The Caregiver's Handbook

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Objectives

1. Discuss four important elements of caregiving, including:
    - Goals of Care Conversations
    - Advance Care Planning
    - Serious Illness Care
    - Caring for the Caregiver

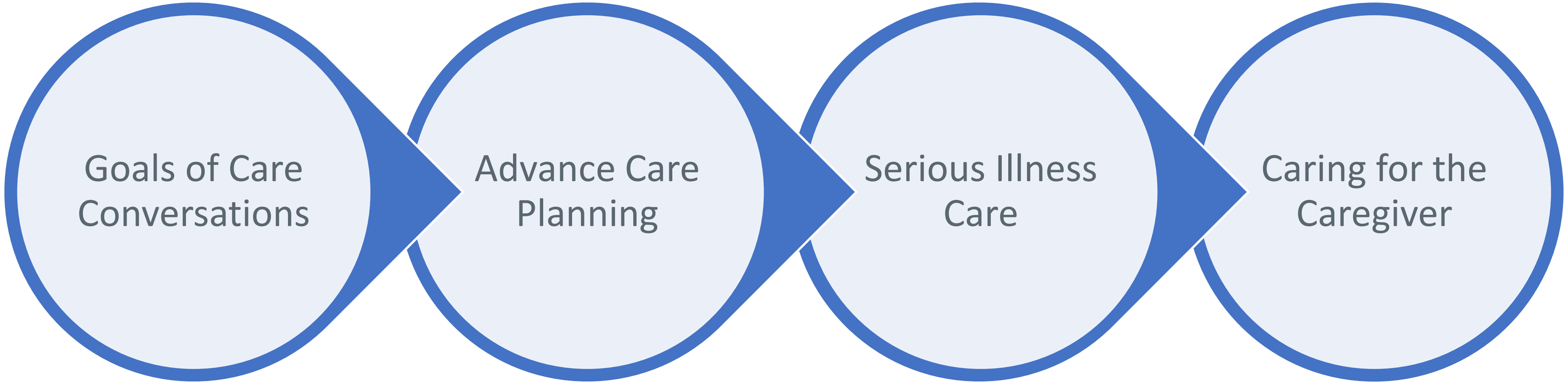
2. Identify resources to support caregivers and provide a take-home toolkit of key references

Why Is It Important to Talk About Caregiving?

- Many of us will find ourselves in a caregiving role sooner or later – if we aren't already.
- According to the National Alliance for Caregiving and AARP 2020 report *Caregiving in the U.S. 2020*[1]*:*
    - The number of Americans providing unpaid care increased each year from 2015-2020
    - 61% of family caregivers also maintain employment
    - 41% of caregivers are Baby Boomers or older, while 59% are Gen X, Millennials, or Gen Z

1 Caregiving in the U.S. 2020

Caregiving on a Continuum



Goals of Care Conversations

- Conversations to establish values, priorities, and goals

Advance Care Planning

- Legal documents to guide medical treatment decisions

Serious Illness Care

- Palliative Care
- Hospice Care

Caring for the Caregiver

- Accessing resources to provide support and reduce risk of burnout

Goals of Care Conversations

Goals of Care Conversations

- As illness develops or progresses, it is important to have open conversations with loved ones and healthcare providers
  - Medical decisions often become more complicated and more difficult to make
  - Discussions surrounding prognosis, expected trajectory, and individual goals are important to help ensure quality of life in serious illness
- Goals of care conversations refer to the entire spectrum of medical decision making, including discussion of the patient's values, goals, and treatment preferences[1]
  - These conversations can include making decisions about current or future treatments

[1] Comer A, Fettig L, Torke AM. Identifying Goals of Care. Med Clin North Am. 2020 Sep;104(5):767-775. doi: 10.1016/j.mcna.2020.06.002. PMID: 32773044; PMCID: PMC7458156.

How to Have a Difficult Conversation

- Find the right time and place
  - Choose a quiet, private setting
  - Make sure that you have enough uninterrupted time
- Ask for permission
  - "I'd like to talk to you about what you'd want if you got sicker, is that ok?"
  - "I want to be sure that I understand what you would want if you got very ill, can we talk about it?"
- Listen more than you speak
  - You may need to have a series of conversations instead of only one
  - This conversation is about *their* goals, not yours. Try to listen and understand, not argue.
- Offer to support a goals of care conversation with their medical provider

Goals of Care Conversations

What questions should I ask?

