



CARING
ACROSS
GENERATIONS

GUIDE FOR CARE RECIPIENTS:

Talking to Family, Friends, and
Loved Ones About Care



What does it mean to receive care?

At some point in our lives, we will all give or receive care. **Receiving care can take many forms: from physical care, like needing assistance with cooking and cleaning; to emotional care, like having quality time with your loved ones; to self care, like taking a bath to decompress or asking for support when you need it.**

You can receive care from anyone — related and chosen family, friends, neighbors, even strangers. Care can be paid or unpaid: paid care is provided by direct care workers, who are most often paid through Medicaid through a mix of state and federal dollars. Family members in some states can also be paid to do direct care work. Medicaid is the primary funder for home care, which is funded through Home and Community-based Services (HCBS) Waivers, though what is available varies by state (see our Resources section below for more information).

Receiving care, support, and help is so essential to who we are as human beings that many of us don't think of it as "receiving care" — we just think of it as part of life. But the lack of conversation around what it means to receive care can make it harder to ask for help when we need it, especially because our society, rooted in individualism and ableism, teaches us that we should be able to handle everything on our own. **Defining care as something we will all receive at some point in our lives means we can come together to ask for support, advocate for ourselves, find community, and work towards collective solutions to our care needs.**

How to explain what it means to receive care

Though we all have received and will receive care in our lives, receiving care can be hard to explain. Explaining your care needs can be vulnerable and uncomfortable. And due to societal pressures, many of us have been conditioned to feel at fault or ashamed if we need care.

That's why explaining our care needs is so important: it can help us feel connected to each other, find support, and combat the stigmas that keep us from having these essential conversations. Every conversation about receiving care will be different, because people are coming at the issue from different lived experiences and perspectives. But here are a few tips for having the discussion:

- 1. Share your personal story:** People can connect more to specifics than generalities, which is why sharing your own experience is so powerful.
- 2. Find common experiences:** Talk about how you've seen the person you're talking to receive or give care in their lives, or use shared care experiences as examples (e.g. discuss a shared family member who you've seen receive or give care).
- 3. Be specific:** For people who are unfamiliar with receiving care, it can be hard to know what it actually entails. Be specific about the number of hours of care you need in an average week and what kinds of support you need (as long as you are comfortable sharing that information).

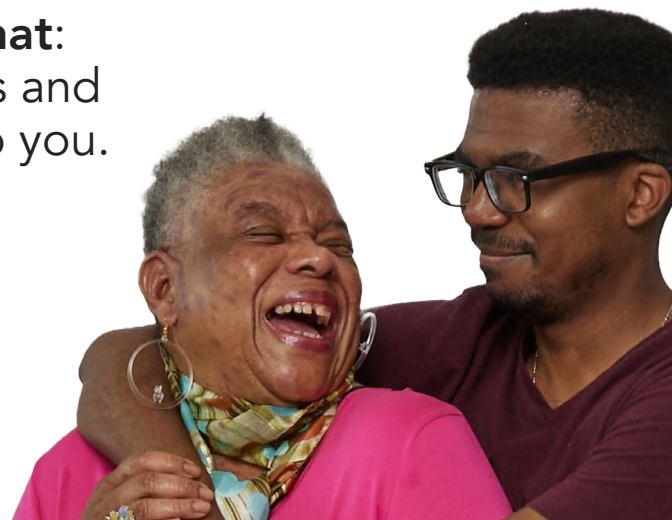
4. **Explain what supports you have access to now, and what you would have in an ideal world:** This can help the person you're speaking with understand the difficulties you might be facing in accessing care, and how they can support you, either with your care needs or through direct advocacy.
5. **Be patient and sensitive, with the person you are speaking with and with yourself:** The person you are speaking with may be uncomfortable discussing receiving care, and it may take several conversations to feel like you're getting somewhere. And if you are finding the conversation difficult, it's okay to take breaks, come back to the conversation later, or decide the conversation with this person is not serving you.

How to Ask for Support

While everyone is different and circumstances may be unique, it could be time to ask for help with care support when you no longer are able to do your daily routines as you used to, when you feel unsafe navigating your home alone, or when you feel isolated, anxious, or are finding less joy in doing the activities that you once found pleasurable.

- **Map out who to ask to do what:** Make a list of your connections and the people you can ask to help you. Write a list of the chores or activities you need assistance with. Map out which person would be the best fit for each task.

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- **Describe the situation:** When you approach someone, explain the situation, explain how you're feeling, and share why you're asking for this help now.
- **Make the ask specific and direct:** Be direct with what you need and be specific — share details, times, locations, dates, or any other background information that is needed for the person to take on the task. Be specific about the task(s) you're asking them to do and be honest about what your own limits are.
- **Make plans:** Will you need care support again in the future? If so, map out what exactly you need assistance with, and figure out if this is a sustained need or a specific one-time/few-time occasion when you need support. Can this assistance request be fulfilled by a loved one or will you need to look for a paid caregiver?
- **Figure out your preferences:** Some people who receive care prefer to hire paid workers, rather than rely on family or friends, because they may feel they have more control and/or do not have to rely on relationships where dynamics may be complicated. Consider your needs, relationships, finances, and your access to government support, such as Medicaid, while making these decisions.



How to Advocate And Share Your Story

There are many ways to advocate for yourself as a care recipient – this includes asking for assistance when you need it, sharing your story, or volunteering with a care advocacy organization like Caring Across Generations.

Sharing your care story can be challenging because it's deeply personal, but it can also be liberating and a source of advocacy. When sharing your story, remember it is your experience and only you can share your care story – it's uniquely yours! This list is meant to serve as a guide, but remember that there is no wrong way to share your story.

1. **Share background information:** This should be whatever you feel comfortable sharing, but may include background information on how and when you became a care recipient and how you receive the care that you need.
2. **Explain how the journey has been for you:** How has receiving care impacted your life? What has receiving care meant for you? What are your feelings surrounding being a care recipient?



3. **Engage with your loved ones:** Ask if they have questions or thoughts.
4. **Look for community and continue sharing your story:** There are many resources and groups that encourage the telling of these care recipient stories and that provide a venue for you to do (see a list in the “Resources” section below). You may also opt to [share your story with Caring Across Generations](#) and use your story as a form of care advocacy.



Care Recipient Resources

- [Manage stress: Strengthen your support network](#) - Guide to building your network
- [Find your Local Center for Independent Living](#) - connect with local supports
- [The Alzheimer's Association](#) - Resources, helpline and support
- [Sibling Transformation Project](#) - Join an affinity group
- [The Arc](#) - Find a chapter in your area
- [National Disability Rights Network](#) - access your state advocacy organization
- Medicaid Information:
 - [Medicaid HCBS Waivers](#) - key information on Medicaid HCBS Waivers
 - [Medicaid State Information](#) - information on Medicaid Programs by State
 - [Kaiser Family Foundation](#) - Q+A on Medicaid HCBS Waivers and waiting lists
 - [Medicare and Medicaid Research Review](#) - article on how Medicaid Waivers vary across states

