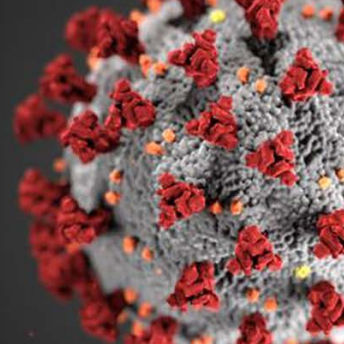


# How ACL's Disability and Aging Networks Can Help People with Long COVID



## What is Long COVID?

While most people with COVID-19 get better within weeks, some continue to have symptoms—or develop new ones—after their initial recovery. The technical term for this is “Post-Acute Sequelae of SARS-CoV-2,” or PASC, but it is more commonly called “long COVID.” People with long COVID are often called “long-haulers.”

[Long COVID](#) can happen to anyone who has had COVID-19, even those who had only mild symptoms. It can persist for a long time, and severity can range from mild to incapacitating. If you have long COVID, you may need assistance to do things you did by yourself in the past. You also may need to make changes in your life or to your home to adapt to the changes in your abilities.

Finding the resources and supports you need can be overwhelming, but the [Administration for Community Living's programs](#), and the disability and aging networks that provide them, may be able to help. These networks and programs offer a wide range of services and supports to help people with disabilities—including disabilities caused by long COVID—and older adults live independently, go to school and work, and fully participate in all of life's activities.

We compiled this guide to help you connect to services and supports in your community. (Please note that eligibility for specific services and supports will be based on a combination of factors, including your individual needs for and availability of program resources.)

## Not sure where to start?

### Disability Information and Assistance Line (DIAL)

- » DIAL can provide information about services you may be eligible for and connect you to them. DIAL also can help you get vaccinated if long COVID is making it difficult for you to find vaccine sites, make or keep appointments, or find the information you need to make decisions. Learn more at [acl.gov/DIAL](https://acl.gov/DIAL).
- » To use DIAL, call 888-677-1199 Monday-Friday from 9 a.m. to 8 p.m. (Eastern) or email [DIAL@n4a.org](mailto:DIAL@n4a.org).
- » Older adults also can call the Eldercare Locator at 800-677-1116 or visit [eldercare.acl.gov](https://eldercare.acl.gov) to chat live or browse resources.

## Community-based organizations that provide a range of services

### Centers for Independent Living (CILs)

- » Serve people with all types of disabilities.
- » CILs offer, at a minimum, the following services: information and referral, independent living skills training, peer counseling, individual and systems advocacy, transition and diversion from nursing homes and other institutional settings back into the community, and transition of youth to postsecondary life. [Find a local CIL](#).
- » **For people with long COVID:** Your local CIL may be able to coordinate services; arrange accessible transportation; locate and/or provide mobility equipment, and personal care attendant services; assist with arranging reasonable accommodations; and address accessibility barriers in housing, medical care, employment, and other areas; and more.

### Aging and Disability Resource Centers (ADRCs)

- » Serve older adults and people with all types of disabilities.
- » Provide objective information, advice, counseling and assistance, and help people access public and private programs.
- » Contact information for many ADRCs can be found through the [Eldercare Locator](#).
- » **For people with long COVID:** ADRCs can help you navigate your state's systems of services, including determining eligibility and connecting you to the organizations, critical resources, and services that can help meet your needs.

### Area Agencies on Aging (AAAs)

- » Serve older adults (age 60+) and family caregivers. Most also serve people with disabilities.
- » The specific names of AAAs vary. To find your local AAA, visit the [Eldercare Locator](#) or call 800-677-1116.

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- » AAAs contract with 20,000+ local providers nationwide to provide services and programs that may include congregate and home-delivered meals, information and assistance, evidence-based chronic disease prevention programs, caregiver respite, case management, transportation, homemaker support, and personal care.
- » **For people with long COVID:** AAAs may help identify and provide personal care and homemaking services you now need as a result of long COVID; facilitate transportation to and from medical appointments; and provide meals. AAAs can also identify and reach out to underserved older adults, including people who are homebound, live in rural areas, or have limited English proficiency, to connect them with services they may need if they have long COVID.

## Specialized programs

### Protection and Advocacy Systems (P&As)

- » Serve individuals with all types of disabilities.
- » P&As are in every state and territory. There is also one P&A that serves the Navajo and Hopi Nations in New Mexico, Arizona, and Utah.
- » P&As are congressionally mandated agencies that provide a range of legal advocacy services to people with disabilities who have been denied access to a service or an opportunity to take part in an activity, such as employment or education. P&As address allegations of neglect or abuse and conduct monitoring and investigations of facilities. [Find a local P&A.](#)
- » **For people with long COVID:** Your local P&A may help assess your status and needs, provide case management, ensure access to services, and address accessibility barriers.

### State Assistive Technology (AT) Programs

- » Serve individuals with disabilities of all ages and their families.
- » AT programs in every state and territory help make AT devices/equipment and services available. Their efforts range from “low tech” (e.g., built-up handle on spoon to improve ability to grasp) to “high tech” (e.g., computers controlled with eye movement). Other examples of supports are home automation solutions and services to obtain and use devices. AT support can also include assessment, customization, repair, and training. [Find a local AT program.](#)

- » **For people with long COVID:** Your state program may be able to provide you with AT you now need. They can also ensure the accessibility of websites and outreach materials educating people on long COVID and the resources available to assist those with long COVID; and provide subject matter expertise and technical assistance related to accessibility and AT.

