

UCSF Weill Institute for Neurosciences

Memory and Aging Center

Advocacy in Health and Community Care Settings

Sarah Dulaney, RN, MS, CNS
Helen Bundy Medsger, LBD Caregiver



Sarah Dulaney RN, MS, CNS

Clinical Nurse Specialist

- **University of California, San Francisco, CA**
 - Master's Entry Program in Nursing (MEPN)
 - Master's of Science in Gerontological Nursing
- Experience working with patients with Lewy body disease at the VA Palo Alto and the UCSF Memory and Aging Center.
- Work focuses on providing education, support, and care coordination for patients and families living with dementia through the Care Ecosystem.



Helen Bundy Medsger

Family caregiver, advocate, and support group leader

- For over 30 years, Helen has been the primary caregiver and health care advocate for two generations of her family with Lewy Body Dementia
- She co-facilitates an LBD support group, participates in the Family Advisory Council and consults for the Care Ecosystem study at the UCSF Memory & Aging Center, and volunteers for the Brain Support Network.
- Helen is committed to improving the lives of persons with dementia and their care partners, and is a staunch advocate and active participant in neurodegenerative disease and genetic research.



Advocacy in a Health Care Setting

Family Caregivers are Healthcare Advocates

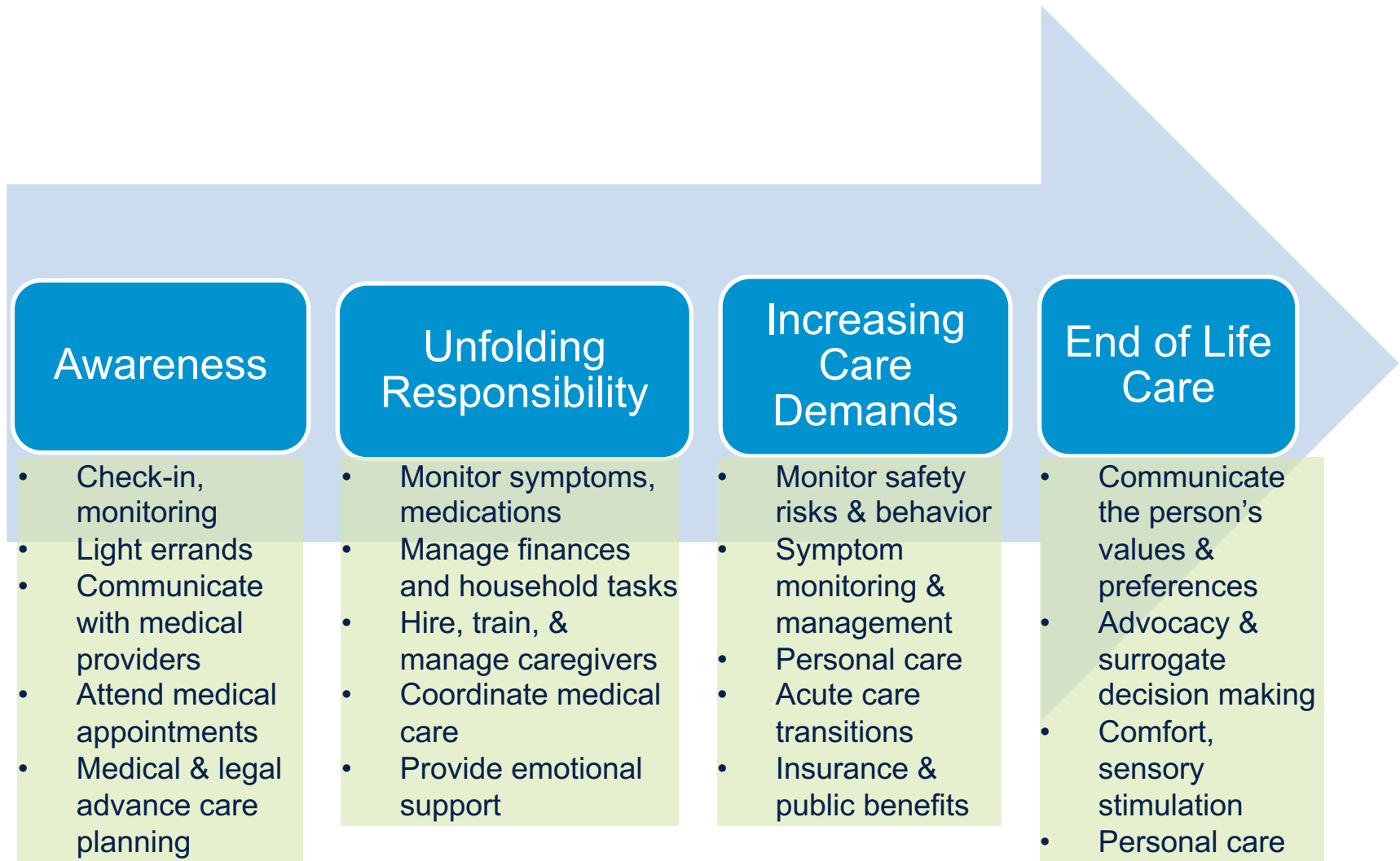
As family caregivers, we often play many roles, including scheduler, financial manager, housecleaner, encourager, nurse, navigator, nurturer and more. Perhaps the most important role, though, is advocate, as we ensure the best life possible for our family and friends when they are vulnerable.

