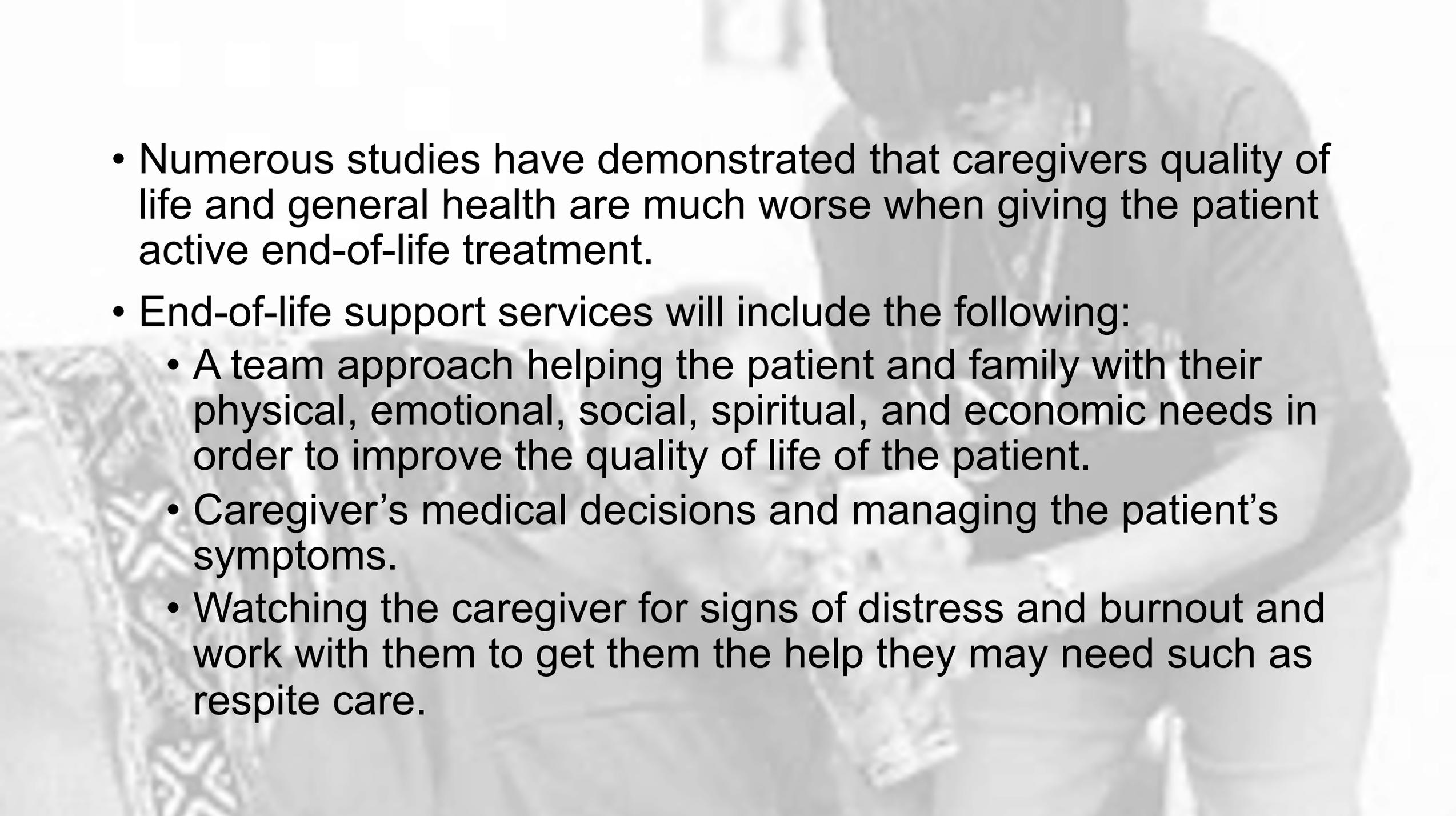
- Some patients and caregivers expect that life will go back to the way it was before the cancer was diagnosed.
- Caregiver stress continues after treatment stops because now roles have changes again.
- Some caregivers have problems adjusting for 1-2 years.
  - This is partly due to the worry that the cancer will return.
- When the caregiver is the spouse, there can be sexual challenges.
- Studies have found that these adjustments are usually handled in time.

- Obvious problems may occur if any of the following are present:
  - Relationship issues with the patient and caregiver.
  - Poor communication between the caregiver and the patient.
  - Lack of social support



# At the End of Life

- This brings a new set of challenges for the caregiver as they grieve and adjust to the “new normal”.
- At the end of life, the patient depends even more on the caregiver for physical, emotional and spiritual support.
- The patient’s symptoms may be more difficult to manage.
- The caregiver is often overwhelmed with these new challenges.
- The caregiver may feel even more stress when the patient goes into hospice care.

- 
- Numerous studies have demonstrated that caregivers quality of life and general health are much worse when giving the patient active end-of-life treatment.
  - End-of-life support services will include the following:
    - A team approach helping the patient and family with their physical, emotional, social, spiritual, and economic needs in order to improve the quality of life of the patient.
    - Caregiver's medical decisions and managing the patient's symptoms.
    - Watching the caregiver for signs of distress and burnout and work with them to get them the help they may need such as respite care.

