

Asking for Help

Caring for someone can add up to a lot of tasks and hours. In fact, a survey found that care partners spend up to 45 hours a week on caregiving tasks. And while many care partners want help, 81% feel guilty asking for it.

Creating a support system that works for your situation can help reduce stress and help during transitions in your loved-one's care needs. If you live on your own without a built-in support system, then creating a plan will offer peace of mind and more control when more help is needed.

At some point in life, we all have had the challenge of asking, accepting, or even trying to provide another with help. It's difficult!

Some of the challenges to seeking help can include:

- » Guilt
- » Inability to release control
- » Uncomfortable asking
- » Fear of rejection or receiving a "no"
- » Feeling like nobody wants to help
- » Don't want to be perceived as weak if you are the person with the disease
- » You feel like it's your responsibility
- » They will not do it as well as you

In a recent survey, care partners reported the top four tasks they spend their time on:

92%

Providing emotional support to their loved one

81%

Managing doctor appointments

81%

Transportation to appointments

74%

Helping with memory



PMD Alliance
Parkinson & Movement Disorder Alliance

Asking for Help



WHY YOU SHOULD ASK FOR HELP

Over time, the physical, emotional, and psychological toll of helping a loved-one without support can cause burnout which leads to exhaustion, stress, anxiety, depression, mood swings, sleeplessness, anger, frustration, and resentment followed by guilt.

Additional factors that contribute to burnout can include:

ROLE CONFLICT: conflicting demands and difficulty balancing the needs of your loved one, your job, family, friends, and yourself. This is often a significant challenge for adult children.

ROLE CONFUSION: the merging of your role as care partner and your relationship with your loved one. You may find you refer to yourself as "caregiver or care partner" instead of spouse, partner, or child.

LACK OF MARGIN: the gap between rest and exhaustion, a boundary that is built into your day where you have time to relax, unwind, and enjoy moments of freedom to do something you enjoy. Even if this is just a few minutes a day, many people find their margin has disappeared.

UNREALISTIC EXPECTATIONS: whether you place them on yourself, or they are demands placed by family members, not setting some boundaries on what you can and cannot do can increase your burden.

WHEN TO ASK FOR HELP

Caregiving burnout is sneaky. Often by the time you realize you need help, you are already overwhelmed and the ability to make decisions and coping with challenges can be more difficult. Some people don't ask for help until they are in a crisis. Waiting to that point reduces the chances of having options. Not only will your loved one's needs continue to increase, but you will also have changing needs, abilities, and limits of your own to consider.

HOW TO ASK FOR HELP

MAKE A LIST/CALENDAR: Make a list of tasks that would be helpful to you such as transportation, grocery shopping, chores, errands, walking the dog, or spending time visiting with your loved one while you rest or go do something for yourself. Keep it up to date and give people options. Post it and allow others to share it.

CONSIDER WHO YOU ASK: Some tasks can be addressed by friends, family, or volunteers and others might be better hired out.

BE CLEAR: Make a specific request and be clear in what you are asking for and give options, so they see that you are flexible.

BUILD YOUR SUPPORT NETWORK: There are some that might seem obvious like friends or family, but think outside the box about others who might be able to help. Are you involved in a church or synagogue that has a ministry that helps? Many communities have service organizations that provide support services to older adults. Check with your local Area Agency on Aging for a list. Some supports can be formal such as food delivery services, yard services, home care, adult day care, etc.

SHOW YOUR GRATITUDE: Saying thanks through cards, buying lunch or other ways of showing appreciation for the help others give goes a long way!

The Art and Practice of Planning:

Asking for Help

TYPES OF SUPPORT

FORMAL SUPPORT: Provided by individuals or organizations that you either pay or are provided by a professional. Examples include: hired companion services or talking with a social worker.

INFORMAL SUPPORT: Support provided by people who are in your personal social network such as family, friends, neighbors, church, community, or support group.

BUILDING YOUR TEAM (SUPPORT SYSTEM)

First Steps: If you haven't asked for help yet, there is no better time than the present. Think of something small to begin with and who you might ask.

What type of support do I need?

What task(s) do I need help with?

Who can I ask? Where can I get it?

When am I asking? Set a time:

DON'T FORGET TO ALSO PLAN FOR EMERGENCIES

If you happen to need help for yourself because you are sick or need hospitalization, who do you call (especially in the middle of the night) to be with your loved-one?



PMD Alliance
Parkinson & Movement Disorder Alliance

Roadmap to Care Series and toolkit made possible with a sponsorship from Kyowa Kirin.