(Amy Goyer, AARP's Family & Caregiving Expert, Oct. 26, 2016)



Getty Images

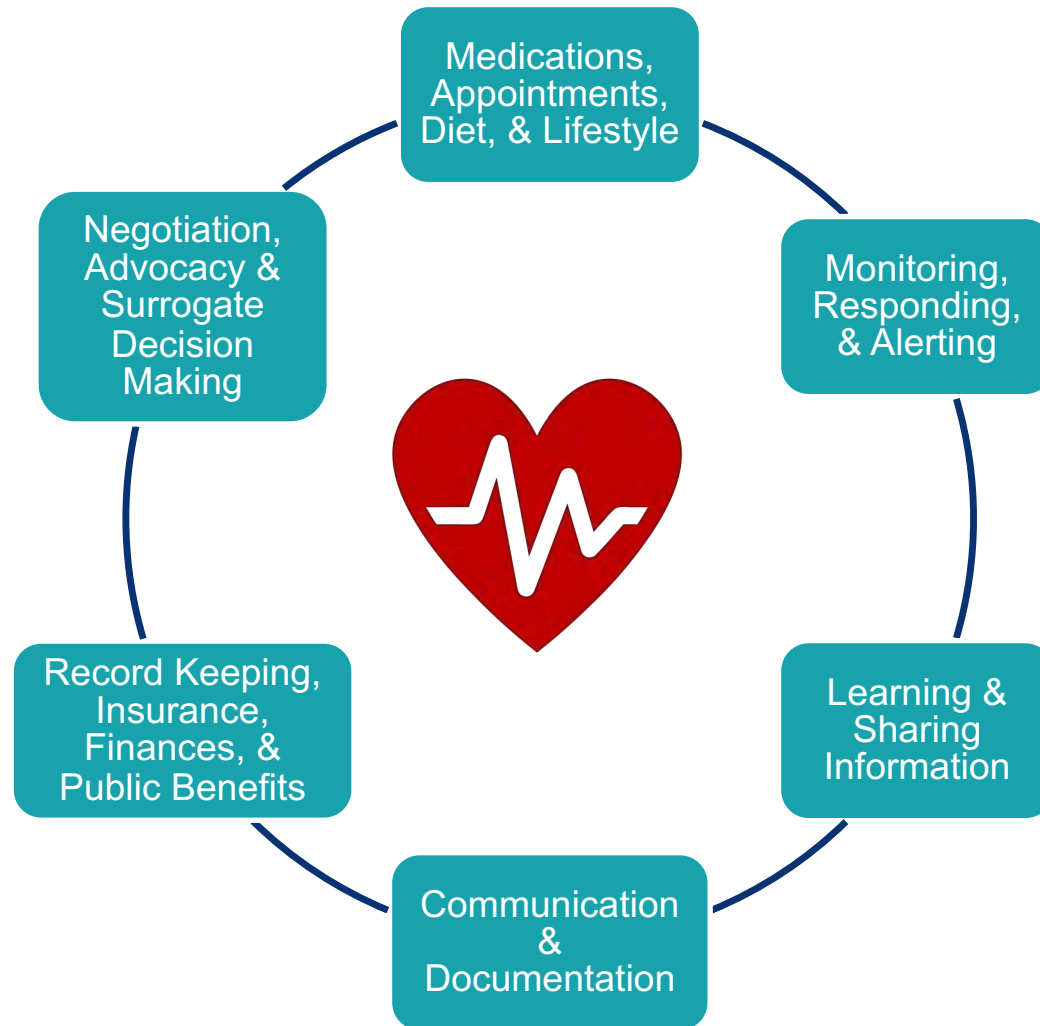
Sample Dementia Caregiving Trajectory



What Family Caregivers Do for Persons Living With Lewy Body Dementia



How Family Caregivers Promote, Manage, & Coordinate Health-Related Care



Some Caregiving Responsibilities Can Be Shared or Delegated

- Family, friend, or neighbor
- Respite care (home care, day program, housekeeping, meal delivery)
- Private care manager or fiduciary
- Publicly appointed conservator or guardian
- County case manager (mostly low income)



<https://www.caregiver.org/caregiver-health>

Healthcare Advocacy Tips & Strategies



- Organize important documents and information
- Learn about Lewy Body Dementia
- Understand the person's needs, preferences, goals and values
- Build a "village of care" team

Compile & Organize Important Information

- ✓ Patient's medical information
 - Medical history and list of current diagnoses
 - Current list of medications (name/purpose/dose/route/schedule)
 - List of allergies or contraindicated medications
- ✓ Emergency contacts (name, email, phone number)
- ✓ Patient's ID, insurance card and medical record number
- ✓ Names and contact information for patient's medical providers