- Is it more important to you to achieve cure or to prioritize comfort?
- If you become sicker, would you prefer to be at home or move to a facility like an assisted living, nursing home, or hospice house?
- What religious or spiritual values are most important to you?
- Are there specific medical treatments that you'd like to avoid?
- What are your goals when it comes to managing your illness?
- *What is most important to you right now?*

Talking to the Healthcare Provider

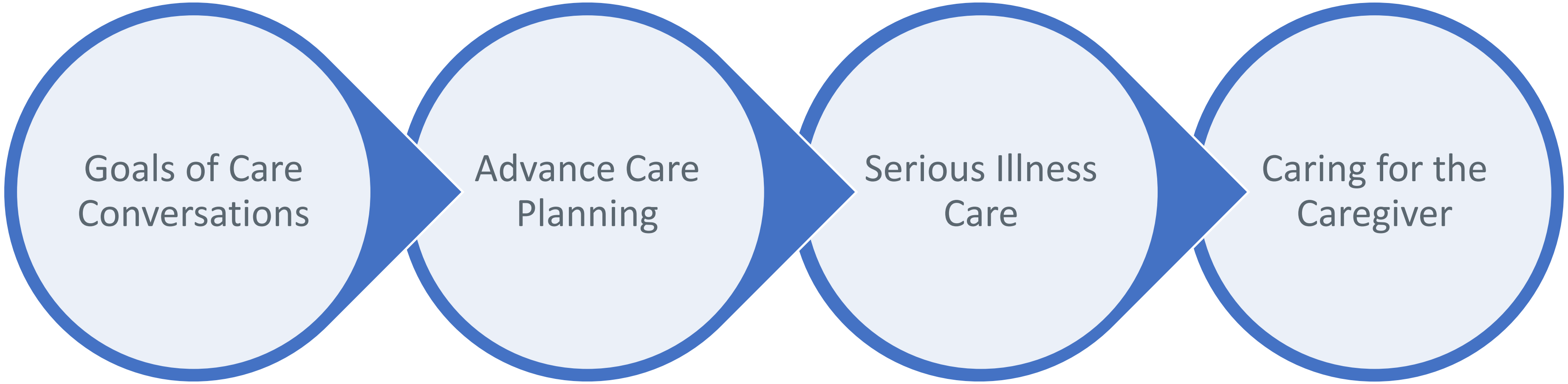
- Help your loved one to schedule an appointment with their healthcare provider to discuss goals of care

- Think about the conversation you had with your loved one
  - Be prepared to discuss their goals and preferences, and make sure that the healthcare provider helps create a plan for how to meet them

- *Does the current treatment plan correspond to what your loved one said they wanted?*

Goals of Care Inform Advance Directives

- Goals of care conversations should feed into advance care planning
  - Decisions made as part of goals of care conversations can be used to inform legal documents that will guide future treatments



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Advance Care Planning

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- Advance care planning is the process of planning for future care based on a person’s values, beliefs, preferences, and medical issues.
  - An advance directive is a record of this process
  - The purpose of an advance directive is to allow an individual to communicate their wishes for care and treatment prior to a crisis event

Advance Care Planning

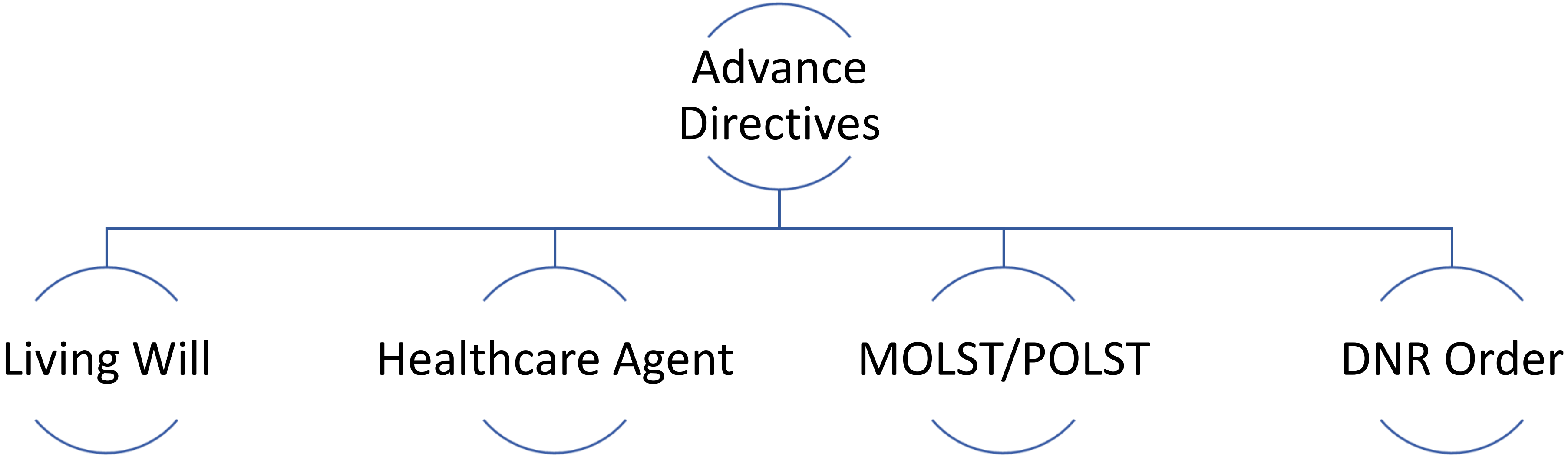
Discussing wishes with loved ones and medical providers is important during all stages of life, whether a legal advance directive is in place or not