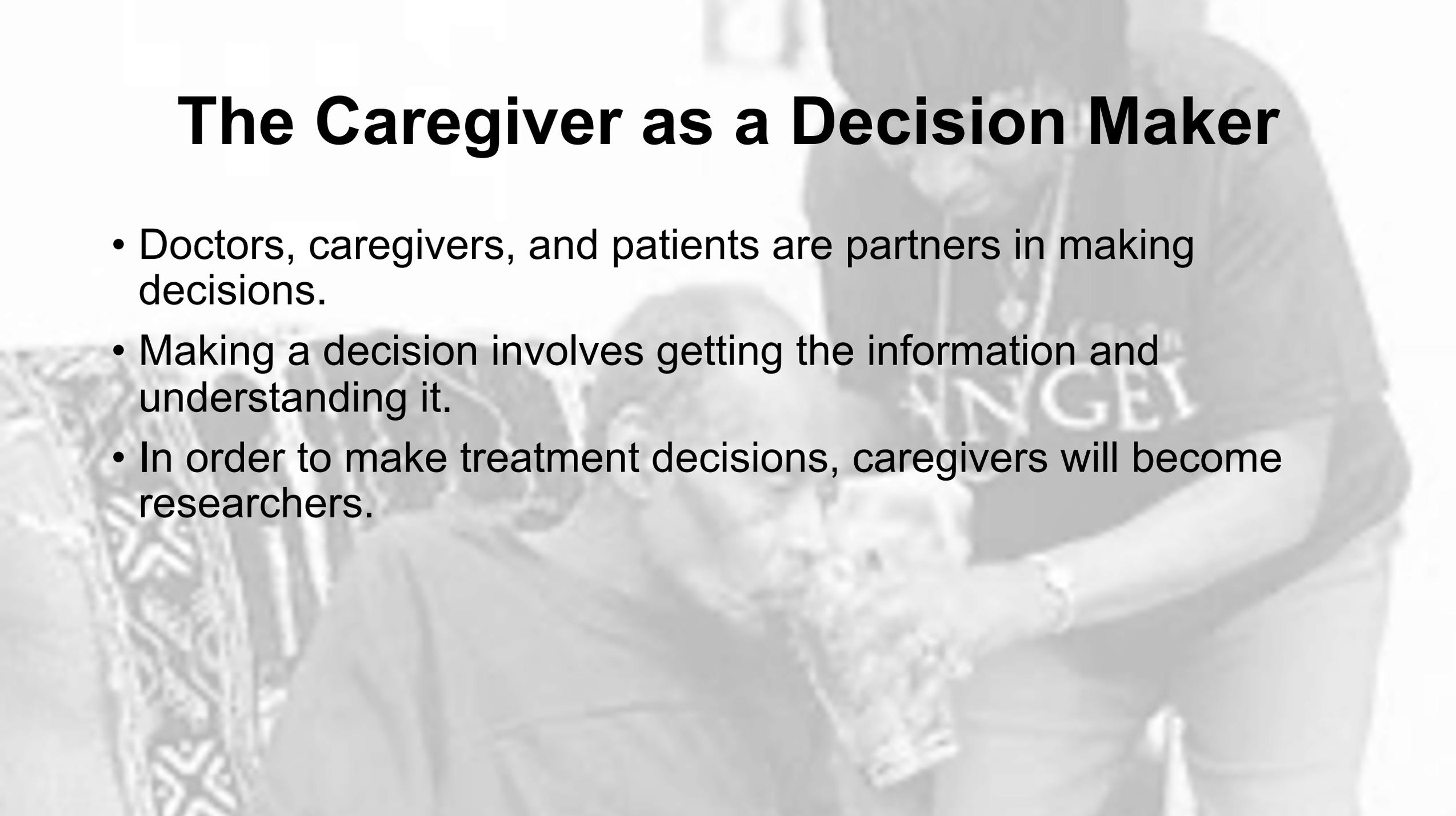
# Roles for the Family Caregiver

A grayscale photograph showing a caregiver from behind, wearing a dark t-shirt, assisting an elderly person. The caregiver is holding a walker for the elderly person, who is wearing a patterned shawl. The scene is set in what appears to be a home or a care facility.

- The family caregiver has many roles besides giving the patient hands-on care.
- The caregiver takes on different roles so that the patient gets all the information, support, and treatment that they need.
- The major roles are
  - Decision maker
  - Advocate
  - Communicator

