



## **Making Decisions About Caregiving**

January 12, 2023

**Debbie Emerson, M.S.**, Community Health Educator, CARES® Dementia Specialist

### Session Agenda

- Care Planning 101
- In-Home and Home Health Care
- Residential Care Facilities
- Paying for Long Term Care Services
- Locating Housing and Services
- Questions and Answers



## Goals

- Identify yourself as a care partner
- Recognize importance of communication
- Learn about options for long-term care
- Become aware of resources and services in the community and online
- Understand that . . .
  - every situation is unique
  - there is no right or wrong
  - everything you do involves trial and error
  - dementia adds another layer of complexity
  - you must become a critical evaluator and an informed consumer



## Projected Needs for LTC

- **Long Term Care:** a variety of services that help people with their medical and non-medical needs over a period of time.
- Most long-term care is **custodial care** that involves help with bathing, dressing, eating, toileting, transferring, housekeeping, etc.
- **70% of 65-year-olds will need *some* form of long-term support and services:**
  - 42% will have a need that lasts less than a year at home.
  - 37% will have a need that lasts less than a year in a facility.
  - Average duration is 3 years (3.7 years women, 2.2 years men).
  - 20% will need some sort of help for >5 years.

Source: U.S. Dept. of Health and Human Services 2020  
<https://longtermcare.acl.gov/the-basics/how-much-care-will-you-need.html>



## Keys to Successful Care Planning

- Preparation
- Organization
- Documentation
- Communication
- Flexibility
  - Circumstances change
  - Relationships change
- Always make your loved one's needs and wishes your #1 priority

## "The Talk"

- Don't wait for a crisis – plan ahead
- Find a good time to talk – avoid being rushed or distracted
- Ask questions; be a good listener
- Empathize – *"I've been thinking about what I might like if I were in your situation...."*
- Be prepared to take baby steps
- Sometimes things have to get worse to get better

## Shifting the Perspective

- Partnering, not parenting
- Reassure
  - You're on the same team
  - Your goal is to collaborate, not control
  - You're not switching roles
- Intend to be trusted
  - Make every action worthy of trust
  - Don't manipulate or coerce
  - Listen



## Family Dynamics Are Complex

- Care discussions may cause family tensions to erupt
  - Unresolved hostilities may surface
  - Concerns, grievances, hurts, pains, and rivalries can expand with age
  - Childhood roles can persist into adulthood
- Resistance in discussing important issues
  - Choosing power(s) of attorney, executors, trustees
  - Revealing/discussing finances
  - Communicating preferences about end-of-life care



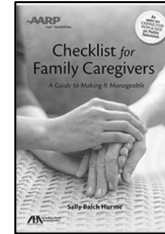
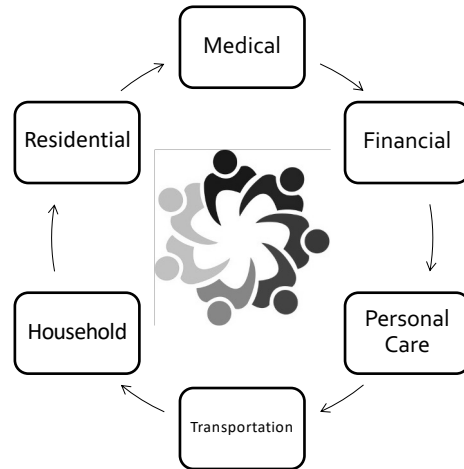
## Family Dynamics Are Complex

- Issues compounded by new layers and potential new rivalries:
  - Step-parents
  - Step- and half-siblings
  - In-laws
  - Exes
- Distance

## Working TOGETHER with Family Members

- Steer clear of power struggles over loved one's assignment of legal powers
- Don't let inheritance disputes tear your family apart
- Communicate with everyone
  - Avoid exclusive alliances
  - Don't exclude "difficult" family members
  - Don't withhold important information
- Consider holding a family meeting (see article on Resource List)

