

Caregiving Toolkit

KEYS TO CAREGIVING FOR THE SANDWICH GENERATION





Caring for others is never a selfish act!

Caring for a loved one as they age is different for everyone. You may be a young adult caring for a parent or a member of the Sandwich Generation, caring for your own children and your parents at the same time. This booklet provides basic information and resources that can help caregivers navigate their way through being a caregiver.

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Communication

Start the conversation! Planning for the silver years can create a sense of comfort as your loved one ages. Having a plan in place and knowing what actions to take is essential in navigating the caregiving role.

Talk to Your Loved One, Family and Trusted Friends

If you find it difficult to talk with your loved one directly, practice the conversation with others that have experienced caring for an aging adult (parent or grandparent). Talking with others can help you lay the groundwork for how you will talk with your loved ones. Every conversation will be different based on timing and circumstances.

DISCUSS YOUR LOVED ONE'S "FIVE WISHES"

1. The person I want to make care decisions for me when I can't. *Example:* Choose someone who knows you very well, cares about you, and who can make difficult decisions. Whomever you choose to be your health care agent, make sure you talk with them about these wishes and be sure this person agrees to respect and follow them.

2. The kind of medical treatment I want (or don't want). *Example:* I do not want to be in pain. Share your Advanced Directives and/or Living Will with your caregiver, family and health care provider.

3. How comfortable I want to be. *Example:* I want my doctor to give me enough medicine to relieve my pain, even if that means I will be drowsy or sleep more. I want to have a cool moist cloth put on my head if I have a fever. I wish to have warm baths often. I wish to have religious readings and well-loved poems read aloud.

4. How I want people to treat me. *Example:* To be cared for with kindness and cheerfulness and not sadness. I wish to have my hand held and to be talked to, even if I don't seem to respond to voice or touch. I wish to be visited by a chaplain or clergy.

5. What I want my loved ones to know. *Example:* To know I love them. I wish to be forgiven for the times I have hurt them and know that I forgive them for when they may have hurt me in my life. To remember me as I was before I was ill.

Plan for the Future

Having a caregiving plan in place will provide peace of mind for your loved one and family. Every caregiving plan will be unique and should center around the wishes of the individual receiving care.

DISCUSS FUTURE CARE NEEDS

- Understand and respect your loved one's values and goals.
- Ask for help. Schedule a family meeting where you can delegate tasks and rally support from within.
- Create a support team for yourself and your loved one.
- Maintain this conversation over time.

Financial Discussion

While money can be a sensitive subject, it is very important to have a firm understanding of financial obligations for future/current caregiving needs. This will be a key in planning for the future.

- Does your loved one have health insurance, Medicare, Medicaid, Veterans benefits, Long-Term Care insurance?
- Review all known assets (bank accounts, house, auto, stocks and bonds).

NAVIGATING LONG-TERM CARE COSTS

Medicare is funded by Social Security tax contributions. Medicare does not cover a majority of Long-Term Care (LTC) needs such as Custodial Care or Nursing Care.

Medicaid is a low-income, needs-based program that disabled and elderly individuals can apply for when requiring a nursing facility and will cover some LTC support needs.

Much of LTC costs are paid for by loved ones or family and friends. When determining how to pay for LTC, start with a loved one's savings, pensions, investments, Social Security benefits, and the option of selling a car or house to help with the cost.

Understand and respect your loved one's values and goals.



Documentation

Keeping track of medical, financial and legal documents for aging parents is important. Their care needs can change quickly, requiring you or them to move fast and have paperwork ready. Your loved one may become ill, need to move, or have to file for state, federal, or veterans benefits. It becomes increasingly important to quickly locate medical and/or legal documents so your aging loved one can have them on hand when required. From deeds/title documents and power of attorney to living wills and medical history, read on to see which documents all of us should have in order.

Create a Medical History Binder

The Medical History Binder provides important medical history to providers, nurses and other treatment services. This binder should be on hand and taken to appointments, emergency room visits or hospital stays to update with new information.

HAVE A RECORD OF ALL MAJOR INCIDENTS:

- Surgery Dates and Outcomes
- Medical Episodes, Dates and Outcomes
- Changes or Reactions to Treatments or Medication
- Copies of Recent Important Tests (Bloodwork, X-Ray, MRI, etc.)
- Any Known or New Allergies
- Medical Diagnoses
- Hospitalization and/or Rehabilitation Stays
- Upcoming Appointment Calendar

Create a Health Surrogate Binder

You or your loved one may want to share a copy of the Health Surrogate Binder with family members, an attorney, your loved one's doctor, and/or trusted friends.

