

## Tools and aids that make life easier

Many tools we use all the time are taken for granted. When you live with amyotrophic lateral sclerosis (ALS), you may find that some everyday tasks have become harder. Don't worry. There are many tools that can make your life easier.

Not sure what you need or where to start? Talk with your doctor. Your doctor can assess if aids or tools are right for you, or if your treatment needs to be adjusted.

You can also ask your doctor about an occupational or physical therapist. Such therapists can help you see where you struggle or are at risk. They can also help you choose the most helpful aids for any given task. Therapists can train you to use these aids and get the most out of them.

The right tool can make a big difference. Such items include electric toothbrushes, electric razors, and touch on/off lamps. Do normal hand-held utensils and tools strain your grip? Try utensils and cups with special handles to help you dine with less effort. There are ways to make cleaning yourself easier as well. Try strap-fitted hairbrushes, hand-held shower heads, raised toilet seats, and handles on toilet seats. These aids can all make your time in the bathroom easier and safer.

Those living with ALS can struggle to stay mobile. Braces for the foot and ankle can give your joints support. For those who fatigue quickly, walkers with wheels and wheelchairs can help. They can also keep you safe by lowering your risk of falling.

For those who need caregiver support, durable medical equipment (DME) may be needed. As ALS progresses, transfer boards and slides can make moving from a bed to a chair or toilet easier. A mechanical lift can help a caregiver to safely move someone.

For those who can no longer speak, text to speech technology has come a long way. These computer programs and apps allow you to type without your hands. They then turn what you type into audio, or speech. To learn more, go to the ALS Association website at [www.als.org](http://www.als.org) and search for “Augmentative Communication.”

You can also talk about assistive tools with your program nurse. To get started, give your nurse a call today.

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## Tips for making daily life easier

When you live with chronic inflammatory demyelinating polyneuropathy (CIDP), you may find that some everyday tasks have become harder. Don't worry. Many tools can make life easier. Not sure what you need or where to start? Talk with your doctor. Your doctor can assess if aids or tools are right for you, or if your treatment needs to be adjusted.

Symptoms of CIDP vary greatly from person to person. Some with CIDP just have mild loss of reflexes or muscle weakness. If treated early, the amount of nerve damage from CIDP can be limited. Some people can be cured altogether or go into remission. But for others, simply getting around and daily living can be affected.

If your CIDP causes muscle weakness in your legs, you may struggle to stay mobile. Using a cane or walker can help make up for muscle weakness. Braces for the foot and ankle can give your joints support. If you fatigue quickly, walkers with wheels can help you travel further. These devices can also help keep you safe and lower your risk of falling.

For those having issues with weakness, the right tools at home can be a big help. Electric toothbrushes or razors can help. Also try strap-fitted hairbrushes, handheld shower heads, or raised toilet seats with handles. These can all make bathrooms easier and safer. For the kitchen, utensils and cups with special handles can help you eat with less effort. Touch on/off lamps can also be helpful.

Ask your doctor about occupational or physical therapy. Therapists can help you choose the most helpful aids. They can also train you to get the most out of them. A therapist might work with you to exercise in a pool or large tub. This can help get your muscles moving if you're not able to move

them well on your own. Exercise can be a big help for those with CIPD to regain strength and maintain a good quality of life. Ask your insurance provider about the types of programs and/or devices covered under your plan.

Also check out the GBS/CIDP Foundation Centers of Excellence (COE) program. Local chapters exist all over the world. To learn more, visit <https://www.gbs-cidp.org/support/>.

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### Tools and aids that make life easier

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Not sure what you need or where to start? Talk with your CF team. Your team members can assess if aids or tools are right for you, or if your treatment needs to be adjusted.

For example, you can talk to your respiratory therapist about tools used for therapy. They can help you see where you struggle or are at risk for complications. If you don't have a respiratory therapist on the team, your doctor could perhaps find one to talk to. They can also help you choose the most helpful aids for any given task. Therapists can train you to use these aids and get the most out of them. It is good to have your respiratory therapist review your skill at using your current airway clearance equipment.

Here are some devices that can help you manage your CF:

- High-frequency chest wall oscillation device: this is an inflatable vest that vibrates the chest to loosen mucus.
- Nebulizer: is a device that turns liquid medications into a mist that you inhale. It is important to learn how to clean your nebulizer. This will help to prevent you from breathing in germs.
- Positive expiratory pressure devices: these are devices that helps to clear mucus out of your airways. It slows the flow of your breath going out by creating resistance to airflow. Some of

these devices also vary the resistance so the airflow will oscillate, which also will help to move the mucus in your airways.

You can also talk about assistive tools with your program nurse. To get started, give your nurse a call today.

### **This month is Wear Yellow Day for CF Awareness**

Spread the word! It's a great time to teach those around you more about CF.

