



Making Decisions About Caregiving

January 14, 2021

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

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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



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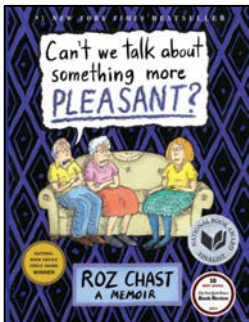
Goals

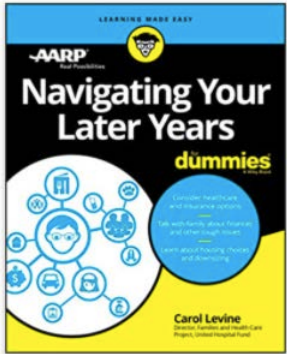
- Identify yourself as a care partner.
- Recognize importance of communication.
- Learn about options for long-term care.
- Become aware of resources and services in the community and online.
- Understand that . . .
 - every situation is unique;
 - there is no right or wrong;
 - everything you do involves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



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Recommended Resources





FAMILY CAREGIVER EDUCATION SERIES
Webinar: Making Decisions About Caregiving - January 2015
Debra Foxman, M.S., Community Health Educator
 (2017 Dementia Specialist (Dementia's Association))

PRINT RESOURCES

Check Out Caregiver Talk About Something More Pleasant @ Memoir (2016)
 Home Care Checklist for Family Caregivers (American Geriatrics Society/National Alzheimer's Association) (2015)
 Alzheimer's Association: The Alzheimer's Caregiver: Finding Ease in the Changing Seasons (2014)
 Institute of Aging (AARP): Navigating Your Later Years for December (2018). (Also available on Kindle)

ONLINE RESOURCES

AARP Long Term Care Calculator
www.aarp.org/longtermcare/financialplanning/2017/long-term-care-calculator.aspx

Ageing in Place - Growing Old at Home (archived from National Institute on Ageing)
www.nia.nih.gov/health/aging-in-place

Area Agencies on Aging (Each county in the U.S. has an area agency on aging that provides comprehensive services and services for elderly and disabled individuals and their caregivers.)
www.aaas.org

CAADHR - California Advocates for Nursing Home Reform
 Consumer resources and for attorneys, health care, families, and many other topics related to other care.
www.caadhr.org

California Adult Family Care (AFC) For other states, go to www.hhs.gov/longtermcare/resources/index.html
www.aadhr.ca.gov

Care Options for Those with Dementia
www.alz.org/longtermcare/longtermcare.aspx

Comparison Chart: Goals for Nursing Homes by State
www.alz.org/longtermcare/longtermcare.aspx

Eldercare Locator - U.S. Department of Health and Human Services Administration on Aging
www.eldercare.gov

Family Care Navigator - Family Caregiver Alliance (online tool for finding long term care services in the US)
www.familycarenavigator.org

Homecare Resource Center (online tool for finding long term care services by geographic area)
www.hrc.org

Geriatric Care Managers or Certified Senior Advisors (CSAs)
 Many Long Term Care Services National Association of Geriatric Care Managers
www.nagcm.org

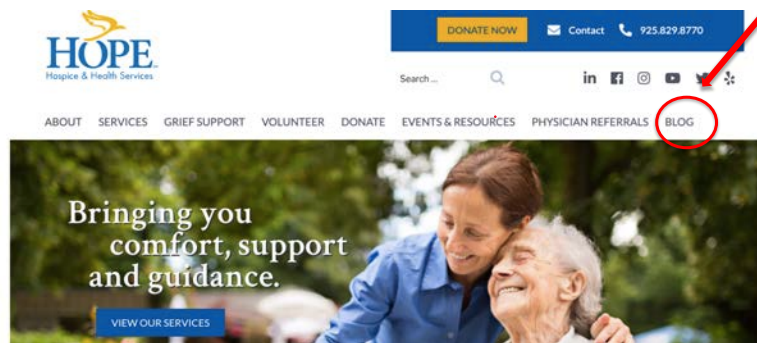


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Caregiver Mistake Series - Blog

www.HopeHospice.com/blog

- Advance Planning
- Hiring In-Home Help
- Working Together with Family Members



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Projected Needs for Long Term Care

- **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.
- **About 70% of nursing home residents are women.**
- **Average age of admission is 80 years old.**

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



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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.



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"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.



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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.



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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.
 - Family roles can persist into adulthood.
- Resistance in discussing important issues:
 - Choosing power(s) of attorney, executors, trustees.
 - Communicating preferences about end-of-life care.
 - Revealing/discussing finances.



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Family Dynamics Are Complex

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

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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.



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Assessing Needs

The diagram illustrates a cycle of interconnected needs for assessing an individual's requirements. The areas are: Residential, Medical, Financial, Personal Care, Transportation, and Household. Each area is represented by a colored box, and arrows indicate a continuous relationship between them. Accompanying resources include 'Next Step in Care' and 'Checklist for Family Caregivers'.

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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?
 - Is the home aging-friendly?
 - Are modifications possible?
 - 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?