- ✓ Legal documents...



<https://www.caregiver.org/where-find-my-important-papers>

Important Medical Forms and Legal Documents

- HIPAA Release of Information (one for each health setting)
- Advance Healthcare Directive or Durable Power of Attorney for Healthcare
 - prepareforyourcare.org
- POLST (Physician's Order for Life Sustaining Treatment)
 - National - <https://polst.org/national-form/#form-download>
 - California - <https://capolst.org/polst-for-healthcare-providers/forms/>



Important Financial Forms and Legal Documents

- Durable Power of Attorney for Finances
 - consumerfinance.gov/consumer-tools/managing-someone-elses-money/
- Representative Payee (Social Security)
 - <https://www.ssa.gov/payee/faqrep.htm>
- VA Fiduciary (Veteran's benefits)
 - <https://benefits.va.gov/BENEFITS/factsheets/fiduciary/FiduciaryFactSheet.pdf>

Learn about common symptoms and risks associated with Lewy Body Dementia

- Cognitive and functional decline
- Lack of safety awareness
- Mobility problems and fall risks
- Swallowing problems and weight loss
- Mood and behavioral symptoms
- Sleep disruption
- Dysautonomic symptoms: Urinary, digestive, and blood pressure regulation changes



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Neurosciences | Aging Center