Join in for Wear Yellow Day for CF Awareness through the CF Trust at

[www.cysticfibrosis.org](http://www.cysticfibrosis.org).

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Those living with Gaucher are at higher risk for bone disease and bone crisis. The best thing to do to prevent bone issues is to take your medicine as prescribed and monitor for osteoporosis and other bone issues. You can also do weight-bearing exercise to make bones stronger. Assistive aids can be used to further reduce your risk on top of treatment.

Not sure what you need or where to start? Talk with your doctor. Your doctor can assess if aids or tools are right for you, or if your treatment should be adjusted.

Aids such as seats in showers and raised toilets can make your life easier and safer. So can improved lighting. Remove rugs or other tripping hazards and install handrails in the bathroom. For those who fatigue quickly, walkers with wheels and wheelchairs can help. They can also keep you safe by lowering your risk of falling.

You can also ask your doctor about an occupational or physical therapist. Such therapists can help you see where you struggle or are at risk. They can also help you choose the most helpful aids for any given task. Therapists can train you to use these aids and get the most out of them.



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### Taking care of infusion supplies

Do you infuse factor at home? For those living with hemophilia, it is important to take care and keep track of supplies. Many may be on non-factor replacement treatment, but you may still keep factor on hand for a bleed.

Keep track of your supplies and when they expire. This will help you know when to order more before you run out. Each bottle of factor should list the expiration date.

How you store supplies is also important. Each bottle of factor has instructions for how to store it. Some brands should stay in a refrigerator. Others can store at room temperature. Factor should never get hot. It should also never be frozen. If you must travel with factor, use a cooler. This will protect it from temperature changes.

You should also keep either sterile water or sterile saline on hand. These are mixed with factor before infusion. They can be stored at room temperature or in a refrigerator. They will need to warm to room temperature before use, however. Factor bottles should have instructions for how long factor can sit at room temperature after it is mixed.

Keep all other supplies clean and dry. They should also be easy to reach and clearly labeled, in case of a bleed. You should also include a copy of your treatment action plan.

Have questions? Talk with your doctor or hemophilia treatment center (HTC). You can also talk with your program nurse. To get started, give your nurse a call today.

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### Tools and aids that make life easier

Many people with lupus struggle with feeling tired throughout the day. When you live with lupus, you may find that some everyday tasks have become harder. Don't worry. There are many tools that can make your life easier. Not sure what you need or where to start? Talk with your doctor. Your doctor can assess if aids or tools are right for you, or if your treatment needs to be adjusted.

Because lupus can cause fatigue, it may be helpful to plan your day ahead. Try to choose only activities that are most important. Allow yourself time to rest after. When you need to run errands, try the pick-up option. Or use a drive-up location to avoid walking around stores and long lines. If you fatigue easily, a cane or walker can help you travel farther.

Exercise can help those with lupus feel their best. It can help you manage your lupus symptoms and reduce fatigue. Even simple low-impact movements will make muscles less stiff and increase your range of motion. Yoga, swimming, cycling, and other aerobic exercise are all good for people with lupus. These can help reduce your risk of heart disease and help you control your weight. They can even boost your mental health. Be sure to talk to your doctor about the type of exercises that are best for you.

At home, the right personal tools can make a big difference for people with lupus. Items such as shower chairs and transfer benches can help you use less energy in the shower. Raised toilet seats with handles can also help make your time in the bathroom easier and safer.

Screen readers are pieces of hardware or software that read text on the screen out loud for you. They can be useful if you find reading tiring or cannot look at the screen for long.

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### Tools and aids that make life easier

When you live with multiple sclerosis (MS), you may find that some everyday tasks have become harder. Don't worry. There are many tools that can make your life easier. Not sure what you need or where to start? Be sure you see a doctor who has experience treating patients with MS. Your doctor can assess whether aids or tools are right for you, or if your treatment needs to be adjusted. Make sure you take your medicines on schedule.

Occupational or physical therapy may be a good idea for you. Therapists can help you use devices such as braces and splints. They can train you to get the most out of certain aids. Check with your insurance provider about the types of programs and devices that are covered under your plan.

If MS results in weakness in the legs, a walker or cane can help you get around. These can help make up for muscle weakness. Braces for the foot and ankle can help support your joints. If you fatigue quickly, walkers with wheels, scooters, or wheelchairs can help you travel further. They can also lower your risk of falling.

Exercise plays a big role in slowing down some effects of MS. Aerobic exercise—the type that gets you breathing hard—can improve heart function for those with MS. Even if you use a walker or wheelchair, you can still benefit from exercise. Ask your doctor about types of exercises that may be right for you.

The right personal hygiene tools can be a big help for those living with MS. Items such as electric toothbrushes and razors can be helpful. Try strap-fitted hairbrushes, handheld shower heads and

raised toilet seats with handles. All of these can make bathrooms easier to use and safer. For the kitchen, utensils and cups with special handles can help you dine with less effort. Touch on/off lamps are a good idea too.