### State Long-Term Care Ombudsman Programs

- » State Long-Term Care Ombudsman Programs advocate for people living in nursing homes, board-and-care homes, assisted living facilities, and similar facilities to resolve individual problems and to bring about changes that improve their care, quality of life, and rights.
- » Call 800-677-1116 or visit the [program locator](#) to find your local ombudsman program.
- » **For people with long COVID living in LTC facilities:** Your ombudsman may serve as a resource to provide information on long COVID and help you if any issues arise in meeting new needs as a result of long COVID.

### For Tribal and Native American Elders

- » Age for eligibility is determined by each tribe.
- » There are 282 grantees serving over 400 tribes.
- » Provide supportive services, nutrition services, and caregiver support to native elders and their families. [Find services in your area.](#)
- » **For tribal and Native American elders with long COVID:** These programs may provide case management and assistance organizing transportation. They may also help educate individuals and communities on long COVID and the resources available to assist people with long COVID and caregivers.

## More resources

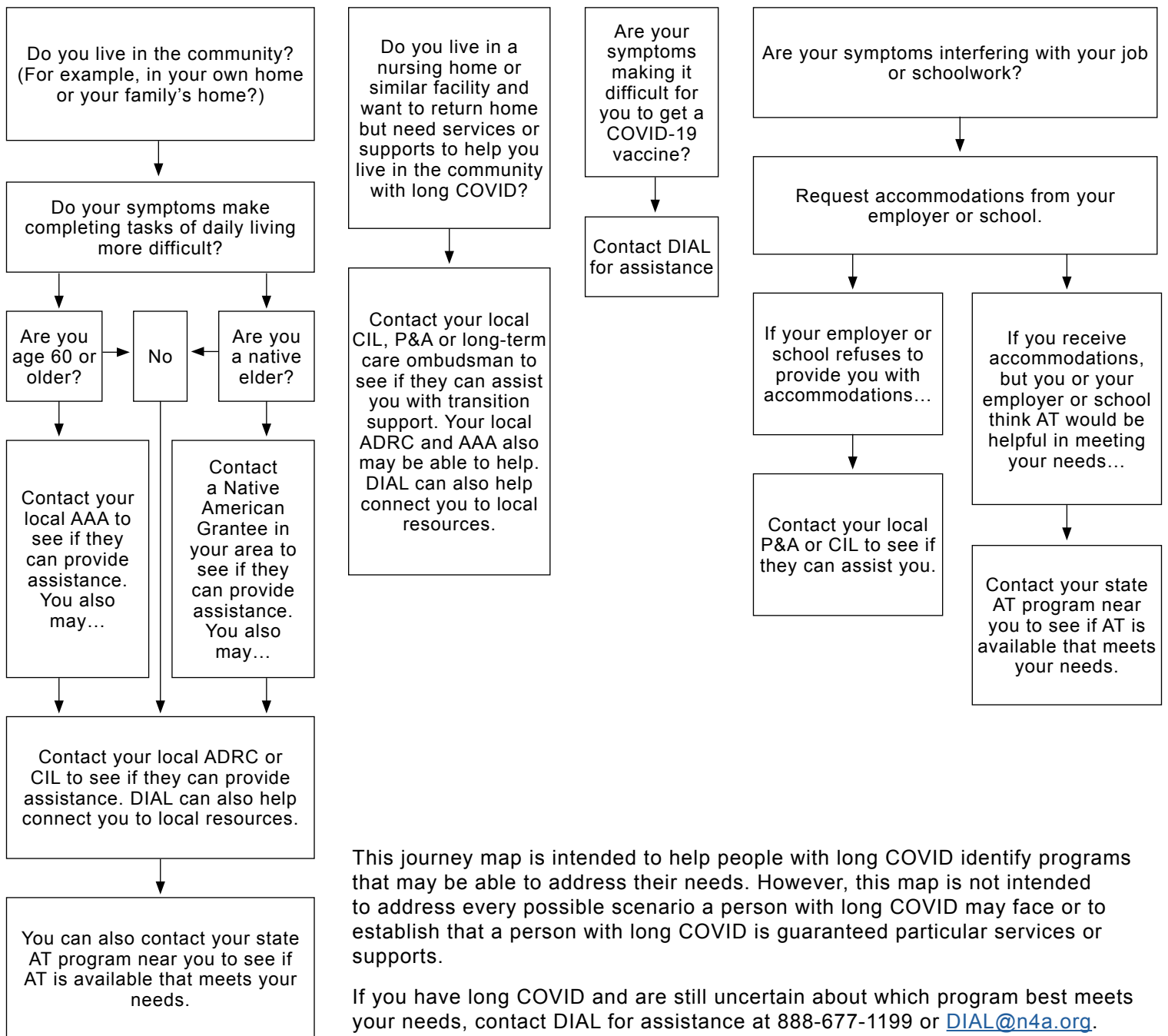
### When is long COVID a disability?

- » This [guidance](#) from the HHS Office for Civil Rights (OCR) and the Department of Justice explains when long COVID can be a disability under various civil rights laws.

### Learn more about long COVID

- » CDC’s [web page on post-COVID conditions](#) includes information about long COVID.

## If you have long COVID...



This journey map is intended to help people with long COVID identify programs that may be able to address their needs. However, this map is not intended to address every possible scenario a person with long COVID may face or to establish that a person with long COVID is guaranteed particular services or supports.

If you have long COVID and are still uncertain about which program best meets your needs, contact DIAL for assistance at 888-677-1199 or [DIAL@n4a.org](mailto:DIAL@n4a.org).