# The Caregiver as a Decision Maker

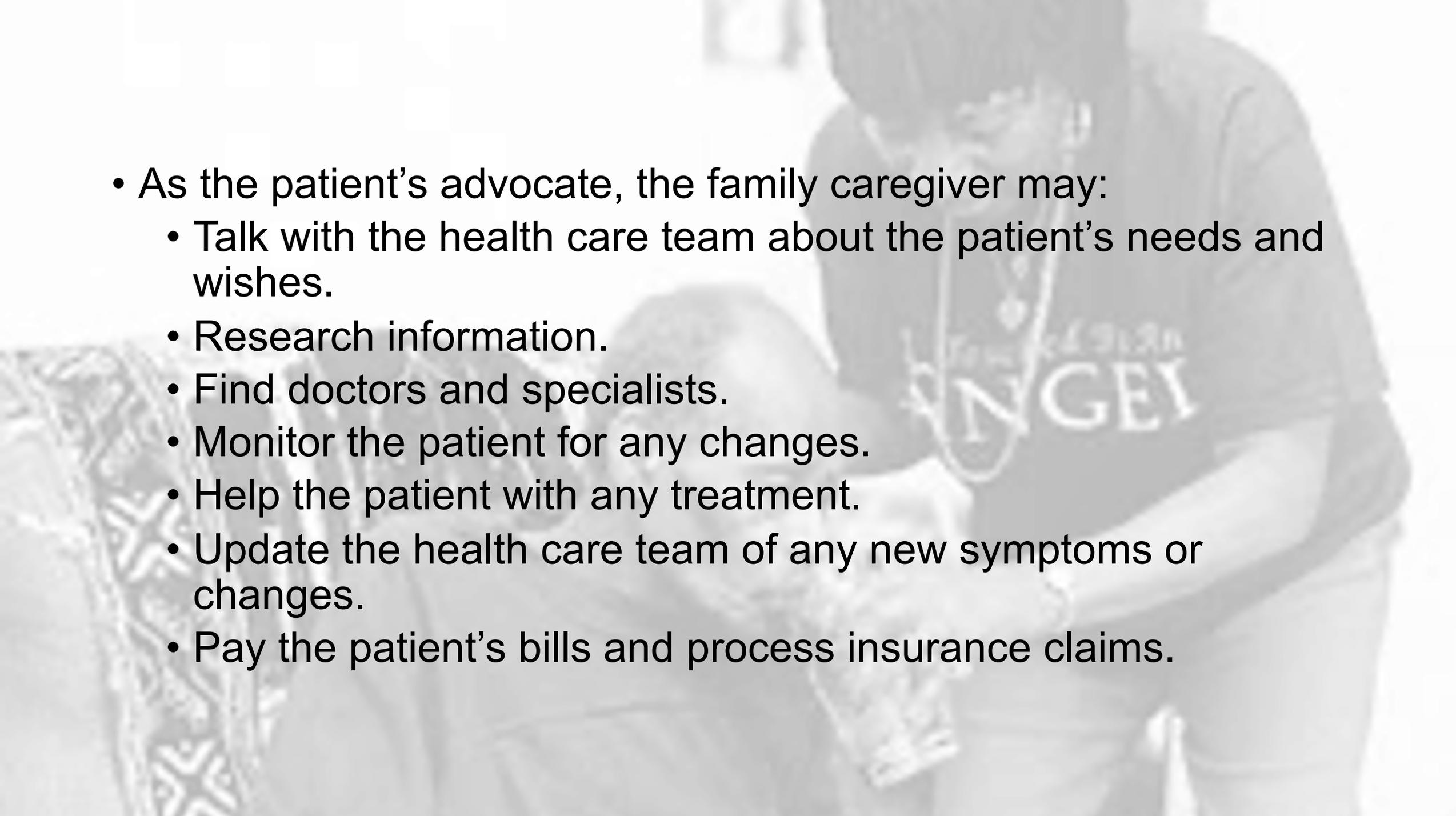
- Doctors, caregivers, and patients are partners in making decisions.
- Making a decision involves getting the information and understanding it.
- In order to make treatment decisions, caregivers will become researchers.



# The Caregiver as an Advocate

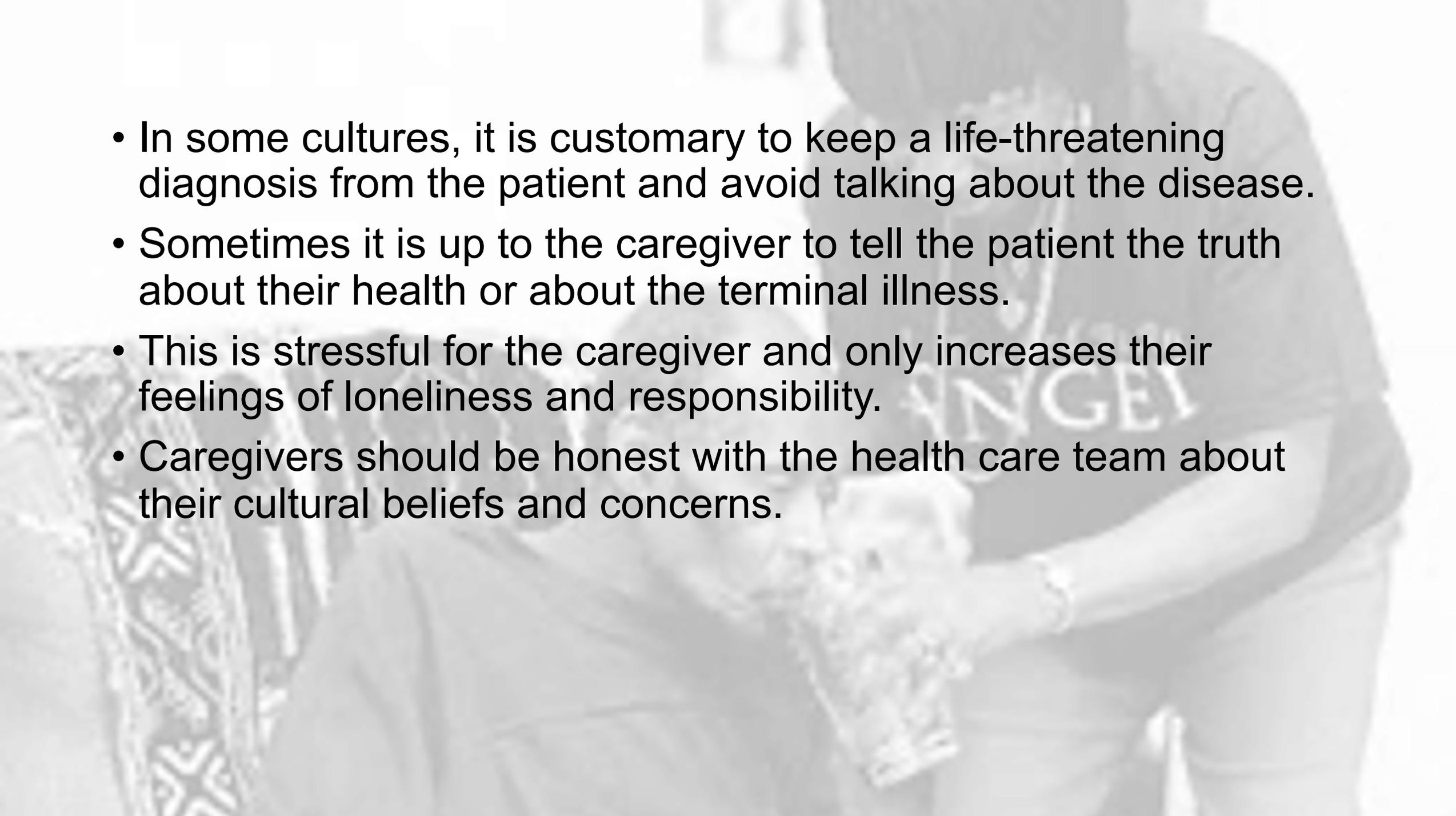
- The family caregiver knows and understands the needs of the patient.
- The caregiver advocates for the patient by providing information and feedback to the health care team.
- This information can be helpful to the medical team to in deciding and analyzing treatment options.