As an individual ages or faces serious illness, it is important to develop a legal advance directive to guide healthcare decisions

Even with a healthcare agent in place, many decisions require a written directive in order to withhold or withdrawal treatments

Advance Care Planning

The term Advance Directive can refer to a specific document, or to the overarching concept of defining and documenting medical treatment decisions.



Advance Directives

Living Will

Healthcare Agent

MOLST/POLST

DNR Order

Advance Care Planning

- Living Will
  - A document that outlines the care and treatment that an individual would want in the event that they are unable to speak for themselves
- Healthcare Agent or Power of Attorney
  - A document that designates the person who can make healthcare decisions on an individual's behalf if that person is unable to do so
  - Differs from a Financial Power of Attorney, which provides authority to make financial decisions

Advance Care Planning

- Medical/Portable Orders for Life-Sustaining Treatment (MOLST/POLST)
  - A document that provides specific instructions for the medical treatments that an individual would want or not want in the event that they are in a terminal or vegetative condition.
  - Typically address treatments such as dialysis, ventilation, and artificial nutrition.
  - May include instructions regarding resuscitation status
  - Must be honored by medical professionals, including emergency medical personnel
- Do Not Resuscitate (DNR)
  - A medical order that provides instructions regarding whether or not to provide resuscitation efforts in the event that an individual’s heart stops or they stop breathing

Advance Directives

- Advance directives vary by state and are not always recognized across state lines
  - Find the appropriate advance directive for your state at CaringInfo: Advance Directives by State[1]
- It's important to ensure that healthcare agents, family members, and medical providers have copies of all current advance directives
  - Patients should also carry a copy to any medical appointments or procedures
  - Services for scanning and storing electronic copies[1]:
    - AD Vault
    - U.S. Advanced Care Plan
    - Medic Alert Foundation
    - My Directives

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1 Caring Info | Advance Directives

Serious Illness Care

Serious Illness Care

Serious Illness

- A health condition that carries a high risk of mortality (death) and either negatively impacts a person's daily function or quality of life, or excessively strains their caregivers.[1]

Examples may include:

- Cancer
- Parkinson's Disease
- Congestive heart failure (CHF)
- Chronic kidney disease
- Chronic obstructive lung disease (COPD)
- Advanced dementia