As your MS changes over time, what you need to stay mobile may also change. For example, transfer boards and slides can make moving from bed to a chair much easier. A mechanical lift may be something to think about. It can help your caregiver safely move you if needed. You can also talk about assistive tools with your program nurse. To get started, give your nurse a call today.

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### Tools and aids that make life easier

When you live with myasthenia gravis (MG), you may find that some everyday tasks have become harder. Don't worry. There are many tools that can make your life easier. Not sure what you need or where to start? Talk with your doctor. Your doctor can assess if aids or tools are right for you, or if your treatment needs to be adjusted.

MG symptoms vary greatly from person to person. Maybe your MG started with double vision or droopy eyelids? Weakness in eye muscles is one of the most common MG symptoms. Using an eye patch while reading or watching TV can help. But be sure that you can still blink so that your eyes do not become dry. If reading is tiring, look for audiobooks. Special computer software like ZoomText can also help you read easier.

Muscle weakness in the legs may occur in a few with MG. Talk to your doctor to see if a walker or cane is right for you to get around. Braces for the foot and ankle can provide support. Walkers with wheels can help you travel further. When shopping, use a cart or grocery scooter. A handicapped parking sticker or license plate can shorten your walk.

Strength exercises are very helpful for those with MG. But if the MG is not very well controlled, avoid exercising in the heat. This may increase MG-related fatigue and weakness. Make sure to take your medicines as prescribed. Also, if you take Mestinon® (pyridostigmine bromide), time your exercise and activities around its peak effect for best results. Ask your doctor about occupational or physical therapy especially if you have become out of shape. Therapists can plan the most

helpful exercise program for you. Ask your insurance company about types of therapy and resources offered under your plan.

To find MG doctors near you, visit: [Myasthenia Gravis Foundation of America > Partners in MG Care](#).

### June is MG Awareness Month around the world!

Spread the word! It's a great time to teach those around you more about myasthenia gravis. Join in at [www.myasthenia.org](http://www.myasthenia.org).

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### Tools and aids that make life easier

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You can also ask your doctor about occupational or physical therapy. Such therapists can also help you choose the most helpful aids for any given task. They can train you to use these aids and get the most out of them. They can help you with an exercise program to help build muscle strength and prevent fatigue.

Myositis symptoms vary greatly from person to person. It often causes some degree of muscle weakness. But this can vary from mild to severe. If muscle weakness in the legs makes it hard to get around, a walker or cane can help. These devices can also lower your risk of falling. Braces for the foot and ankle can provide support. When shopping, make sure to use a cart or grocery scooter. A handicapped parking sticker or license plate can make your walk shorter.

In the kitchen, items such as electric can openers or mixers can help conserve your energy. Choose small lightweight plastic dishes and silverware. Utensils and cups with special handles can help you dine with less effort.

In the bathroom, install grab bars in the shower and tub. Use a plastic shower chair and a hose for the shower head so you can sit while washing. The right personal hygiene tools can also help. Items such as electric toothbrushes and razors can be helpful. Strap-fitted hairbrushes, handheld shower heads, and raised toilet seats with handles can all make bathrooms easier and safer.

You can also talk about assistive tools with your program nurse. To get started, give your nurse a call today.

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### Tools and aids that make life easier

When you live with Parkinson's disease (PD), you may find that some everyday tasks have become more difficult. Don't worry. There are many tools that can make your life easier. Not sure what you need or where to start? Talk with your doctor. Your doctor can assess if aids or tools are right for you, or if your treatment needs to be adjusted.

As PD changes over time, even simple daily activities of home and self-care may get harder.

Assistive devices can help you stay more in control. Examples include:

- Pen grips that make writing easier.
- Grab devices that allow you to pick up items without bending over.
- A cane, walker, or wheelchair, if needed.
- An adapter with large buttons that fits over the phone to make dialing easier for people with hand tremors.
- Safer living areas. Install handrails along walls, halls, and stairwells to help with walking. A bedrail can help you get out of bed. A nightlight is also useful.
- Kitchen changes. Look into special utensils, such as forks and spoons with easy-to-grip handles and a knife that works with a rocking rather than sawing motion. Lower your countertop to access kitchen items from a chair or wheelchair.
- Better bathroom. Add grab bars in the tub or shower and use a shower chair. Add special door pulls to make doors easier to manage than gripping a regular knob.

Service dogs can help people with PD with a number of symptoms. They can help with issues like loss of balance and freezing episodes. They can be trained to provide support when a person has fallen. They are also known to help those with PD deal with mental issues like anxiety, depression, or social isolation.