- 
- A grayscale photograph of a caregiver in a dark t-shirt with 'NYGEY' printed on it, leaning over a patient in a hospital bed. The caregiver is holding the patient's hand. The patient is lying in a bed with a patterned blanket. The background is a plain wall.
- As the patient's advocate, the family caregiver may:
    - Talk with the health care team about the patient's needs and wishes.
    - Research information.
    - Find doctors and specialists.
    - Monitor the patient for any changes.
    - Help the patient with any treatment.
    - Update the health care team of any new symptoms or changes.
    - Pay the patient's bills and process insurance claims.

# The Caregiver as a Communicator

- Good communication between the patient, doctor, and caregiver can dramatically improve the patient's care.
- The family caregiver will often take on the role of speaking for the patient while also keeping the patient informed.
- Doctors need to hear about the patient's concerns, and caregivers need to understand the disease and treatment options.
- Poor communication can cause confusion about treatment.
- Cultural differences between the doctors and the caregivers or patient can affect communication.

- 
- A grayscale photograph of a caregiver, wearing a dark t-shirt with the word 'ANGEL' printed on the back, holding the hand of a patient. The patient is wearing a patterned blanket. The background is softly blurred.
- In some cultures, it is customary to keep a life-threatening diagnosis from the patient and avoid talking about the disease.
  - Sometimes it is up to the caregiver to tell the patient the truth about their health or about the terminal illness.
  - This is stressful for the caregiver and only increases their feelings of loneliness and responsibility.
  - Caregivers should be honest with the health care team about their cultural beliefs and concerns.

