

The 5 stages of family caregiving

By Dr. Mark Frankel

Caregiving is like being in a dramatic movie where the inevitable end is already known but the story itself is unpredictable and full of twists and turns, highs and lows, peaks of joy and sorrow, high anxiety and quiet satisfaction. Although you already know the ending, looking after a parent is full of surprises that may just cause you to wonder “What comes next?” while you catch your breath!

But there is, however, a distinct pattern and storyline to it all, despite the day-to-day rewards and hurdles. What comes next, in fact, is that family caregiving typically unfolds into five distinct stages. Knowing those stages, including their challenges, costs and opportunities, can give you a head start.

Stage 1

Theme: Independence

Soundtrack: My Way

The storyline

This may not seem like a “caregiving” stage at all, but stage 1 is the period when elderly parents don’t want any help. It is often a time when adult children “see” their parents as older and less capable than do the parents themselves. Regardless of perceptions, seniors at this stage are usually quite capable of taking care of themselves, though perhaps not in the ways preferred by their children. They may indeed be experiencing some of the chronic ailments associated with aging (e.g., heart conditions, diabetes, arthritis, hearing or visual impairments), but they are able to com-



pensate on their own for any loss of function.

Some adult children take pleasure in seeing their parents at this stage. But many others worry about their parents’ health, judgment and what will happen if a parent falls seriously ill. Besides worrying, there are indeed some proactive things that adult children can do at this stage.

Resources for family caregivers

- Financial planners and legal advisors. You can model good legal and financial planning for your parents. Let your parents know about

your own arrangements for the future—will, living will, powers of attorney, financial plan, insurance—and respectfully encourage them to start to plan if they have not already done so.

- There is a vast array of educational material in books, magazines, newspapers and online on the topic of aging. Educate yourself about the emotional, physical, social and spiritual dimensions of aging, so that you can be better aware of your parents' experiences and challenges.

Stage 2

Theme: Interdependence

Soundtrack: *We are Family*

A typical scene

Mrs. Morris is an 86-year-old widow still living on her own, for the most part, in a three-bedroom multi-level townhouse. She has four grown children on whom she is very dependent. They have a rotating schedule for caring for/checking in on her every day. She suffers from severe arthritis, a heart condition, is losing her sight and hearing and may be showing some early signs of dementia (undiagnosed). She requires assistance for many aspects of daily living, including meal preparation, house cleaning, laundry, transportation to doctor's appointments and grocery shopping.

This situation is extremely stressful for everyone. Mrs. Morris's children all agree she needs to have someone with her 24/7 or be in a facility with continuous care and monitoring. However, Mrs. Morris is refusing, does not want to even consider outside help and does not want to leave her home and all the memories of the past 60 years.

The storyline

At this stage, seniors may, due to disabilities, need substantial assistance. However, they are firmly resistant to hiring outside help, either citing the cost, denying the need or both. What most seniors will accept at this stage is family help. If you can prepare some meals or drive mom or dad to the bank, doctor or supermarket or assist in other practical ways, this support is usually accepted.



Resources for family caregivers

At Stage 2, seniors are more likely to accept technical devices that help them and their loved ones to stay in touch. For example, emergency call systems are increasingly popular. They enable the user to wear a pendant or a wristband that they can activate if they fall or need help. Internet-based video systems have become more sophisticated and less expensive and enable elderly parents and adult children living far away to stay in touch visually as well as by voice.

More exotic electronic systems are also coming onto the market now, including “smart homes” with a variety of monitoring devices to keep track of the occupant's activities and “carebots”—sophisticated mobile robots that can also serve as helpful communication and monitoring devices.

Finally, Stage 2 is a time when a retirement residence is appealing to some seniors, depending on their preferred lifestyle and their financial means. Retirement residences are multi-unit residential buildings with amenities to make life easier for the seniors living there. These residences are not health-care facilities. Instead they stress independent living and thus are often acceptable to independence-minded seniors.

“We are young only once, after that we need some other excuse.”

Unknown



Stage 3

Theme: Supportive living

Soundtrack: Home! Sweet Home!

A typical scene

Mr. and Mrs. Black, both in their late 60s, live in their own two-storey home. Mr. Black, diagnosed with Parkinson's approximately 10 years ago, is now dealing with many of its symptoms. He has problems walking and with other daily living activities. Mrs. Black has recently had a hip replacement. This has made it impossible for her to assist her husband, and she herself has needed care.