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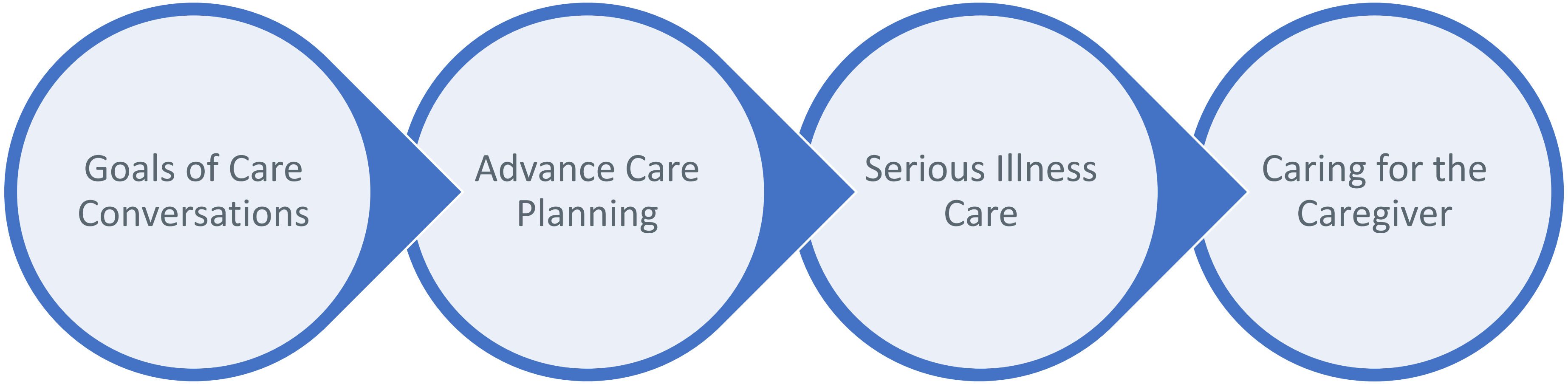
[1] Kelley AS, Bollens-Lund E. Identifying the Population with Serious Illness: The "Denominator" Challenge. J Palliat Med. 2018 Mar;21(S2):S7-S16. doi: 10.1089/jpm.2017.0548. Epub 2017 Nov 10. PMID: 29125784; PMCID: PMC5756466.

Serious Illness Care



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Serious Illness Care

Palliative Care

- Focuses on reducing symptom burden and improving quality of life
- Appropriate at any stage of a serious illness, not limited to end of life
- Provides additional support to the patient and family by providing consultative care directly, as well as coordinating with the existing medical team
- Palliative care is a medical specialty, just like neurology, cardiology, etc., and may be provided in the patient’s home, via telehealth, in an outpatient setting, or in the hospital.

Hospice Care

- Focuses on reducing symptom burden and improving quality of life
- Appropriate for individuals with a life-limiting illness
- Provides an interdisciplinary team of professionals to deliver medical, nursing, psychosocial, spiritual, and bereavement care to the patient and family
- In-person care is provided wherever the patient calls home.

Palliative Care

- Available to anyone with a serious illness, regardless of life expectancy
- Can be provided alongside curative treatment
- Palliative care team works alongside patient's existing medical team to provide additional expertise and support
- Includes
  - Symptom management
  - Help with advance care planning
  - Goals of care conversations
  - Referrals to community resources (meal delivery, transportation, etc.)
- Provided in any setting
  - Providers may visit the patient, or visits may be in an outpatient setting
- May include interdisciplinary team, but most often includes physician and/or nurse practitioner with some support from social work or spiritual care providers
- Covered by Medicare Part B, Medicaid, and most private insurance plans

Palliative Care

When should palliative care be considered?

- Advanced, chronic illness
- Receiving maximum therapy but still having symptom management issues
- Need help with goals of care or advance care planning
- Recurrent hospitalizations
- Caregiver strain

How do we access palliative care?

- Ask medical provider, hospital, nursing home for a palliative care consult
- Referral may be necessary depending on insurance

Hospice Care

- Available to individuals with a terminal prognosis, defined by Medicare as a life expectancy of 6 months or less
- Focused on comfort and is provided when curative treatments are no longer providing benefit to the patient
- Includes
  - Symptom management
  - 24-hour on call support
  - In-person visits from interdisciplinary team
  - Medical equipment and supplies
  - Medications related to the terminal illness
  - Volunteer support
  - Bereavement support
- Hospice is not a “place”
  - Care is provided wherever the patient calls home
  - Some hospices operate freestanding facilities, must most hospice care is provided in the patient’s own home or nursing home
- Interdisciplinary team
  - Physician
  - Nurse
  - Social Worker
  - Chaplain
  - Hospice Aide
  - Bereavement Coordinator
  - Volunteer
- Covered by Medicare Part A, Medicaid, and most private insurance plans

Hospice Care

When should hospice care be considered?

- Terminal prognosis
- Symptom management issues despite maximum therapy
- Recurrent hospitalizations
- Caregiver strain
- Discontinuation of curative treatment

How do we access hospice care?