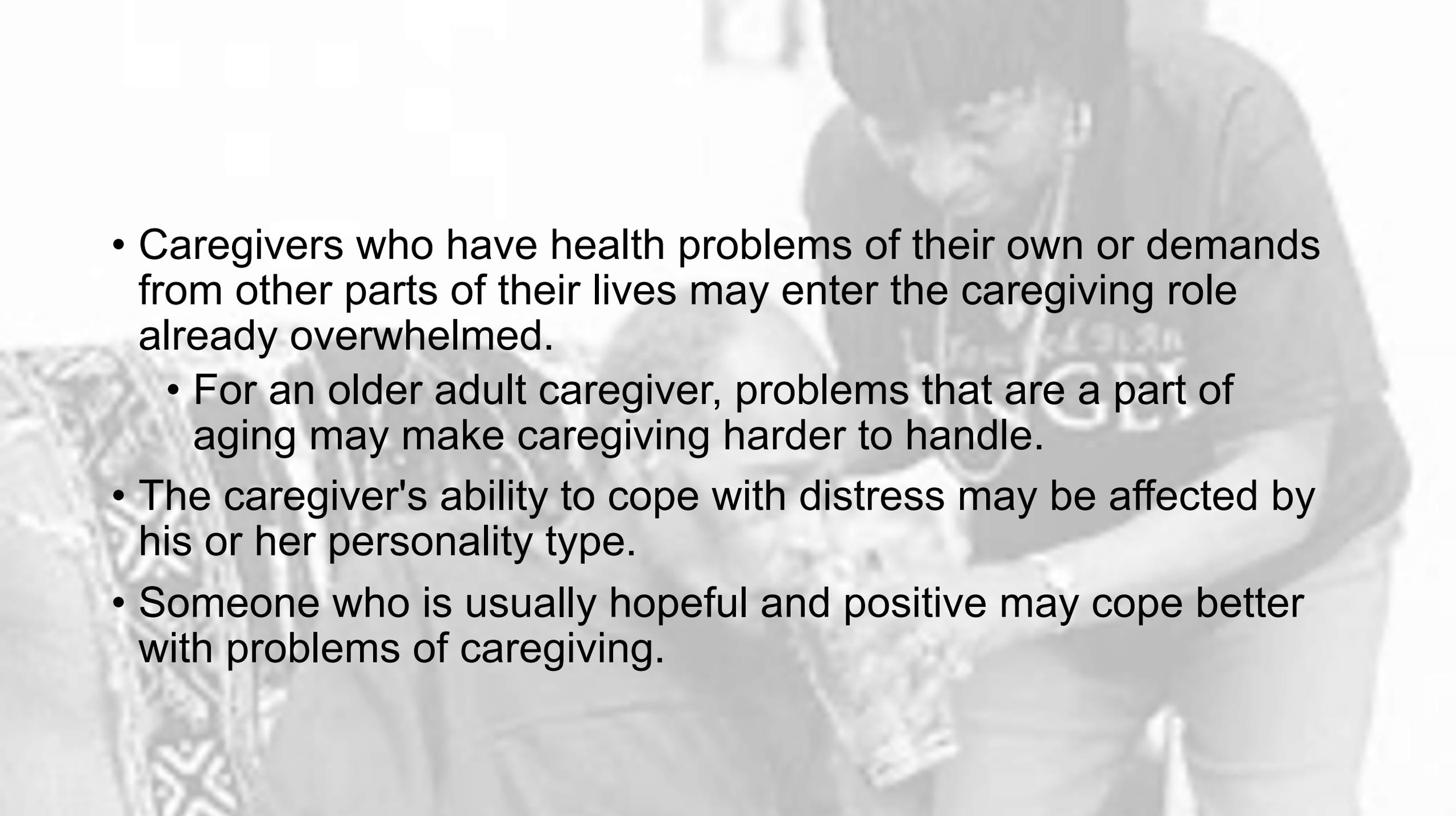
# The Caregiver's Quality of Life

- Family caregivers usually begin caregiving without training and are expected to meet many demands without much help.
- A caregiver often neglects his or her own quality of life by putting the patient's needs first.
- Health care providers watch for signs of caregiver distress during the course of the patient's cancer treatment.
- When caregiver strain affects the quality of caregiving, the patient's well-being is also affected. Helping the caregiver also helps the patient.
- Caring for a patient with cancer dramatically affects the caregiver's quality of life in many areas.



# Psychological Issues

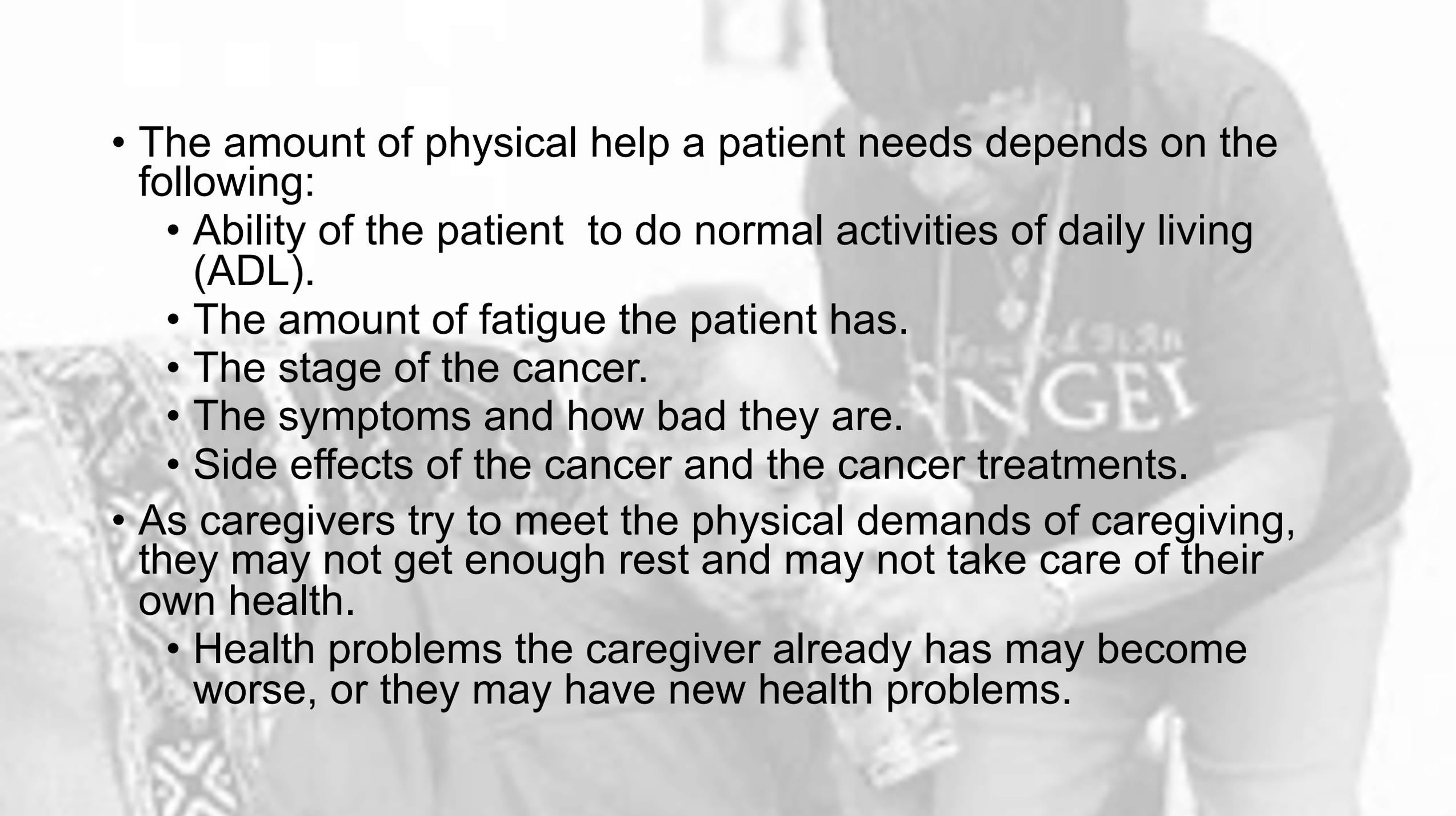
- Psychological distress is the most common effect of caregiving on the caregiver's quality of life.
- Caring for a cancer patient is a difficult and stressful job.
- Caregiver distress comes from the practical demands of the caregiver role as well the emotional ones, such as seeing the patient suffer.
- Family members seeing a loved one with cancer may feel as much or more distress than the patient does.
  - Distress is usually worse when the cancer is advanced and the patient is no longer being treated to cure the cancer.