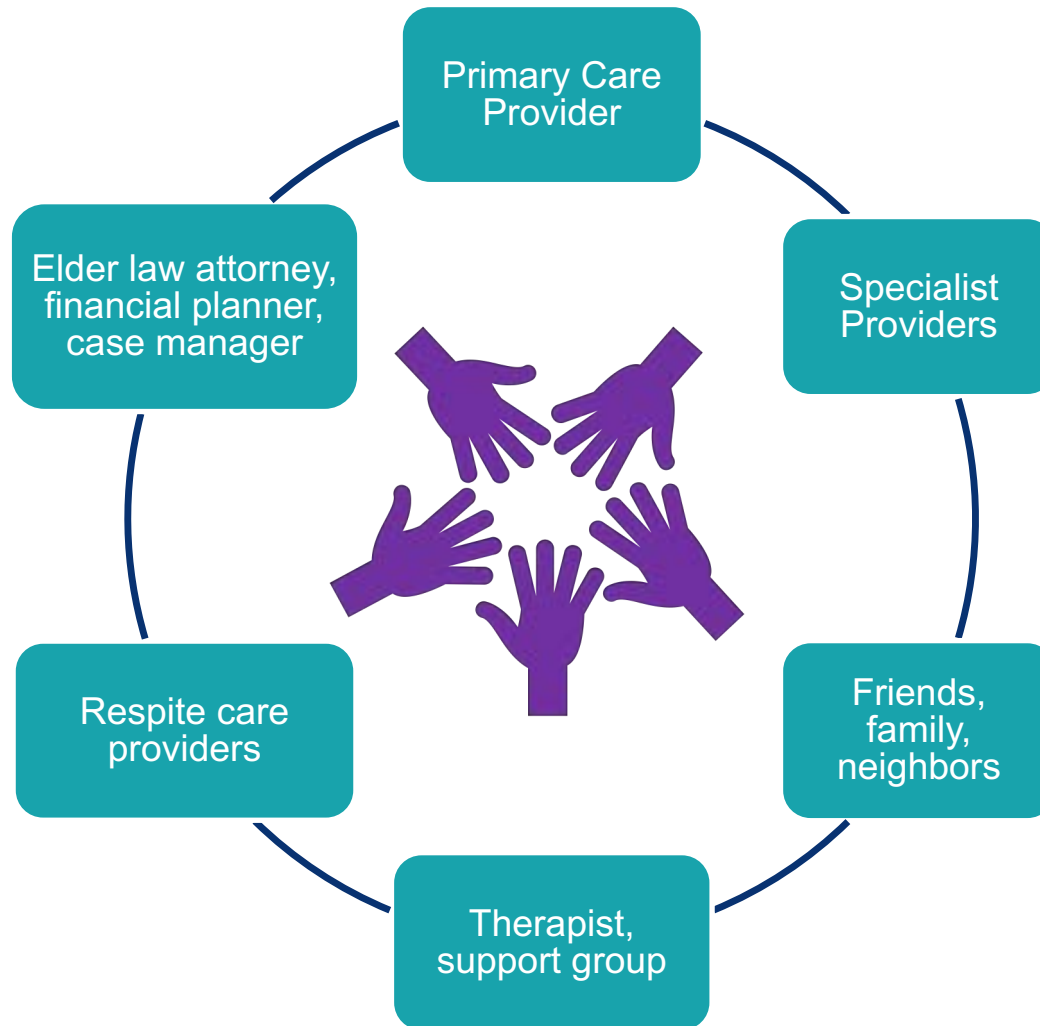
Prioritize needs and goals

- Physical/Medical
- Emotional/Psychological
- Social/Familial
- Legal/Financial



[https://www.lbda.org/sites/default/files/facing lewy body dementia together brochure.pdf](https://www.lbda.org/sites/default/files/facing_lewy_body_dementia_together_brochure.pdf)

Build a “village of care” team



Care in ambulatory clinics

TEAM

- Clinic coordinator
- Social worker
- Triage nurse
- Provider (physician, advanced practice nurse, physician assistant)

TYPES OF HELP

- Triage urgent care needs
- Diagnostic and routine follow-up appointments
- Medication refills and prior authorization
- Help with forms
- Referrals for specialty care, home health, outpatient rehab, durable medical equipment
- Information and resources

Consider the Best Way to Communicate

- Electronic medical record messaging
- Secure email
- Phone
- Fax
- Scheduled phone or video visit
- Routine or urgent in-person visit
- Quarterly care planning meetings (long term care facility)



<https://www.piqsels.com/en/public-domain-photo-flstn>

Get the most out of visits with providers



Prepare & prioritize 3-4 concerns to bring up during the visit



Stay focused briefly describe symptom or change, when it started, how often and when it happens, and if it seems to be getting worse or better



Be honest even if it may be uncomfortable



Advocate if you feel your concerns are not being addressed



Accept that sometimes providers are not able to provide the answers you seek. If your concerns seem ignored, it may be wise to seek a second opinion

Learn what is covered by your insurance

- Contact your insurance company
- Medicare
 - <https://www.medicare.gov/what-medicare-covers/what-part-b-covers>
- Medicare Rights National Helpline (Mon-Fri): 1-800-333-4114
 - <https://www.medicarerights.org/programs/national-helpline>
- Veteran's benefits
 - <https://www.va.gov/health-care/about-va-health-benefits/>
- Compare medication prices
 - <https://www.goodrx.com/>

