



The Sojourner Project

...help for the journey

The Four Journeys

Not all family caregivers are the same. Each of you is on a unique journey with your particular loved one and their individual needs and concerns. Some of you are more active in your loved one's care, while others have a much smaller role. It is important to understand the different path that your caregiving journey might take so you can be prepared for the challenges ahead. Depending on the reason for the caregiving journey some of you might need to do more work and preparation upfront while other have more time to plan and prepare. Below I have identified the four different paths you might find yourself traveling. Some caregivers begin their journey on one path and then find themselves on another as circumstances change. But knowing where you are now will give you a place to start.

1. Just Old Age

For these family caregivers the person you are caring for is generally in good health with no major physical issues. On this journey your loved one is just getting older and increasingly more frail. Your aging spouse or parent is active in their care decisions, and their judgment and reasoning abilities are in tact. These are individuals who just need a little extra help and oversight in the beginning and but increasingly need more care over time. Eventually they will no longer be able to manage things on their own and usually need more daily assistance. Some eventually move in with family or to a residential setting where their safety and daily needs can be met more easily.

2. Physical Disease or Disability

The individual being cared for on this journey is struggling with the physical symptoms of either disease or disability but has no impaired judgment or reasoning ability. On this journey the family caregiver takes on more responsibility in either providing or overseeing the physical care of their loved one who is still an active participant in their care decisions. Examples include cancer or diseases that affect the heart, lung or kidney functioning or a physical disability due to stroke or joint injury.

3. From Disease to Dementia

Family caregivers on this journey begin when a loved one is diagnosed with an illness that begins with physical decline but eventually will progress to increased cognitive impairment or dementia. Those diagnosed with neurological disorders that initially affect a person's physical functioning and in the more advanced stages cause increased confusion, disorientation, or forgetfulness. Caregivers on this journey begin managing physical symptoms but need to be prepared to protect their loved one from impaired decision making. Examples include brain injury, stroke, Parkinson's disease and some cancers that metastasize or spread to the brain.

4. From Dementia to Disease

Disorders primarily of the brain most notably Alzheimer's creates a much different journey for the family caregiver. This road begins with impaired judgment and reasoning, which are usually masked and go undetected for quite some time until the symptoms become too obvious to ignore. Your loved one continues to be physically healthy and active but their faulty memory and confused thinking require you the caregiver to take over decision-making early in this journey. Later you will evolve into providing or overseeing their physical care but that is usually in the middle to the end of this long and arduous journey.

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