- 
- Caregivers who have health problems of their own or demands from other parts of their lives may enter the caregiving role already overwhelmed.
    - For an older adult caregiver, problems that are a part of aging may make caregiving harder to handle.
  - The caregiver's ability to cope with distress may be affected by his or her personality type.
  - Someone who is usually hopeful and positive may cope better with problems of caregiving.

# Physical Issues

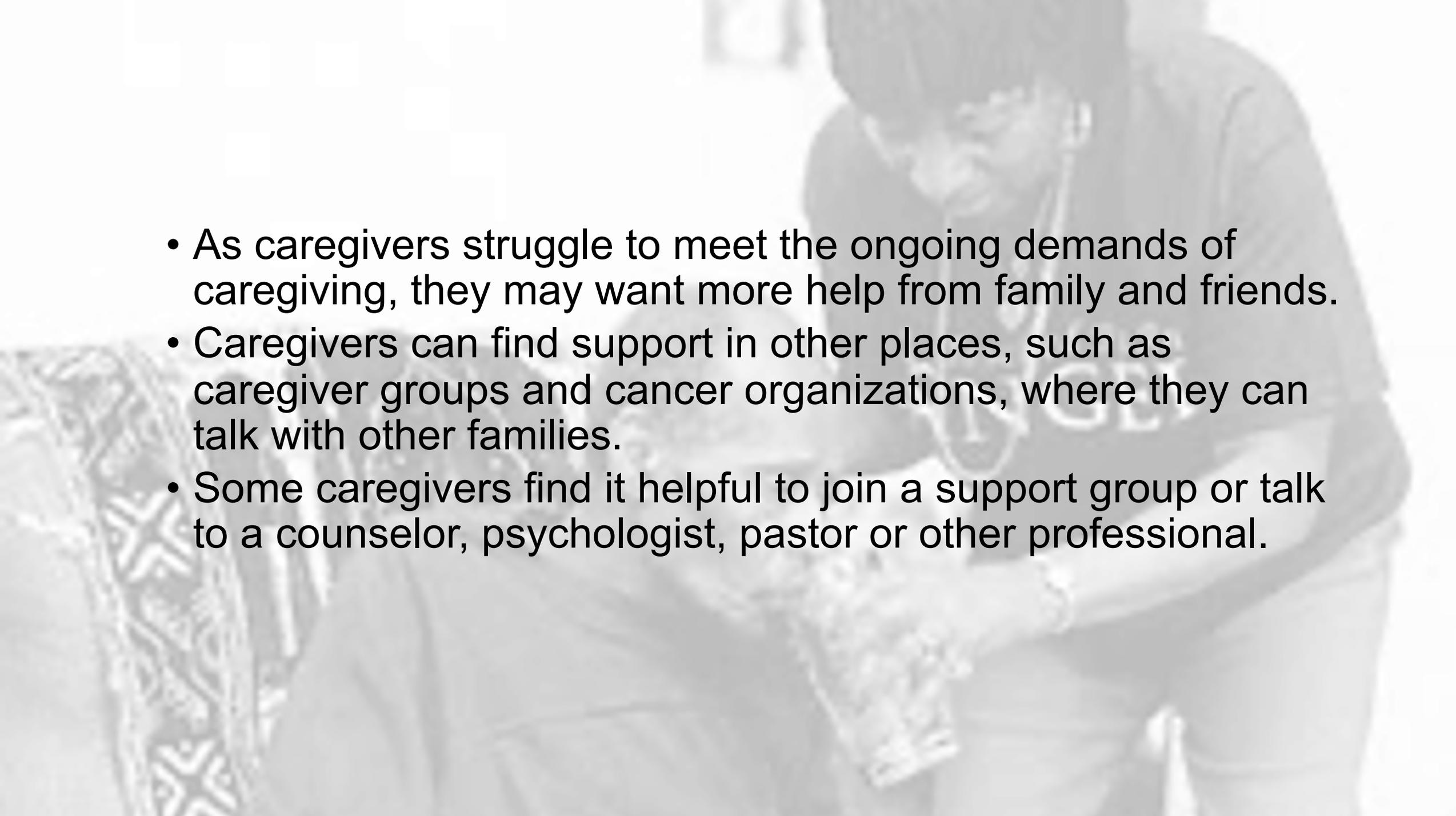
- Cancer patients often need a lot of physical help during their illness.
- This is physically demanding for the caregiver, who may need to help the patient with many activities during the day such as:
  - Toilet use, eating, change positions in bed, patient transfers, using medical equipment.