- Ask medical provider, hospital, nursing home for a hospice consult
- Visit Care Compare or NHPCO Find a Provider to find services in your area
- You do not need the doctor to call hospice for you, you can make your own referral

Hospice FAQs

- Does hospice staff stay with the patient 24 hours per day?
  - No. Primary caregiving is still provided by the patient’s family, facility staff, or paid caregivers. Hospice staff visit routinely to provide support and educate caregivers on how to care for the patient.
  - Hospice does provide respite care for short-term facility stays for patients with caregiving needs, as well as short-term intensive in-home or facility care for patients with uncontrolled symptoms.
- Should I wait until my loved one is very close to the end of life to call hospice?
  - No. Hospice can provide much more support to the patient and family, and measurable improvements in quality of life, the sooner they are involved.

Caring for the Caregiver

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Caring for the Caregiver

- Nearly one-third of the U.S. adult population are caregivers, providing an average of 20 hours of care per week[1]
- There are many types of caregivers[2]
  - Crisis caregivers: Sudden caregiving required by acute illness or emergency.
  - Long-term caregivers: Taking care of someone with a chronic illness for a prolonged period of time
  - Long-distance caregivers: Those who live far away yet both feel and are responsible for care
  - Sandwiched caregivers: Those who have other full-time obligations such as a job or young children

[1] https://www.caregiveraction.org

[2] https://www.caringinfo.org/planning/caregiving/what-is-caregiving/

Caring for the Caregiver

- Support Groups
  - Consider joining a support group (many are virtual!) specific to the type of care you are providing
  - CaringInfo provides links to support groups specific to certain diagnoses, religions, etc.
  - Your local Office on Aging, senior centers, and hospice organizations often host community support groups
- Develop a Network
  - Even if you don’t feel like you need any specific resources, staying connected to others who are experiencing caregiving can give you access to a critical network of support and resources for *if* and *when* you need it.