# Assessing Needs



## Aging in Place

- *The ability to live in one's own home and community safely, independently, and comfortably, regardless of age, income, or ability level.* - U.S. CDC
- Considerations
  - Medical and personal care needs
  - Cognitive issues
  - "Aging-friendly" home
  - Modifications to home
  - Level of independence
  - Budget
  - Family and friends nearby
  - Access to social activities/interactions
  - Transportation
  - Financial capability for round-the-clock in-home care if needed?
  - Availability of home care workers



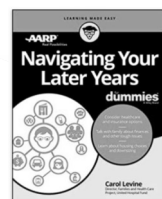
## Decisions, decisions, decisions

### Care at Home

- Whose home?  
*Yours? Theirs? Ours?*
- What are your reasons for choosing home?
  - Safety
  - Emotional
  - Financial
  - Sense of obligation
  - Lack of other options



## Considerations Before Moving Loved One into Your Home



- Loved one's preferences
- Amount and type of care needed:
  - Medical
  - Supervision
  - Social/emotional
- Your ability to spend a significant amount of time providing care
- Physical and emotional challenges
- Changing roles
- Financial considerations
- Changes necessary to make home accessible
- Unresolved issues such as strained relationships, abuse, neglect, alcoholism, divorce
- Impact on other family members



## Relocating a Loved One - “Transfer Trauma”

- Recognize how difficult it will be for your loved one to move
- Acknowledge emotions associated with the move: Abandonment, rejection, fear of the unknown, depression, grief
- Work through concerns together; communication is key
- As much as is possible, involve your loved one in selecting a residence



## In-Home/ Personal Care

- **Home Care:** non-medical care that focuses on personal care, household duties, meal prep, transportation to medical appointments, companionship, etc.
- AKA – Personal Home Care Services; Custodial Care
- In-home care services are offered **wherever the client resides:** private residence, assisted living, skilled nursing – anywhere services are needed
- Private pay
- Some agencies train staff in dementia care strategies: ex., Senior Helpers, Visiting Angels, ComforCare, Comfort Keepers





## Home Health Care

- Part-time services provided by *skilled* professionals: nurses, physical therapists, occupational therapists, speech pathologists, respiratory therapists, etc.
- May also include durable medical equipment (DME) and medical supplies for use at home
- Must be under care of physician; deemed medically necessary; homebound
- Paid under Medicare Part A and/or Part B
- Agencies regulated by state and federal laws
- Medicare and Medicaid (Medi-Cal) certified

[www.Medicare.gov/care-compare/](http://www.Medicare.gov/care-compare/)



## Addressing Guilt

- When the time comes and you are unable to provide all the necessary care at home, it does **NOT** mean that you're giving up . . .
  - on the person,
  - on your relationship,
  - on your responsibilities, or
  - on control.
- What you're recognizing is that . . .
  - You can't (nor should you) do it alone.
  - You need to build a support system and trust that others can help.
  - You need to support the others who are helping you provide care.
  - **You still have a powerful role:**  
That of an advocate for your loved one.



## Decisions, decisions, decisions

### Facility Care

- What type of facility is most appropriate?
- Is it affordable?
- How do we find a facility? How do we know it's good? Safe? COVID precautions, vaccines?
- What type of medical care is available?
- Is there a plan in place for when medical or cognitive changes occur?
- Will we have to supplement with outside caregivers?
- Location, location, location.
- Relocation/transfer trauma.



## Facility Care

- **Independent Senior Living**
  - Apartments/homes in large facility or complex
  - Residents do not need hands-on care
  - Meals, housekeeping available; social and physical activities
- **Assisted Living Facility (AL)**
  - Private apartments; monthly rental
  - Need some assistance with daily tasks, but not 24/7 skilled nursing care
  - Assistance with activities of daily living and medication management
  - Meals; housekeeping; activities
- **Memory Care Units**
  - Often part of assisted living; secure
  - 24-hour supervision by specially trained staff
  - Private or semi-private rooms
  - Meals; housekeeping; activities



## Facility Care

- **Residential Care Homes**  
(Board and Care)
  - Supervised care, meals, activities and health management
  - Private or semi-private room in a house
  - Usually about 4-6 residents
- **Skilled Nursing Facility - SNF**  
(Nursing Home)
  - Requires physician orders
  - 24-hour monitoring and medical care
  - Bed-ridden and/or wheelchair bound
  - Dining rooms for those who are able
  - Individual and group activities