- 
- The amount of physical help a patient needs depends on the following:
    - Ability of the patient to do normal activities of daily living (ADL).
    - The amount of fatigue the patient has.
    - The stage of the cancer.
    - The symptoms and how bad they are.
    - Side effects of the cancer and the cancer treatments.
  - As caregivers try to meet the physical demands of caregiving, they may not get enough rest and may not take care of their own health.
    - Health problems the caregiver already has may become worse, or they may have new health problems.

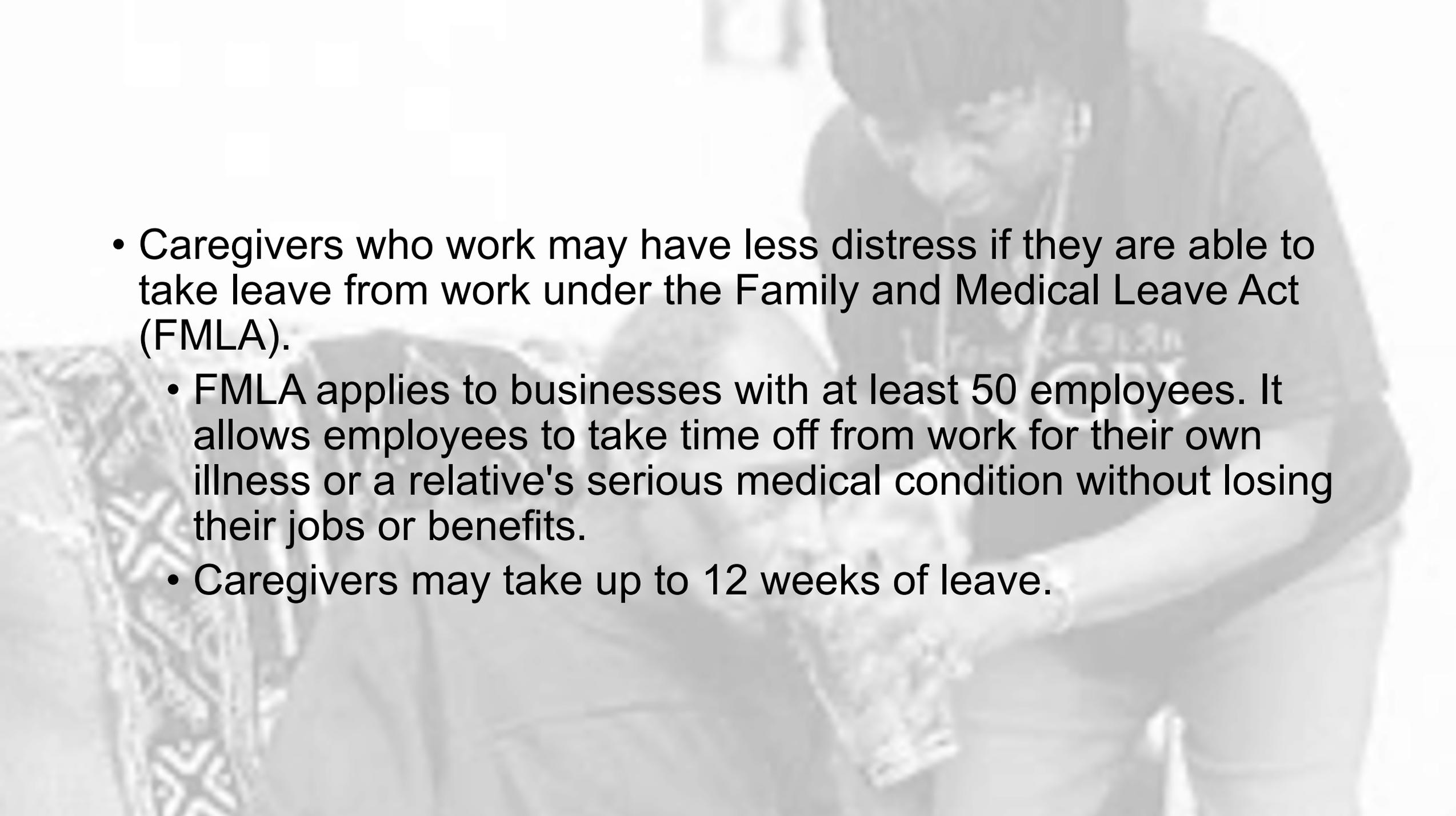
# Social Issues

- Caregivers often have less time to spend with friends and in the community as their days are filled with caring for the cancer patient.
- If there are problems in the relationship between the caregiver and the patient, the caregiver may feel even more alone.
- In the beginning, there may be a lot of support from friends.
  - The caregiver may be able to continue working and keep up work relationships.
  - When care continues for a long time, the caregiver may need to stop working and friends may call or visit less often.

- 
- As caregivers struggle to meet the ongoing demands of caregiving, they may want more help from family and friends.
  - Caregivers can find support in other places, such as caregiver groups and cancer organizations, where they can talk with other families.
  - Some caregivers find it helpful to join a support group or talk to a counselor, psychologist, pastor or other professional.

