

Caregiver, Who? Me?

Identifying Needs and Community Resources



Del Mar Caregiver Resource Center
Supporting Caregivers through their Journey

A family caregiver's world is turned upside down when a loved one is diagnosed with a neurological condition. At first, you may not know what questions to ask. You may struggle in understanding the diagnosis and what to expect. This paper offers guidance and resource information to get you started on your caregiving journey.

Let us first identify what a neurological condition is. Neurological conditions are diseases that affect brain functioning and the central nervous system. Common conditions include Alzheimer's disease, Parkinson's disease, Stroke and Traumatic Brain Injury. These are conditions that may result in symptoms of dementia causing memory loss, confusion and impaired judgement.

The questions to ask and what to expect, are influenced by the stage and severity of your loved one's condition. Neurological conditions are often progressive in nature, moving from mild, to moderate, to advanced stages of the illness.

Stages and Progression of Care

In the **mild stage** of an illness your family member may still perform their own care and make decisions. During this stage the caregiver is a support person, with minimal requests for hands-on care or assistance. Much time is spent gathering information and learning about the condition during this stage.

In the **moderate stage** of an illness your family member may begin to have difficulty with cooking and cleaning, driving, or performing their own personal care such as bathing, dressing and grooming. Development of problems with memory loss, and confusion, may require a higher level of supervision.

In the **advanced stage** of an illness your family member may require assistance getting to a standing position and walking. The level of personal care increases, including help with toileting, feeding and paramedical tasks such as checking blood sugar levels, giving injections, wound care, checking blood pressure, catheter care, and use of feeding tubes. Advanced symptoms of dementia may render the person unable to recognize family members, express themselves, or speak.

At Time of Diagnosis

A great deal of time will be spent learning about your loved one's diagnosis. Understanding the symptoms, course of the disease and treatment recommendations, will help with planning and identifying needs. Time of diagnosis is unsettling, acquiring knowledge and information will help restore some balance.

Questions to consider:

- Is the condition progressive?
 - Is progression likely to be rapid or slow?
 - What physical symptoms and behavioral changes may develop?
 - May the condition result in symptoms of dementia?
 - How will the condition affect the person's ability to care for themselves?
 - How will the physician treat and monitor the condition?
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Patient Health Journal

Being organized will support making confident decisions. The one constant in a caregiver's life is "change."

A Patient Health Journal is a tool that centralizes important medical and patient information for quick access and use. Using a Patient Health Journal helps to prevent confusion, make decisions with confidence, and reduce stress.

What goes in a Patient Health Journal?

- List of prescribed & over the counter medications
 - List of allergies
 - Name and contact information of primary physician & specialists
 - Physician reports of diagnosis and treatment plans
 - Name and contact information of home care nurse & social worker
 - Name and contact information of community service organizations(s)
 - Name and contact information of back-up "emergency" family caregiver
 - Running list of Medical appointments and hospitalizations completed
 - Copy of Power of Attorney for Health Care (*Advanced Health Care Directive)
 - Copy of Power of Attorney for Finances
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Caregiver, who? Me?

Family members are the largest group of individuals providing care to a loved one. According to the National Alliance for Caregiving (NAC), 53 million Americans are providing unpaid care to an ill or disabled relative in 2020 (NAC, AARP, 2020 Report). Often sudden, and without preparation, caregivers find themselves in uncharted territory.

Questions for the New Caregiver:

- Who in the family is best suited to assume the role of caregiver?
- What family values and traditions influence how family care is provided?
- How might your loved one feel and respond to receiving care?
- What matters most to your loved one?
- What feelings may you, the caregiver have?
- What will empower your confidence in caregiving?
- What arrangements can be made to free up time to perform caregiving?

- How will you know when outside assistance is needed?
 - If outside help is used, how will it be financed?
 - What areas of care may be more challenging e.g. emotional, physical, social, financial, legal?
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Caregiver Toolbox

Family caregivers wear multiple hats; companion, housekeeper, nurse, social worker, banker, planner and manager. Because caregiving dynamics continuously develop and change, it is important to set up a Caregiver Toolbox. A Caregiver Toolbox brings order to moments of chaos.

What is in a Caregiver Toolbox?

- Designate a space in your home to serve as “Caregiver Central.” Caregiver Central is where you put in work time for planning, organizing and making decisions. Limit these activities to this space. Doing this establishes a physical and psychological boundary within your home.
 - Place a large annual calendar on your desk or worktable to keep track of your schedule. The calendar will serve as an “at-a-glance” reminder.
 - Use an app such as Sticky Notes to place post-it notes on your computer screen or smart phone.
 - Use a digital voice recorder to record questions that come to mind, reminders, thoughts and observations.
 - Start a written chronological log, of important issues, situations and events. Write out your thoughts, discoveries, questions and ideas.
 - Ask professionals for their business card. Purchase a business card holder to store them. After speaking with someone on the phone or video conference, ask them to mail you their business card and brochure.
 - Keep music playing softly in the background.
 - Keep a jar of your favorite candy in arms reach.
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Identifying Caregiver Needs

Organize thinking about your loved one’s care needs into the following categories; Social, Physical, Emotional, Financial & Legal.

Social needs include companionship and socialization. Services at Senior Centers and Adult Day Care programs help reduce risk of loneliness and isolation. Other social programs include volunteer companion/visitation services, senior well-ness programs and support groups for patients and family caregivers.