HAVE A COPY OF ALL MAJOR MEDICAL DOCUMENTS:

- Driver's License/ID Card
- Advance Directive (Living Will, DNR, DPOA, Surrogate, Proxy, POLST)
- Insurance ID Cards
- Medication List
- Physician's Names, Addresses and Phone Numbers
- Daily/Weekly/Monthly Schedule/Activity Log

Create a Legal Binder

There are specific legal documents that should be gathered and a copy provided to family and/or attorney.

HAVE A COPY OF ALL MAJOR LEGAL DOCUMENTS:

- Birth Certificate
- Social Security Card
- Citizenship Documents
- Life Insurance Plan Information
- Will
- Trust Documents
- Guardianship Documentation
- Deeds/Title Documents
- Rental Contracts
- Military/Discharge Records
- Sources of Income (Pension, IRAs, 401(k)s etc.)

Did You Know?

1

DNR's must be printed on yellow paper in order to be legally valid in the State of Florida and made readily available for medical professionals.

2

Durable Power of Attorneys (DPOA) are important tools to have, however they cannot be used to close a bank account after someone passes away for the simple reason that a DPOA expires once the principal passes away.

3

Originals are required for Wills and Trust documents. These are sometimes stored in safety deposit boxes.

4

Fraud among the elderly is rising. Don't become a victim. If you think your loved one has fallen victim to elder fraud, contact the National Elder Fraud Hotline at (833) 372-8311.



Support

The caregiver and the one receiving the care both need support along the way. Not all support is the same and it is important to know the different support options you or your loved one will need.

The Hidden Patient

Many caregivers sole focus is on the one they are caring for. As a result, they can become what is referred to as “The Hidden Patient.”

PRIORITIZE YOUR OWN SELF-CARE

Balancing the workload of caring for an elderly loved one and your own child(ren) while working and maintaining other family obligations can be stressful. One of the most difficult parts can be the demand of your time. YOU ARE IMPORTANT TOO!! Stress can play a negative role on your health and well being as well as your ability to provide care to others. Take time for yourself and make it a priority.

DON'T UNDERESTIMATE THE BENEFITS OF THERAPY AND SUPPORT GROUPS

Recognize your emotions. Look for local resources and services that can help support you along your journey. Finding and talking to others who are experiencing and balancing the same workload as you can be comforting.

ASK FOR HELP, ASK FOR HELP, ASK FOR HELP

Remember your loved one will also benefit from having a bigger caregiving team and don't feel guilty for reaching out to others to help when needed. After taking time to care for yourself, you are then able to return to your responsibilities with a refreshed, open-minded feeling.

RESPIRE CARE

All caregivers need short-term breaks from caregiving to take care of their own needs. Whether utilizing an available bed in a health care facility where skilled care is offered, limited time services in another family member's home, or attending an adult day service center know the options available and utilize these services as a temporary relief from providing care.



“Caregivers kind of become what's referred to as ‘the hidden patient.’ The physical and emotional toll that they suffer really gets overlooked because they're so focused on whom they're identifying as needy.”

– Debbie Oberlander, LCSW

Technology for the Caregiver

Many caregivers are attempting to balance the ever changing needs of an aging loved one along with their own personal needs, work, parenting and other demands in their lives. Digital technology can help offer solutions for caregivers. Utilize available devices, applications and websites to help manage care. Here are a few examples:

- Lifeline Medical Alert System
- GPS System
- Medication Management (MediSafe Mobile App)
- Personal Health Record Tracking
- Stay Connected (Alexa Together, Google Nest, Depend)
- Transportation Services (Find a Ride Florida)
- Home Safety Checklist
- Online Shopping for Goods/Services (Meals on Wheels America, Uber Eats, Instacart)



Types of Senior Living

Navigating senior care living options can be quite the challenge. Many of our loved ones will choose in-home care while others choose to be under the care of a facility. All facilities are different. Some are geared toward retirees who are active and independent, while other communities assist with daily living, medical support, or specialized care. It is important for your loved one to know the benefits of each when deciding if now is the time to discuss senior living.

IN-HOME CARE

Staying at home or moving in with a relative may be the best option for your loved one for many reasons. Home care can include professional support from a home service provider, nurses, caregivers, family and friends. Here are some helpful tips for In-Home care:

- Home health care services to help with maintaining daily living activities
- Hourly Adult Care or Respite Care
- Daytime assistance while primary In-Home Caregiver is busy (Respite Care)
- Geriatric Care Manager
- Adult Daycare
- Friendly Visit and Senior Companion Services
- Utilize local community resources
- Simple fixes to help make a safer and more comfortable home

INDEPENDENT LIVING

Senior Apartment/Condo style living for individuals that may not need the medical assistance included with assisted living but would like the opportunity to live around others, maintenance free, and the security of the facility and staff.