# Money Issues

- The financial costs of cancer can be staggering.
- Families must pay insurance deductibles, copayments, and for services that are not covered by insurance.
- Some caregivers give up their jobs and income so they can stay home with the patient, which makes it harder to pay for everything.

- 
- Caregivers who work may have less distress if they are able to take leave from work under the Family and Medical Leave Act (FMLA).
    - FMLA applies to businesses with at least 50 employees. It allows employees to take time off from work for their own illness or a relative's serious medical condition without losing their jobs or benefits.
    - Caregivers may take up to 12 weeks of leave.

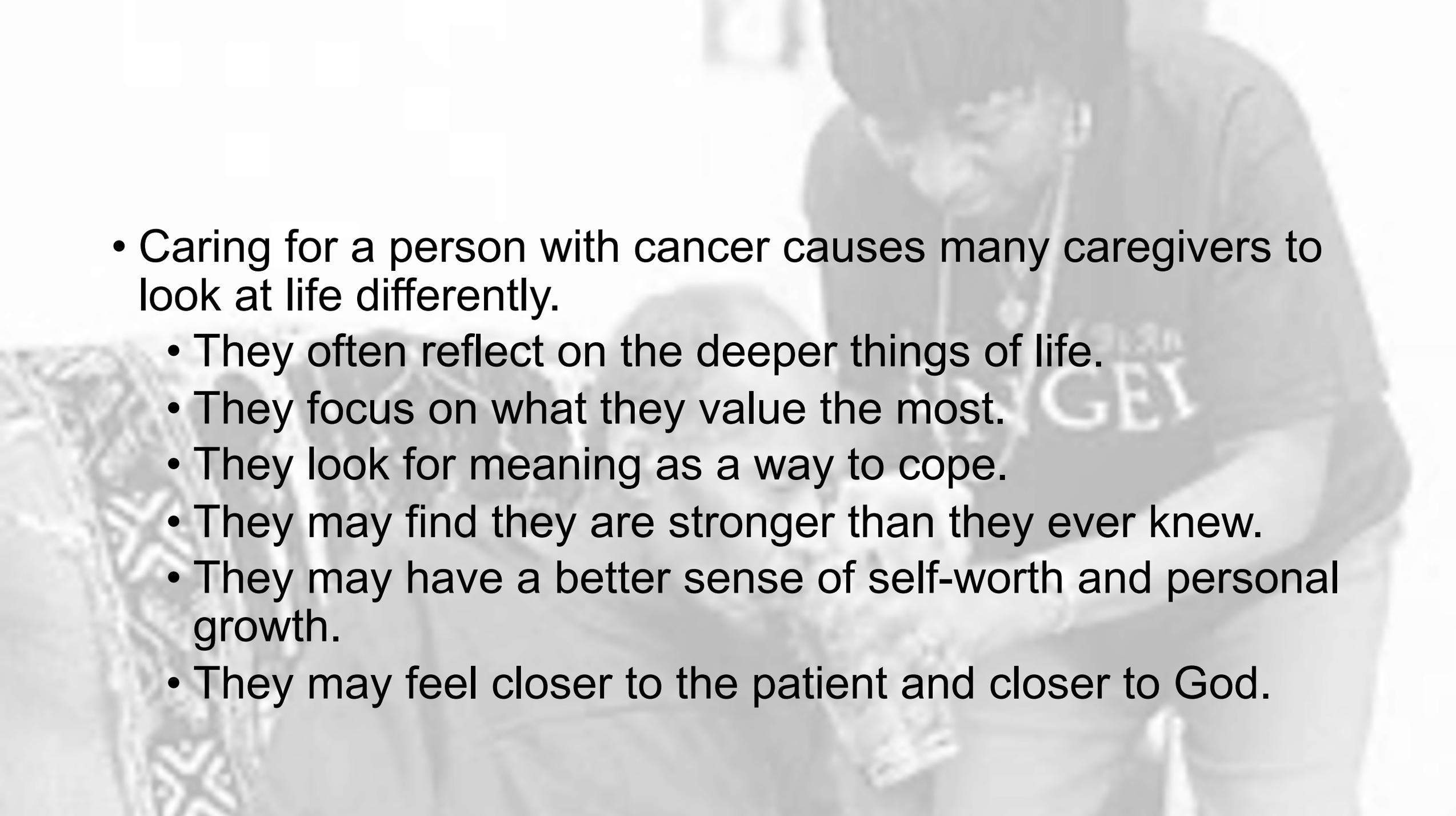
# Spiritual Issues

- Feelings of spiritual well-being may lower the caregiver's stress.
- Keeping faith and finding meaning and hope have been shown to decrease the caregiver's stress and mental health.
- Being at peace spiritually may help some caregiver's be more helpful and more accepting of the cancer experience.

# Rewards of Caregiving

- Caregivers become caregivers for many different reasons.
  - Some feel it is natural to care for someone you love.
  - Sometimes there are practical reasons such as limited insurance or resources to pay for home health care.



- 
- Caring for a person with cancer causes many caregivers to look at life differently.
    - They often reflect on the deeper things of life.
    - They focus on what they value the most.
    - They look for meaning as a way to cope.
    - They may find they are stronger than they ever knew.
    - They may have a better sense of self-worth and personal growth.
    - They may feel closer to the patient and closer to God.