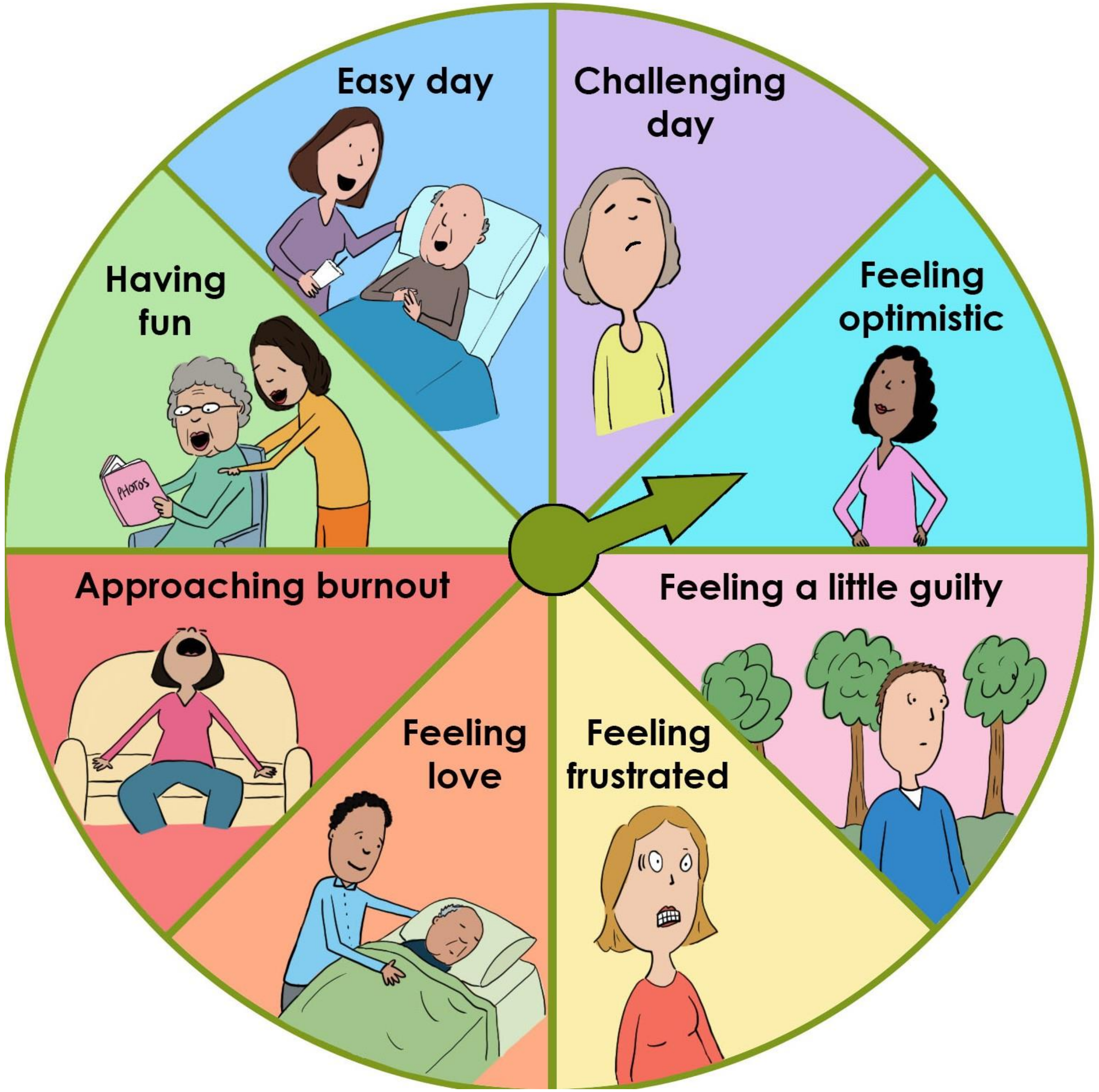
Caring for the Caregiver

- Private Caregiving
  - Hiring private duty caregivers for short or long-term care can help support caregivers who are working, caring for children, do not live locally, or are physically unable to provide hands-on care
  - Ensure that you are asking appropriate interview questions prior to hiring a private caregiver
    - Experience
    - Able to administer medications
    - Familiarity with specific disease process
    - Comfort with necessary tasks (bathing, toileting, patients who wander, etc.)
    - Find interview checklists on Care.com and A Place for Mom
  - Many local agencies such as hospices, Office on Aging, and hospitals carry updated lists of qualified local caregivers as well as recommended interview questions

Caring for the Caregiver: Stress and Burnout

- Prevalence of Caregiver Stress and Burnout
  - In a 2020 study, 36% of family caregivers described their situation as “highly stressful”[1]
  - In a 2021 study of family caregivers, Genworth reported[2]:
    - 42% experience depression, mood swing, or resentment
    - 30% experience sleep deprivation
    - 43% said that caregiving responsibilities have negatively affected their relationship with a spouse or partner
- Caregiver stress is real, and needs to be identified and addressed

[1] AARP: 1 in 5 Americans Now Provide Unpaid Family Care
[2] Genworth: How Caregiving Impacts Families, Communities, and Society



www.landmarkhealth.org

Caring for the Caregiver: Stress and Burnout

- Risk factors for caregiver stress include[1]:
  - Being female
  - Having fewer years of formal education
  - Living with the person you are caring for
  - Social isolation
  - Having depression
  - Financial difficulties
  - High number of hours spent caregiving
  - Lack of coping skills
  - Lack of choice in being a caregiver

[1] Mayo Clinic: Caregiver Stress

Caring for the Caregiver: Stress and Burnout

Signs of caregiver stress include[1, 2]:

- Feeling overwhelmed or constantly worried
- Feeling anger or frustration toward the person you're caring for
- Feeling exhausted
- Suffering from sleeplessness/insomnia
- Gaining or losing weight
- Becoming easily irritated or angry
- Losing interest in activities you used to enjoy, withdrawing from friend groups
- Feeling depressed or anxious
- Increasing health problems, such as frequent headaches, body pain, or other physical symptoms
- Abusing alcohol or drugs, including prescription medications

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1 Mayo Clinic: Caregiver Stress
2 AARP: 1 in 5 Americans Now Provide Unpaid Family Care

Caring for the Caregiver: Stress and Burnout

- Strategies for dealing with caregiver stress include[1,2]:
  - Accept help
    - Allow friends and relatives to bring meals, help with childcare, pick up medications
    - Set up a calendar for family and friends to share in caregiving responsibilities
  - Simplify communication
    - Explore web-based options like CaringBridge for keeping friends and family up-to-date
    - Designate a trusted friend or family member as the family spokesperson
  - Get connected with other caregivers, join a support group
  - Seek social support
  - Set personal health goals
  - See your doctor
  - Seek respite care for your loved one
  - Explore options for FMLA leave

1 Mayo Clinic: Caregiver Stress
2 AARP: 1 in 5 Americans Now Provide Unpaid Family Care

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- National Hospice and Palliative Care Organization https://nhpco.org
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