ASSISTED LIVING

Assisted living for active seniors provides the comfort of home and basic medical care that individuals may need. Caregivers and nurses are on staff to assist with dressing, bathing, and transportation. The staff will work directly with an individual and/or their family to determine necessary care.

BOARD AND CARE HOMES

Smaller living facilities with very few residents.

90% of people say that talking with their loved ones about end-of-life care is important. 27% have actually done so.



MEMORY CARE

Many assisted living locations have the ability to transition our loved ones to specialized care for those with Alzheimer's or Dementia. Their programs will have a more structured environment to lower stress and confusion for individuals.

CONTINUING CARE RETIREMENT COMMUNITIES (CCRCs)

An incorporation of the above all at one location. Many individuals would like to retire and move one time. CCRCs have the ability to provide necessary care at different levels as our loved one's age.



PALLIATIVE CARE

Similar to Hospice Care, Palliative Care focuses on easing pain, but it is provided to everyone living with a serious illness and patients will continue to receive treatments for their illness. Palliative Care focuses on quality of life and managing symptoms and should be considered as soon as a loved one is diagnosed. Medicare, Medicaid, some insurance policies, the Department of Veterans Affairs, and private insurance may pay for some Palliative Care services. Visit the National Hospice and Palliative Care Organization's website to find care near you. Many times, Palliative Care will transition into Hospice Care.

Consider This While Vetting Senior Living Options:

1	What is wanted?
2	What is needed?
3	Tour the facilities that are being considered.
4	Discuss cost as each facility is different.
5	Confirm all the services that are included.

HOSPICE CARE

For those individuals that have a life-limiting terminal illness, Hospice Care provides the highest level of comfort care. There may come a time when a person's illness is no longer treatable or when the person has decided not to undergo treatments. At this time, Hospice will help with providing the comfort and necessary care your loved one needs as attempts to cure the illness have stopped.

There are different levels of Hospice Care and an individual may utilize all four levels depending on the circumstance and specific needs. The four levels of Hospice Care are:

- 1. Hospice Care at Home:** Routine visits with a designated home team. Necessary equipment, supplies, and medications are provided.
- 2. Continuous Hospice Care:** In a period of crisis, this provides 24/7 bedside care in the home, a long-term care facility, hospital, or a nursing home.
- 3. Inpatient Hospice Care:** When symptoms can not be managed at home, inpatient support provides acute-care to control pain and stabilize symptoms.
- 4. Respite Care:** Short-term inpatient stays to provide primary caregiver a break, to avoid burnout, while providing round-the-clock, hands on care.



Preparing for End of Life

End of Life discussions and decisions can be the most difficult part of caregiving. Use this page as a starting point when navigating this difficult time.

End of Life Checklist

- ☐ Notify Family & Friends
- ☐ Prepare Obituary
- ☐ Obtain Estate Documents (will or trust agreement) *Will must be filed with Clerk or Court within 10 days after passing.*
- ☐ Inventory Assets
- ☐ Identify Creditors (Failure to pay creditors can result in costly litigation over the estate)
- ☐ Notify Social Security
- ☐ Cancel Memberships
- ☐ Contact Life Insurance Company
- ☐ Homeowner? Call Property Appraiser
- ☐ Notify Department of Motor Vehicle
- ☐ Stop or Forward Mail through the Post Office. Consider forwarding to an appointed Executor.
- ☐ CPA (File Final Tax Return)
- ☐ Credit Agencies
- ☐ Make care arrangements for pets
- ☐ Close Bank Accounts
- ☐ Contact Financial Advisor/Broker
- ☐ Order several certified copies of the death certificate. Will need to provide to banks, insurance companies, creditors, etc.

Resources:

National Suicide and Crisis Text Line(s)

Text 988 or 741741

National Elder Fraud Hotline

(833) 372-8311

Search for Senior Living Facilities

www.aplaceformom.com

Florida Agency for Health Care Administration

www.ahca.myflorida.com

Five Wishes

www.fivewishes.org

Donate Life Florida

www.donatelifeflorida.org

The Conversation Project

theconversationproject.org

Family Caregiver Alliance

www.caregiver.org

AARP®

www.aarp.org/caregiving

Eldercare Locator

www.eldercare.acl.gov

Find A Ride Florida

www.findarideflorida.org

National Hospice and Palliative Care Organization

www.nhpco.org

Meals on Wheels America

www.mealsonwheelsamerica.org