Evaluation tools on resource list:  
*Medicare and CANHR*



## Continuing Care Retirement Communities (CCRC)

- Many levels of care in one community:
  - Independent apartments
  - Assisted Living/Memory Care
  - Skilled Nursing Facility – SNF
- If needs change, can move smoothly to the next level of care w/o having to completely change environment
- Most require buy-in fees and monthly payments

*For more info, see resource list*



## Local Care Communities (examples)

- Continuing Care Communities  
(*Independent, Assisted, Skilled Nursing*)
  - Stoneridge Creek (Pleasanton)
  - Baywood Court (Castro Valley)
  - Piedmont Gardens (Oakland)
- Two+ levels of care
  - Heritage Estates, Livermore  
(*Independent; Assisted living*)
  - The Parkview, Pleasanton  
(*Assisted living; Memory care*)
  - Sunrise, Pleasanton & Oakland  
(*Assisted living, Memory care*)
  - The Villas, Livermore  
(*Assisted, Memory, & Skilled Nursing*)



## Other Options for Long Term Care

- **Veterans Homes**
  - State-operated residential facilities
  - ~ 132 in U.S
  - [Va.gov/geriatrics](http://Va.gov/geriatrics)
  - [Calvet.ca.gov](http://Calvet.ca.gov)
- **Niche or Affinity Communities**
  - Shared interests
  - Prior employment
  - Religious affiliation
- **Cohousing**
  - Neighbors, friends design own community
  - Cohousing Association of the United States
- **House Sharing**



To download, go to: [www.hopehospice.com/family-past](http://www.hopehospice.com/family-past)


Senior Housing and Care Options - SF Metropolitan Area

 HOPE SF Metropolitan Area	Independent Living Communities	Assisted Living Facilities	Memory/Dementia Care Facility	Residential Care Homes (Board & Care)	Skilled Nursing Facilities - SNF	Adult Day Services	Respite Care (short term)	In-Home Care (personal care)
<b>Average Cost<sup>1</sup></b> SF Metropolitan Area	\$3,500 - \$5,000+/month	\$4,500 - \$8,000/mo <sup>2</sup>	\$5,500 - \$7,000+/month <sup>2</sup>	\$2,500 - \$7,000/month	\$11,000 - \$27,000+/mo	\$90 - \$215/day	\$75 - \$200+/day	\$36/hour
Average # of Residents	Many	16+ beds	16+ beds	4-6 beds	110 beds	n/a	n/a	n/a
Meals per Day	Meal Plan options	3+	3+	3+	3+	1+	1 - 3	none
Medication Management	No <sup>3</sup>	Yes	Yes	Yes	Yes	Varies	Yes	Varies
Diabetes Management	No	Varies	Varies	Varies	Yes	No	Usually	Varies
Incontinence Care (excludes colostomy)	No	Usually	Yes	Usually	Yes	Varies	Yes	Yes
Personal Care	No <sup>3</sup>	Yes	Yes	Yes	Yes	Varies	Yes	Yes
Dementia Care	No	Varies	Yes	Varies	Varies	Varies	Varies	Yes
Registered Nurses on site	No	Varies	Yes	Usually not	Yes	Usually not	Varies	Varies
Mobility Assistance	No	Usually	Yes	Usually	Yes	Yes	Usually	Yes
Transportation Services	Yes	Yes	Yes	Varies	No	Varies	Varies	Varies
Housekeeping	Yes	Yes	Yes	Yes	Yes	n/a	Usually	Yes
Personal Laundry	No	Yes	Yes	Yes	Yes	No	Usually	Yes
Activity Programs	Yes	Yes	Yes	Varies	Yes	Yes	Yes	No
Medi-Cal covers cost, if qualifies	No	ALW Program; wait lists	Yes	Possibly - ALW program	Yes	Community Based Adult Services	Medicare may cover	Yes, In Home Supportive Services IHSS
Low-income options	If available	Yes; wait lists	Rarely Available	Yes; wait lists	No	Varies	Varies	No

<sup>1</sup> Costs vary depending on size of room, private/shared, geographic location, level of luxury, services offered.  
<sup>2</sup> Does not include additional level of care costs.  
<sup>3</sup> Personal care services (including medication management) available through privately paid home care agencies.