Physical care needs pertain to Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs). Assessing the ability of your loved one to complete tasks such as housekeeping,

laundry, meal preparation, bathing, dressing, grooming and driving is based upon observation and through a series of questions to assess functioning.

Assessing ADL/IADL Functioning

Observe, and ask:

- How is house cleaning being done? Making the bed? Doing laundry?
- How are meals prepared? Meal cleanup?
- How is shopping and running errands done?
- How is the person bathing/showering? What steps are difficult? How often?
- How is brushing teeth, washing face being done? How often?
- Observe gait, reach, grasping strength.
- Observe state of dress, buttoned, zipped up? Coordinated? Appropriate for the weather?
- Observe for signs in the home things are not getting done.
- Look for mail piling up and unopened.
- Check for scratches or dents on the car.

This line of questioning, with observation, will provide clues to the person's level of functioning.

Emotional/Psychological Functioning

Conditions resulting in dementia affect a person's memory, orientation and judgement. Observation of behavior over time will help assess your loved one's cognitive functioning. Listen to speech patterns; are they making sense, struggling with words to express thoughts and feelings? Are they repeating themselves? Are they making bad decisions? Opening the door to strangers? Taking calls from people they do not know? Individuals with dementia are at risk for scams. Are delinquent bill notices starting to appear?

Some questions to assess orientation:

- What month are we in?
- What season of the year are we in?
- What time of the day are we in?
- Ask the person to point in the direction of the front door.
- Ask the person to point in the direction of downtown, or the ocean.
- Ask the person to walk you to the kitchen or other room.

Observe for signs of emotional distress. Pay attention to general facial expressions and how they move about; for example, slowly with a shuffle, or rushed? Make note of sleep patterns, too much? Not enough? Changes in appetite? Signs of restlessness, impatience, easily irritated, bouts of agitation. Jittery, jumpy, frighten easily? Bouts of shortness of breath? Racing heart? Trembling/shakes?

Questions to assess emotional health:

- Tell me what you are thinking about?
- Tell me how you feel?

- What did you do today?
- What do you worry about?
- How does your body feel?
- What makes you happy?
- Describe your energy level?

A person experiencing memory loss and confusion may not be able to reliably respond to these questions. In this case, observation over time, is the best way to assess emotional health.

Managing Finances

When assessing financial needs look at household budgeting, bill paying, and purchases. What is the source of income? Are bills paid on time? Unexplainable or unnecessary purchases? From where, when, whom? How are deposits and withdrawals made? Is the family member eligible for public assistance such as Cal Fresh (Food Stamps), Medi-Cal insurance?

Legal Affairs

Arranging a Power of Attorney for finances and health care is important before a person loses ability to make their own decisions. Is a Power of Attorney for finances and health care in place? Is a Trust or will in place? Once mental capacity has been lost, the individual is no longer able to have these documents drawn up and families may need to petition the court for conservatorship.

Needs of the Caregiver

Caregivers have needs too. Begin to address your needs by putting together the Patient Health Journal and Caregiver Toolbox previously mentioned. As your loved one progresses through their illness, you will begin to experience the pull of multitasking and time, to complete the items on your to do list.

When someone asks how you are feeling? Do not shut them out. Your loved one, and others, depend on you to stay healthy and well.

In a culture that values independence, self-sufficiency and productivity, it can feel selfish to think about caring for yourself. Far from it, self-care is self-preservation, not selfish. Recharging your battery enables you to be independent, self-sufficient, and productive. The need categories of your loved one apply to you as well; social, physical, emotional, financial and legal. Do not neglect yourself. To acknowledge a need is a sign of strength. Time devoted to wellness will empower your confidence, sense of worth, and readiness to carry on?

Community Resources

Within each community exists a network of community services and supports. The service network consists of public, nonprofit and for-profit agencies. Most public and nonprofit services

are available regardless of income, at no cost. Use a senior resource directory to learn about services in your community.

Senior Resource Directories

In Monterey and Santa Cruz County, senior resource directories are available online:

Santa Cruz County: www.seniornetworkservices.org

Monterey County: www.co.monterey.ca.us/government/departments-i-z/social-services/area-agency-on-aging/resources#aaa

The **Eldercare Locator** is a public service of the U.S. Administration on Aging. This service is nationwide and connects callers to resources throughout the country.

1-800-677-1116 or <https://eldercare.acl.gov/Public/Index.aspx>.

Getting Started: Information & Referral Services

Information & Referral (I&R) services are staffed by resource experts available to answer questions about aging and disability services. I&R is a good place to start when you don't know where to begin. These services are phone based and provided by public or nonprofit service agencies.

Tri-County call **2-1-1**, a 24-hour I&R service managed by the United Way
Santa Cruz County I&R, **(831) 462-1433**, managed by Senior Network Services
Monterey County I&R, **1-800-510-2020**, managed by the County Department of Social Services/Aging and Adult Services Branch
San Benito County I&R, **(831) 637-9275**, managed by Jovenes de Antaño

In Conclusion

Caring for an ill or disabled family member can be a lonely place. No caregiver need be alone. Outlined in this paper is a framework and general approach for what to consider, ask, and where to turn for assistance. In caring for others, it is important to not neglect your own needs. It bears repeating, self-care is not selfish, it is about self-preservation.

For information about caregiver services & support, call:
Del Mar Caregiver Resource Center | 1-800-624-8304
Or visit: www.delmarcaregiver.org

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