Emergency room visits & hospitalizations

TEAM

- Patient care assistant
- Shift nurse
- Charge nurse
- Rehabilitation therapist (PT, OT, ST)
- Discharge planner (typically a nurse or social worker)
- Attending physician

TYPES OF CARE

- Evaluation and treatment of severe symptoms, acute conditions, and serious injuries
- Scheduled operations & procedures
- Discharge plan
 - Follow-up care instructions
 - Follow-up appointment
 - Medications and referrals
 - Home health
 - Skilled nursing facility

Hospital admission status and Medicare reimbursement

- “Observation status” or “social admission” means Medicare will not cover post-hospitalization stay in a skilled nursing facility
- Three-day hospitalization with an “admitting diagnosis” is typically required for Medicare coverage stay in a skilled nursing facility
- It is possible to “contest” an “unsafe discharge”

http://canhr.org/factsheets/resrights_fs/html/fs_challengingdischarge.htm

<https://www.medicare.gov/claims-appeals/your-right-to-a-fast-appeal/getting-a-fast-appeal-in-a-hospital>

<https://www.justiceinaging.org/medicare-patients-placed-under-observation-status-win-right-to-appeal-federal-court-orders/>

Care in long term care settings

TEAM

- Nursing assistant
- Shift nurse
- Activities coordinator
- Rehabilitation therapist (PT, OT, ST)
- Social worker
- Director of nursing
- Provider (physician, advanced practice nurse, physician assistant)
- Administrator

TYPES OF CARE

- Short-term rehab stay
 - Full coverage for up to 20 days
 - Partial coverage by Medicare for 80 more days
 - Requires ability to make progress towards rehab goals
- “Custodial” long term care
 - Private pay
 - Medicaid, if eligible

Advocacy in long term care settings

- Understand resident's rights
- Recognize workforce challenges
- Prioritize needs and communicate concerns with staff
- Participate in quarterly care planning meetings
- Escalate concerns if not addressed
- Contact to local Long Term Care Ombudsmen

Home health care

TYPES OF CARE

- Skilled nursing (wound care, infusions, medication management, teaching)
- Rehabilitation (PT, OT, ST)
- Medical social services
- Durable medical equipment
- Limited home care assistance (bathing)

MEDICARE COVERAGE

- Provider referral and oversight required
- Must be homebound
- Intermittent coverage
 - < 7 days/week
 - < 8 hours/day
 - Over period of 21 days
- There may be a 20% copay