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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



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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.
- Financial considerations.
- Changes necessary to make home accessible.
- Changing roles.
- Unresolved issues such as strained relationships, abuse, neglect, alcoholism, divorce.
- Impact on other family members.



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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.



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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.



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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/



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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.



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Decisions, decisions, decisions

Facility Care

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



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Facility Care

- **Independent Senior Living**
 - Fully-equipped apartments/homes.
 - Do not need hands-on care.
 - Meals, housekeeping available; social and physical activities.
- **Assisted Living Facility (AL)**
 - Private apartments.
 - 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.



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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.

www.Medicare.gov/care-compare/



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Continuing Care Retirement Communities (CCRC)

- **AKA** Life Care Facilities
- 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.



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Continuing Care Retirement Communities (CCRC)

Local examples:

- Stoneridge Creek (Pleasanton)
- Baywood Court (Castro Valley)
- Piedmont Gardens (Oakland)
- *Heritage Estates (Livermore)
- *The Parkview (Pleasanton)
- *Sunrise (Pleasanton)



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Other Options for Long Term Care

- **Veterans Homes**
 - State-operated
 - 132 in U.S
- **Niche or Affinity Communities**
 - Shared interests
 - Prior employment
 - Religious affiliation
- **Cohousing**
 - Neighbors, friends design own community
 - Cohousing Association of the United States
- **House Sharing**



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Senior Housing and Care Options - SF Metropolitan Area

 HOPE Housing Home Health	Independent Living Communities	Assisted Living Facilities	Memory/ Dementia Care Facility	Residential Care Homes (Board & Care)	Skilled Nursing Facilities	Adult Day Services	Respite Care (short term)	In-Home Care (personal care)
Average Cost¹ <small>SF Metropolitan Area</small>	\$2,750 - \$4,800/month	\$4,500 - \$7,000/mo ²	\$5,500 - \$7,000/month ²	\$2,500 - \$7,000/month	\$9,000 - \$13,000+/mo	\$60 - \$215/day	\$75 - \$200+/day	\$20 - \$35/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 ³	Yes	Yes	Yes	Yes	Varies	Yes	Varies
Diabetes Management	No	Varies	Varies	Varies	Yes	No	Usually	Varies
Incontinence Care <small>(excludes colostomy)</small>	No	Usually	Yes	Usually	Yes	Varies	Yes	Yes
Personal Care	No ³	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	Varies	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	No	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; current wait list	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

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

Sources: California Department of Health Care Services www.dhcs.ca.gov; Senior Support Program of the Tri-Valley www.ssptp.org; www.aplaceformom.com; <https://www.genworth.com/corporate/about-genworth/industry-expertise/cost-of-care.html>; www.calregistry.com (800) 777-7575 (CA Department of Public Health)

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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 (3rd party – only if terminally ill).
- Long-term care insurance.




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Paying for Long Term Care Services

Public/Government Funding

- Veterans benefits – some assistance.
- Medi-Cal/Medicaid:
 - Based on low income and medical needs.
 - Pays 100% of nursing home costs.
 - 4-8 hours/day of in-home custodial care for those living at home.
- Medicare:
 - Pays for first 100 days in nursing home.
 - 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.
 - Days 1-20: 100% coverage.
 - Days 21-100: \$185.50 co-insurance/day.
 - Days 101-?: private pay



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Long Term Care Calculators

AARP


<http://www.aarp.org/relationships/caregiving-resource-center/LTCC.html>

Genworth Financial

<https://www.genworth.com/corporate/about-genworth/industry-expertise/cost-of-care.html>



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**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://longtermcare.acl.gov/the-basics/>

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Assistance Finding Housing and Services

- Hospital Social Workers or Discharge Planners
- Family Care Navigator – Family Caregiver Alliance
www.caregiver.org
- Local Senior Centers
- Geriatric Care Managers or Certified Senior Advisors (fee-based)



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Senior Living Placement Services


- Businesses that provide referrals to various services and facilities.
- Some are local; others are national franchises.
- Offer services for “free,” but usually charge fees to the facility or agency for listings and referrals.
- Do your research!!



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Area Agencies on Aging

All AAAs offer five core services under the OAA:



ELDER RIGHTS

includes abuse prevention and long-term care ombudsman programs

CAREGIVERS

NUTRITION

HEALTH & WELLNESS

SUPPORTIVE SERVICES

Information and referral
In-home services
Homemaker & chore services
Transportation
Case management
Home modification
Legal services

The average AAA offers more than a dozen additional services. The most common non-core services offered by AAAs are:

- Insurance Counseling (85%)
- Case Management (82%)
- Senior Medicare Patrol (44%)

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www.n4a.org

Every county in the U.S. has an **Area Agency on Aging** that provides comprehensive resources and services for elderly and disabled individuals **and their caregivers** in that county.

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



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Questions and Answers



Don't forget to complete the online evaluation upon leaving the webinar – or when you get the link in the follow-up email tomorrow.

THANK YOU!



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