Family Support Guide: Navigating a New Diagnosis

A neurodegenerative diagnosis — such as Alzheimer's, Parkinson's, or another form of dementia — can be life-altering for both the individual and their family. This guide offers clear, practical steps to help you process the news, organize care, and maintain emotional resilience throughout this journey.

Take Time to Process

It's normal to feel overwhelmed, confused, or afraid after a diagnosis. Give yourself and your loved one space to absorb the information. You don't need to have all the answers right away.

- Ask for printed or digital materials from your healthcare provider
- Take notes or record appointments (with permission) for later reference
- Lean on a trusted friend or therapist to process emotions

Ask the Right Questions

The next few medical visits are crucial. Here are some essential questions to bring:

- What specific condition has been diagnosed?
- What stage is it currently in?
- What symptoms should we expect in the short and long term?
- What treatment options are available?
- Should we be referred to a neurologist, psychiatrist, or geriatric specialist?
- Are there clinical trials or research studies we should consider?

Create a Care Plan Early

Being proactive can reduce uncertainty. Begin outlining a care plan that includes:

- Medical management: Medications, therapy schedules, follow-ups
- Daily support: Who will assist with meals, transportation, hygiene, or medication reminders?
- Legal/financial planning: Power of attorney, advance directives, budgeting for future care
- Emergency contacts: Doctors, caregivers, and trusted family members

Support Communication and Dignity

As cognitive symptoms progress, communication may become more difficult — but dignity should remain central.

- Speak slowly, clearly, and calmly
- Use simple phrases and maintain eye contact
- Offer choices rather than open-ended questions
- Avoid correcting unnecessarily focus on reassurance, not accuracy
- Validate emotions, even when logic falters

Care for the Caregiver

Supporting someone through neurodegeneration is emotionally and physically demanding. Many caregivers experience burnout, depression, or anxiety. Make a plan for your own well-being:

- Schedule regular breaks or respite care
- Join a caregiver support group (in person or online)
- Talk to a mental health professional when needed
- Set realistic boundaries you cannot do this alone

Stay Connected to Community

Isolation can make this journey harder. Explore support options such as:

- Local Alzheimer's or Parkinson's chapters
- Community memory cafés
- Faith-based programs for elder care
- National hotlines or online forums (see our "Resources" page for links)

Adapt Over Time

Neurodegenerative diseases are progressive — needs will evolve. Regularly revisit and revise care strategies. What works now may not work in six months, and that's okay. Be flexible, patient, and kind to yourself and your loved one.

You are not alone. This diagnosis does not erase the person you love. With the right information, planning, and support, families can find moments of clarity, joy, and connection even in the midst of difficulty.

InMind is here to support you every step of the way.