Hospice care

TEAM

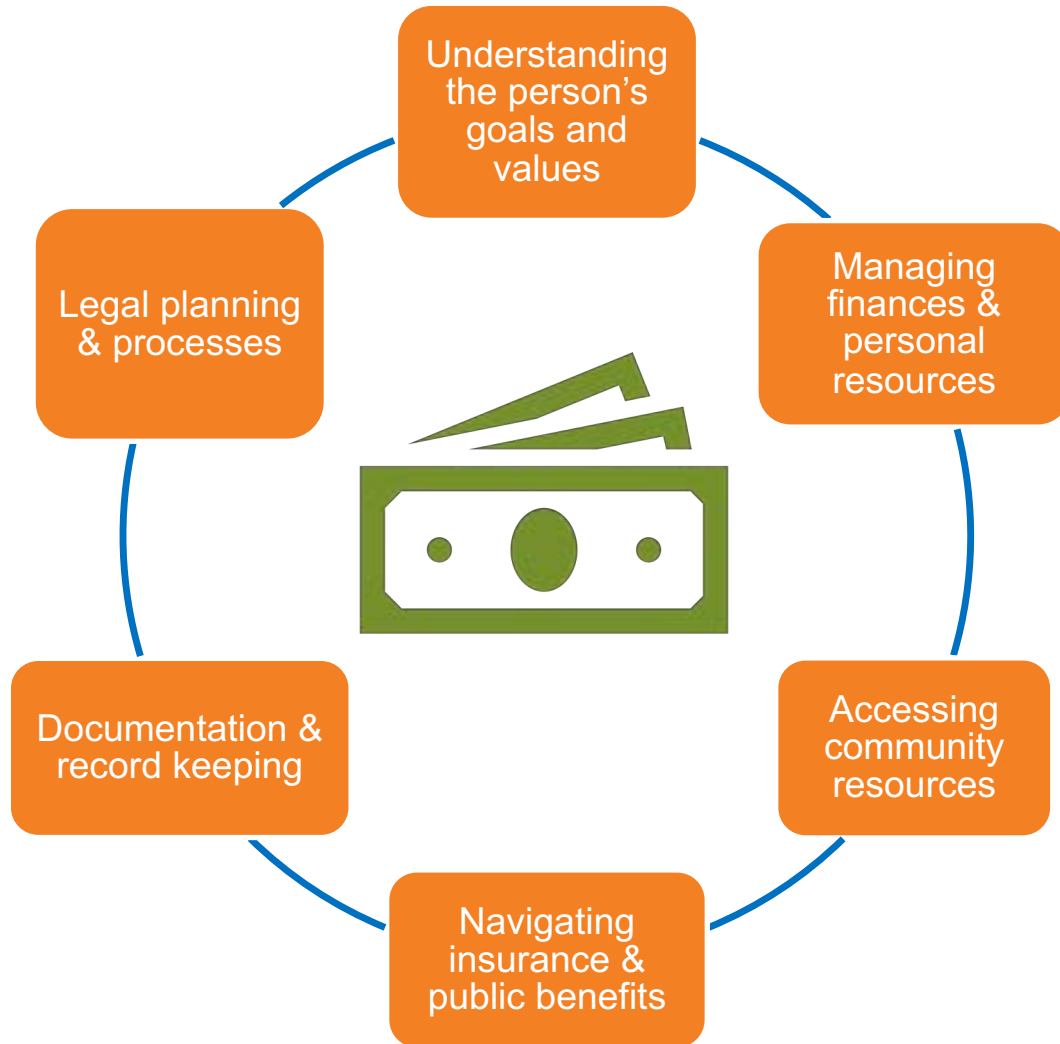
- Home health aide
- Social worker
- Nurse
- Chaplain
- Attending provider (may be PCP or hospice provider)

TYPES OF CARE

- Palliative care program (varies)
- Medications
- Durable medical equipment (including hospital bed)
- Help with bathing
- Incontinence supplies
- 24/7 on call triage nurse
- Weekly in-home nurse visits
- Ancillary services
- Limited respite (varies)

Advocacy in Community Care Settings

Legal/Financial Caregiving



Psychosocial Caregiving



Care management services

SERVICES

- Care needs assessment and recommendations
- Coordination of care and services
- Assistance with home care arrangements and placement

OPTIONS

Private pay

- Hourly rate
- <https://www.aginglifecare.org/>

Subsidized programs

- Caregiver Resource Centers in California
- Medicaid waiver county-based case management programs
- Program for all inclusive care for the elderly (PACE)

<https://www.caregiver.org/california-caregiver-resource-centers-crcs>

<https://www.dhcs.ca.gov/services/medi-cal/Pages/MSSPMedi-CalWaiver.aspx>

<http://www.calpace.org/>

Other community support services



Housekeeping



Meal delivery



Transportation



Money
management



Home
modification

Congregate respite programs

- **Senior centers**

- Free or low cost
- Meals and activities
- May not be appropriate for people with cognitive impairment

- **Social day programs**

- Private pay
- Transportation, meals, activities
- Medication administration

- **Adult day health centers**

- Private pay and Medicaid
- Transportation, meals, activities
- Medication administration
- Rehabilitation services (PT, OT, ST)
- Nursing and social work services

<https://www.n4a.org/>

<https://www.communityresourcefinder.org/>

Home care

Not covered by Medicare



Companion care



Light housekeeping



Supervision



Personal care

Home care options

- Home care agency
 - Agencies handle background checks, liability insurance, staff training and scheduling
- Private caregiver
 - Typically cheaper, potentially higher risk (taxes, liability and labor laws)
- Live-in caregiver
 - Services in exchange for reduced rent (liability and labor laws)
- Medicaid community-based in-home care waiver programs, vary by state
 - <http://www.longtermscorecard.org/promising-practices>
 - <https://www.cdss.ca.gov/in-home-supportive-services>