While Mrs. Black has been convalescing at home, they have both needed the help of personal support workers to assist with meals, bathing and dressing, and Mr. Black will continue to need this extra care. He also has to have a physiotherapist brought into the home to help with mobility and exercise, as well as an occupational therapist to help with daily living activities. At this time they are also relying on family and friends for transportation to medical appointments and grocery shopping.

The storyline

In Stage 3, seniors are trying to cope with multiple disabilities and often chronic pain. This is the stage at which seniors begin to accept outside caregivers who can help with personal care and/or healthcare. Family members are also often heavily involved in helping to find, hire and coordinate formal caregivers (personal support workers, nurses, therapists) and themselves assisting their elderly loved one with activities of daily living.

Resources for family caregivers

Family caregivers can benefit at this stage from a variety of services and programs, including community intake and referral services; home-care and home healthcare agencies; public healthcare facilities offering geriatric and/or psychogeriatric assessments of your loved one; and educational programs, books and online services that can help you learn about and find resources and navigate the system.

Although the vast majority of seniors at this stage have a very strong desire to remain in their own home (no matter what difficulties this presents), some will accept the alternative of assisting living residences (sometimes called "retirement homes"). Assisted living facilities, both private and publically funded, typically offer private or semi-private bedroom accommodations, a dining room, a full activity and recreational program and trained staff who provide direct assistance to residents needing help with any of the basic activities of daily living (eating, dressing, bathing, grooming and mobility).

Stage 4

Theme: Complex care/crisis management

Soundtrack: Help!

A typical scene

Mr. Bauer, an 88-year-old man lives with his 83-year-old wife. He has been dealing with severe Alzheimer's disease for the past four years and his wife has been, for the most part, his only support. Their daughter helps with errands, groceries and doctor's appointments, and their son-in-law looks after home maintenance. Mr. Bauer rarely speaks, has poor balance when walking, cannot dress or feed himself and no longer recognizes his family. A personal care worker has been hired to help dress and feed Mr. Bauer. Lack of sleep and exhaustion have led Mrs. Bauer to seek respite, and she has health concerns of her own.



The storyline

Stage 4 is a difficult and often painful stage for all concerned. Your loved one's physical and/or mental condition has declined to such a degree that he or she is dependent on others for most of the care. There are usually multiple health conditions challenging your parent, requiring a variety of treatments and therapies. If cognitive problems (thinking, memory, impulse control, judgment) are a part of the problem, close, skilled supervision is also required—often around the clock.

Despite the involvement of formal caregivers, the levels of care in the home available to the family at this stage may be inadequate or too expensive, leading to one crisis after another. At this stage, it is common for the only thing preventing a nursing home admission to be an earlier promise to the elderly parent or to one's self to never place the parent in such an institution.

Resources for family caregivers

Self-care for family caregivers is not a luxury at this stage—it is a necessity. This is the stage of family caregiving when the caregiver, be it an adult child, spouse, sibling or friend, finally “burns out” and gives up, resulting in a major crisis. Self-care for caregivers, including stress-management programs, meditation and yoga, is invaluable. So are therapy programs to help the caregiver deal with depression and sleep deprivation.

Community referral services can help you locate these programs as well as respite care programs. A competent geriatric care manager can also help. Geriatric care managers are social workers or nurses specifically trained to assess seniors' needs, devise a comprehensive plan of care and help a family coordinate and manage the care and caregivers required.

Stage 5

Theme: **Dependence**

Theme song: *Missing You*

The storyline

At some point, many families come to see that the well-being of both their elderly loved one and of the remaining family will be better served by a nursing home admission. In fact,

at this stage the patient is often safer and more comfortable with 24-hour institutional health and personal care than with a patchwork of homecare services.

Resources for family caregivers

Anyone who has visited a nursing home, even the best ones, knows how difficult it can be to see a loved one there. However, even here there are valuable resources to assist family members. Written materials can coach family members on how best to advocate for the treatment and welfare of a loved one in a nursing home. There is also usually a social worker in the facility with whom you can discuss concerns and feelings, especially feelings of grief and loss related to the current state of your loved one. Finally, many nursing homes organize family councils where you can address issues of common concern.



Finale

Not all aging individuals and their families pass through all of these five stages. Nor do they pass through all stages at the same pace. We know that most Canadians die either at home or in a hospital and never even see the inside of a nursing home. But the five family caregiving stages provide a framework for understanding the main needs and issues for your family at any point in time, and help in anticipating what the next stage in your journey might be. ●

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