Building a Robust Support System

A guide for individuals and families navigating memory loss and staying connected in the world around them.

This system comes from lessons learned while working with more than ten thousand clients over three decades. It's been further tested and refined through my personal experience of caregiving for four family members with memory loss. What I share here represents the foundations witnessed to be the most successful in addressing current needs and preparing for future needs by building a powerful support team.

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“We do not rise to the level of our goals, we fall to the level of our systems.”
- James Clear

Start early and be kind to yourself. This is a marathon not a sprint.

You are not alone in this journey. What you're facing may be hard, and millions of people have walked this path before you. The good news is we can share the tools and wisdom discovered along the way. You will need support and help is available. There is hope.

Taking early action and seeking answers allows you clarity, confidence and control of the path ahead. Whether this is a concern you have for yourself or a loved one, nearby or far away, this framework will help guide you.

The Three Principles

- **Capacity and resilience** - Expand your potential to meet the challenges ahead with ease. Think advocacy.
- **Right Fit** - Matching the right people to your needs. Think relationships.
- **Resource organization** - Accessing relevant information and utilizing simple systems to organize it. Think efficiency.

Principle #1: Capacity and Resilience

Capacity is our internal readiness to handle the challenges ahead. This impacts everything from the stress of daily decision-making to the complexities of interacting with family members and physicians. Our resilience is the ability to tolerate distress and bounce back from difficult moments.

Studies show that the number one predictor of a person being moved into long-term nursing care is the care partner's tolerance for distress. This tells us how valuable it is to build our own capacity and resilience.

While capacity and resilience are shaped early in life, they can continue to grow and evolve well into adulthood. The primary factors that influence our ability to accept help include:

- **Culture and family values** The norms and experiences we grew up with around asking for help
- **Gender expectations** Women are often expected to be the primary caregiver, regardless of other responsibilities like children, spouses, or professional duties
- **Fear** Fear of judgement, fear of future diagnosis, loss, dependence, or change
- **Belief in scarcity** The feeling that there is never enough time, energy, money or help
- **Isolation** Feeling that no one understands or we don't want to burden anyone with our struggles
- **Personality traits** High achievers, independent types and those who strongly identify as caregivers often struggle to ask for help
- **Nervous system patterns** Our bodies may constantly send signals which we interpret as needing to fight or escape, without the ability to return to calm

Why does this matter? It directly affects:
- Ability to advocate effectively with physicians and specialists
- Whether you follow through with referrals and recommendations
- How effectively you ask for and accept hep
- Your risk for burnout, anxiety and depression

An important question to consider: *Do you respond to stress with self compassion or self criticism?*

Many people will be tempted to skip this section, thinking it feels too “woo woo" or intangible. However, I have seen this demonstrated time and time again as a critical factor in successful caregiving. Perhaps now isn't the moment for you to focus on this, but keep it in the back of your mind because this is often the weak link in an otherwise strong support system.

The first step is to examine your beliefs about asking for and receiving help. It's helpful to reflect on how our parents handled it and what you assume others might think about you. Nowadays, there are many options for accessing support. If you prefer person-to-person conversations, options include caregiver hotlines, support groups (in-person or virtual), a trusted friend, faith-based contacts, private coaching or psychological counseling.

With the rise of Artificial Intelligence (AI), you can privately and at no cost ask for “coaching style reflections” on your situation, which will be generated instantly. A supportive and conversational approach can lead to true insights.

Often, simply recognizing our patterns and how they limit us is enough to start us on an easier path. The goal is frequently to find the same compassion for ourselves that we so readily extend to others, along with healthy ways to calm our nervous system in times of distress.

Please note: The above is not intended to be exhaustive or taken as medical advice. Use your best judgement and speak to healthcare professionals as needed.

Principle #2: Focus on Right Fit

“No matter how many times you walk up and down the isles at the hardware store you will not find the milk”. -Cheryl Richardson

This principle is all about matching the right person to the right supportive role. One person might be perfect for searching for the best neurologist in your area. Someone else might be the one to talk you through a time when you're struggling with anxiety. Another might help with the copays for doctors appointments and therapists.

Finding the right fit takes communication, flexibility and adjustment over time. If you find someone is no longer a good fit for a particular role, consider whether they might take on a new task instead. Try not to shut people out due to anger or disappointment, because as needs change, it will be harder to invite them back into your system.

Why does Right Fit matter?