Care in an assisted living facility

- Board and care home
- Assisted living facility
- Memory care facility

Private pay

<https://www.genworth.com/aging-and-you/finances/cost-of-care.html>

Limited Medicaid assisted living waiver programs, vary by state

<http://www.longtermscorecard.org/promising-practices>



Other Ways to Advocate

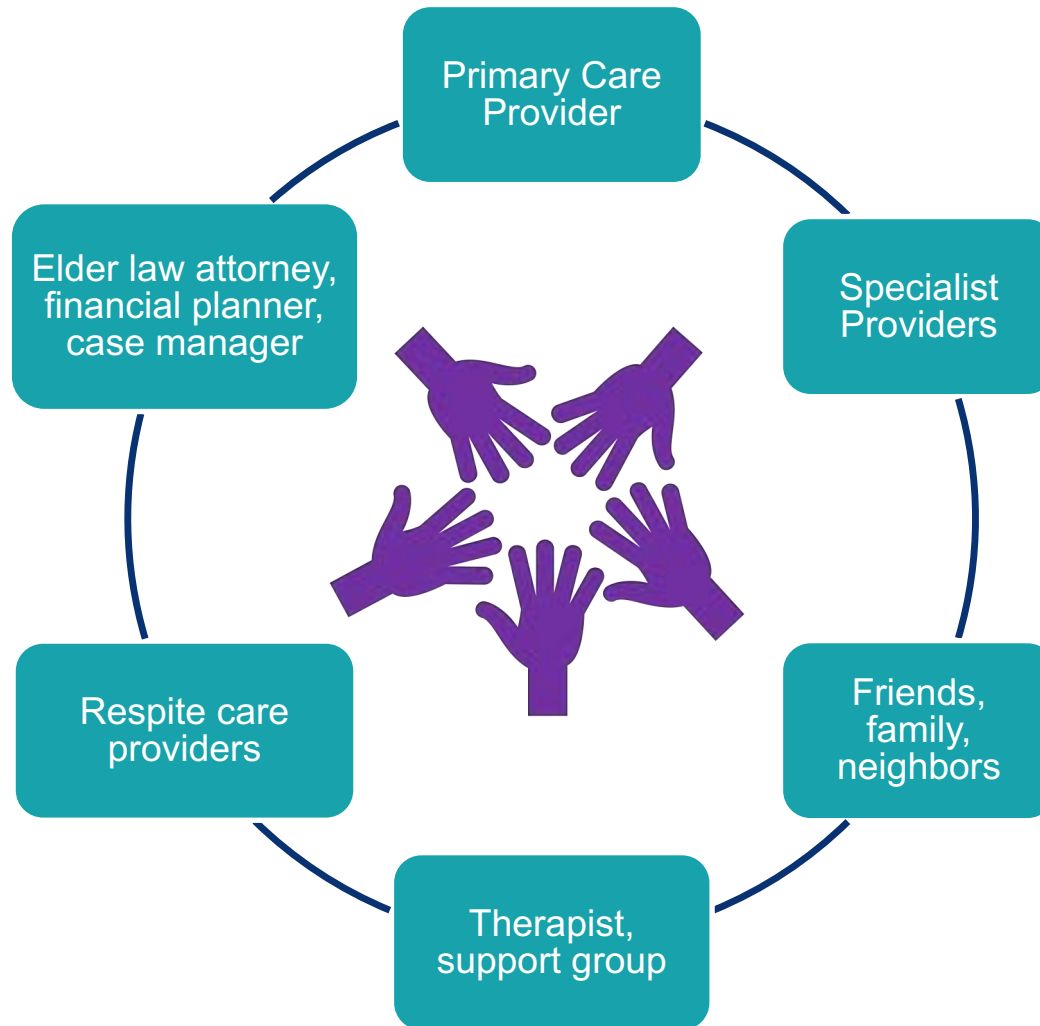
- Participation in research
 - <https://clinicaltrials.gov/>
- Brain donation
 - <https://www.brainsupportnetwork.org>
- Advocacy
 - <https://www.lbda.org/go/volunteer>