**Sources:** California Department of Health Care Services [www.dhcs.ca.gov](http://www.dhcs.ca.gov); Senior Support Program of the Tri-Valley [www.sspvtv.org](http://www.sspvtv.org); [www.aplacefor mom.com](http://www.aplacefor mom.com); <https://www.genworth.com/corporate/about/genworth/industry-expertise/cost-of-care.html>; [www.SeniorCare.com/nursing-home-costs](http://www.SeniorCare.com/nursing-home-costs); [www.calregistry.com](http://www.calregistry.com) (CA Department of Public Health); [www.aarp.org/caregiving/financial-legal/long-term-care-cost-calculator.html](http://www.aarp.org/caregiving/financial-legal/long-term-care-cost-calculator.html)

Emerson 01.2023



**LTC PATHFINDER**

**Planning Ahead**

Planning considerations and options associated with your age:

- [Less than 50](#)
- [Between 51 and 64](#)
- [Age 65 and older](#)

**Receiving LTC**

Resources for people already receiving long-term care services.

- [Already receiving LTC](#)

**LongTermCare.gov**  
 U.S. Department of Health and Human Services

<https://acl.gov/ltc>

## Assistance Finding Housing and Services

- **Hospital Social Workers or Discharge Planners**
- **Family Caregiver Alliance**
  - Family Care Navigator - CareNav™  
[www.caregiver.org/connecting-caregivers/fca-carenav/](http://www.caregiver.org/connecting-caregivers/fca-carenav/)
  - Caregiver Resource Center  
[www.caregiver.org/connecting-caregivers/bay-area-caregiver-center/](http://www.caregiver.org/connecting-caregivers/bay-area-caregiver-center/)  
(800) 445-8106
- **Local Senior Centers**
  - Case management services
  - Referrals for community services such as transportation, nutrition, activities, support groups
- **Geriatric Care Managers or Certified Senior Advisors** (fee-based)  
[www.aginglifecare.org](http://www.aginglifecare.org)



## Senior Living Placement Services

- Businesses that provide referrals to various services and facilities
- Some are local; others are national franchises
- Offer services at no-cost, but usually charge fees to the facility or agency for listings and referrals
- Do your research!!



# Older Americans Act - 1973

## Five Core Services



**USaging.org**  
(formerly Area Agency on Aging)

Every county in the U.S. has a program that provides comprehensive resources and services for elderly and disabled individuals **and their caregivers** in that county.

Many have social workers or geriatric care managers on staff who are available to provide individual consultations with families.

Funded by federal, state, and local sources.



## Paying for Long Term Care Services

### Out-of-pocket or Private Financing

- Savings, annuities, trusts, etc.
- Sale of home
- Reverse mortgages
- Selling life insurance policy
- Viatical Life Settlements (3<sup>rd</sup> party – only if terminally ill)
- Long-term care insurance

Resource:

Paying for Long-Term Care (NIA/NIH)  
[www.nia.nih.gov/health/paying-care](http://www.nia.nih.gov/health/paying-care)



## Paying for Long Term Care Services

### Public/Government Funding

- Veteran benefits – some assistance
- Medicare (skilled nursing facility)
  - IF the person has been released from a minimum of 3-night hospital stay (admitted; not observation)
  - IF the person needs medical care, not just assistance with ADL's
  - Pays only for first 100 days in nursing home:
    - Days 1-20: 100% coverage
    - Days 21-100: **\$200** co-insurance/day
    - Days 101-?: Private pay





## Paying for Long Term Care Services:

### Medi-Cal

- Medi-Cal (CA) vs Medicaid
- Benefits/coverage varies by state
- Based on low income and medical needs
- 4-8 hours/day of in-home custodial care for those living at home (IHSS)
- Pays 100% of nursing home costs for medically necessary conditions, not just ADL
- Assisted Living Waiver Program
  - Pays for assisted living in designated facilities throughout CA