- Relying on the wrong person leads to anger, resentment and ultimately feelings of isolation and abandonment. You might be tempted to say “I knew it. No one will help” or “No one understands what I'm going through.”
- It saves time and energy when you can go directly to the one who can meet that specific need
- It helps you cover all the bases without tapping the same resources too often
- It allows people to support you at the level where they can be successful. Be honest about your needs and clear on expectations. Set them up for success.
- It helps you determine if a task should be delegated or collaborative.

Most families limit their support systems to immediate family and friends. Fortunately, we have more options and easier access to support than in years past. (See resources in Principle #3 for many options to consider.) If you feel that none of the available resources are going to be able to help in the way you need, please revisit Principle #1 for possible self-limiting beliefs that might be holding you back.

What needs do we typically have?

Here are common needs and terms that healthcare professionals use when discussing resources:

- **Activities of Daily Living (ADLs)** basic self care tasks we do on a daily basis, medication management, personal hygiene, dressing, cooking
- **Instrumental Activities of Daily Living (iADLs)** household chores, meal planning, shopping, transportation, managing finances, legal matters. These are more easily delegated responsibilities when someone offers support.
- **Advance Directives**
- **Financial and legal planning**
- **Medical and nursing tasks**
- **Personal sustainability** Addressing complex grief, loss, stress, isolation, decisions about disclosure of a diagnosis
- **Emergency planning**
- **Care plan development and support**

What actions support the Right Fit principle?
Support groups come in different sizes and focus on different categories of resources. It may take time to find your right group size, topic and dynamic for you. Similarly, it may take time to find the right agency or individual coming into the home.

Keep a list. When someone asks if they can help, give them a tangible, clear, and appropriate task with a timeframe. Always say yes immediately and give a choice of 2 options.

Two resources for organizing help are the “Lotsa” App (also known as Lotsa helping hands) and CaringBridge.com. With both platforms you register a recipient on your mobile phone or computer and add tasks to the calendar. You can then invite people to sign-in, where they can see all the options and sign up for a task right from their device. Best of all, both are free.

Principle #3: Locate and Organize Resources

“The mind is for having ideas, not holding them.”   -David Allen

Internet or AI searches can quickly lead to an “information avalanche.” Here I offer a place to begin and a system to organize information so it can be easily accessed by you or those in your support system.

Recommended starting points for information gathering:

- **Area Agency on Aging** Enter your zip code to find contacts and resources specific to your town
- **Alzheimer’s Association** A good place for a broad overview; offers free 24/7 hotline
- **National Institute on Aging** A nice starting point for more generalized information
- **Centers for Medicare and Medicaid** - See the new Medicare Guide Model program at www.cms.gov/priorities/innovation/guide/faqs
- **ROON App** Free and impressive for searching common questions; watch video explanations from healthcare leaders
- **Caregiver Alliance Network** National support lines and education
- **Dementia Friendly America** A grassroots effort to connect people

Once you have identified the resources you need, the key is to **choose one storage method**. This could be a physical 3-ring binder or a digital folder system such as the Notes app, Google Drive or Evernote. Having one centralized place is helpful for sharing information or if someone needs to step in to take your place as coordinator.

Here is a suggested template for organizing your information:

- **Cover page** Emergency contacts and plan, physician information, pharmacy details
- **Medical information** Diagnosis, medication, allergies, healthcare providers
- **Appointment tracker** Visit summaries, recommendations, follow-up planning
- **Daily support** Resources for communication, memory, environment, routines
- **Questions for providers** Dedicated space to capture and answer questions
- **Education and resources** Key learning summaries and simplified takeaways
- **Care planning** Legal documents, financial references, care preferences, advance directives

Here is a list of key words and categories you may use in your search for additional resources:
Primary Care, specialists, case managers, social worker
Medicare, Medicaid, VA, Advantage Plans, private insurance
Universities, medical centers, specialty clinics, medical trials and studies
Day programs, respite care, senior centers, paid private care
Independent Living (IL) and Assisted Living Facilities (ALF)
Nonprofit associations and organizations for a specific diagnosis of dementia
Local Speech Therapy, Occupational Therapy and Physical Therapy providers
Medical skills training and emergency preparedness
“Care Navigators” Often available for private pay through many of the companies under the Medicare Guide Model list of providers (if you don’t qualify for free service)
Clergy or faith based resources, youth groups
You tube, podcasts, Facebook
Free webinars on Eventbrite

Thank you for downloading this resource. I truly hope it has been helpful for you and those you love. If you have questions or suggestions, please feel free to contact me through my website at Brightlegacycare.com

Additional complementary resources available on my website.