<https://clinicaltrials.gov/>

<https://www.brainsupportnetwork.org/>

<https://www.lbda.org/go/volunteer>

Build a “village of care” team



Resource links

- <https://www.caregiver.org/caregiver-health>
- <https://www.caregiver.org/where-find-my-important-papers>
- <https://www.nia.nih.gov/health/online-health-information-it-reliable>
- prepareforyourcare.org
- consumerfinance.gov/consumer-tools/managing-someone-elses-money/
- <https://www.ssa.gov/payee/faqrep.htm>
- <https://benefits.va.gov/BENEFITS/factsheets/fiduciary/FiduciaryFactSheet.pdf>
- <https://polst.org/national-form/#form-download>
- <https://capolst.org/polst-for-healthcare-providers/forms/>
- https://www.lbda.org/sites/default/files/facing_lewy_body_dementia_together_brochure.pdf
- <https://www.caregiver.org/saying-yes-offers-help>
- https://www.nextstepincare.org/Caregiver_Home/
- <https://www.nia.nih.gov/health/5-ways-get-most-out-your-doctors-visit>
- <https://www.medicare.gov/what-medicare-covers/what-part-b-covers>
- <https://www.medicarerights.org/>
- <https://cahealthadvocates.org/hicap/>

Resource links

- <https://www.va.gov/health-care/about-va-health-benefits/>
- <https://www.goodrx.com/>
- <http://canhr.org/factsheets/index.html>
- <https://www.nhpco.org/patients-and-caregivers/>
- <https://www.medicare.gov/claims-appeals/your-right-to-a-fast-appeal/getting-a-fast-appeal-in-a-hospital>
- http://canhr.org/factsheets/resrights_fs/html/fs_challengingdischarge.htm
- <https://www.justiceinaging.org/medicare-patients-placed-under-observation-status-win-right-to-appeal-federal-court-orders/>
- <https://longtermcare.acl.gov/>
- <https://www.medicare.gov/coverage/skilled-nursing-facility-snf-care>
- https://theconsumervoice.org/get_help
- http://canhr.org/factsheets/rcfe_fs/html/rcfe_fs.selfadv.htm
- <https://www.medicare.gov/coverage/home-health-services>
- <https://www.medicare.gov/coverage/hospice-care>
- https://www.nhpco.org/wp-content/uploads/2019/04/Hospice_Care.pdf

Resource links

- <https://www.consumerfinance.gov/consumer-tools/managing-someone-elses-money/>
- <https://www.nia.nih.gov/health/topics/relationships-and-alzheimers-disease>
- <https://www.aginglifecare.org/>
- <https://www.caregiver.org/california-caregiver-resource-centers-crcs>
- <https://www.dhcs.ca.gov/services/medi-cal/Pages/MSSPMedi-CalWaiver.aspx>
- <http://www.calpace.org/>
- <https://www.n4a.org/>
- <https://www.communityresourcefinder.org/>
- <http://www.longtermscorecard.org/promising-practices>
- <https://www.cdss.ca.gov/in-home-supportive-services>
- <https://www.caregiver.org/hiring-home-help>
- <https://www.genworth.com/aging-and-you/finances/cost-of-care.html>
- <https://www.caregiver.org/residential-care-options-five-tip-sheets>
- <https://clinicaltrials.gov/>
- <https://www.brainsupportnetwork.org>
- <https://www.lbda.org/>
- <https://memory.ucsf.edu/dementia/parkinsons/lewy-body-dementias>

Acknowledgement

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Questions & Answers

- Please type in your questions, and any tips and strategies you would like to share in the Q&A box at the bottom of your screen
- Recordings of this webinar series are available at the website below



Image by [Stephen VanHove](#) from [Pixabay](#)

The image features the UCSF logo, which consists of the letters "UCSF" in a white, bold, sans-serif font. The letters are arranged in a slightly staggered, overlapping manner, with the "U" and "C" on the top line and the "S" and "F" on the bottom line. The logo is centered within a dark blue square background.

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