Occupational, physical, and speech therapists can assess your needs and teach you new ways to cope with your challenges. Therapists can help make sure you receive the right aids and correct fit. They can also train you to use these aids and get the most out of them. You can also talk about assistive tools with your program nurse.

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### Tools and aids that make life easier

Many tools we use all the time are taken for granted. When you live with rheumatoid arthritis (RA), you may find that some everyday tasks have become harder. Don't worry. There are many tools that can make your life easier.

Not sure what you need or where to start? Talk with your doctor. Your doctor can assess if aids or tools are right for you, or if your treatment needs to be adjusted.

You can also ask your doctor about an occupational or physical therapist. Such therapists can help you see where you struggle or are at risk. They can also help you choose the most helpful aids for any given task. Therapists can train you to use these aids and get the most out of them.

Do you find it hard to get around? Those living with RA you may struggle to stay mobile. Assistive devices can take some of the stress from your joints ease pain. Devices such as jar openers, reachers and easy-grip utensils are great ones to start with. They can help to relieve stress on your joints and make your life easier.

Walking aids can also help with muscle weakness. Braces for the foot and ankle can give your joints support. For those who fatigue quickly, walkers with wheels and wheelchairs can help. They can also keep you safe by lowering your risk of falling.

You can also talk about assistive tools with your program nurse. To get started, give your nurse a call today.

### **This month is RA Awareness Week!**

Spread the word! It's a great time to teach those around you more about RA. Join in for RA Awareness Week through the National Arthritis Foundation.

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### Tools and aids that make life easier

When you live with scleroderma, you may find that some everyday tasks have become harder. Don't worry. There are many tools that can make your life easier. Not sure what you need or where to start? Talk with your doctor. Your doctor can assess if aids or tools are right for you, or if your treatment needs to be adjusted.

Your doctor may suggest occupational or physical therapy. This may include a program with range-of-motion stretching exercises. These can prevent or slow down the loss of motion in your joints and help keep your skin softer. Such exercises can help reduce stiffness and pain in the hands and wrists. Swimming is another great choice to help stretch tight muscles and keep you flexible.

Muscle pain and weakness may occur with scleroderma. This can make getting around harder. If this affects you, devices such as canes or walkers can be helpful. For those with skin tightening in the hands, bathroom items such as electric toothbrushes and razors can help. Strap-fitted hairbrushes, handheld shower heads, and raised toilet seats with handles can all make bathrooms easier and safer. Touch on/off lamps may also help those with hand problems. In the kitchen, utensils and cups with special handles can help make eating easier.

Are your fingers and toes affected by Raynaud's (a lack of blood flow in response to cold and stress)? Be sure to wear gloves to protect your hands from cold or frozen items. Electric heaters and blankets can also be used to help keep your body warmer.

Scleroderma may cause skin tightening over your face. Your mouth's opening may become smaller, making it harder to keep your mouth open. Ask your dentist about mouth props that you can insert between the upper and lower teeth. Floss holders and pump toothpaste tubes are other items that can help with oral hygiene.

### **June is National Scleroderma Awareness Month!**

Spread the word! It's a great time to teach those around you more about scleroderma. Join in through the National Scleroderma Foundation at

<https://scleroderma.org>.

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### Managing pain with sickle cell disease

There are many reasons why you might be having pain. Pain is very often linked to sickle cell disease. How does sickle cell cause pain? Sickled red blood cells can stick to the walls of blood. This can lead to a lack of oxygen in nearby tissues. This can cause sudden severe pain called pain crises. Repeated lack of blood flow can lead to organ damage over time.

Tell your doctor if you are in pain. Treating acute pain will help it from getting worse. Your doctor may recommend:

- Medicines
- Reducing activities to rest
- Reducing stress
- Avoiding extreme temperatures

You can try these things on your own to help control pain.

- **Make a pain action plan:** track your pain and things that help you to feel better or stay active.
- Review medicines with your doctor to see if any changes are needed.
- If you smoke, vape, or use other nicotine/tobacco products, quit.
- If you are having mood changes, talk to your doctor about counseling.
- Stay hydrated and avoid excess heat and cold temperatures.
- Talk about an exercise plan with your doctor.
- Make sure you're getting enough quality sleep.

You should work with your doctor to create a plan to treat your sickle pain at home. And if that pain is not controlled, have a backup plan such as going to a sickle cell day treatment center. You should also have a letter from your doctor outlining the kind of pain treatments that work best for you so that you can share with ER staff.

### **June 19th is World Sickle Cell Day!**

Spread the word! It's a great time to teach those around you more about sickle cell.

Join in for World Sickle Cell Day through the Sickle Cell Disease Association of America at [www.sicklecelldisease.org](http://www.sicklecelldisease.org).

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## Tools and aids for living with epilepsy

Have you thought about ways to make living with epilepsy safer and easier?

The best way to stay safe with epilepsy is to take your medicine. Get the tests and labs you need and see your neurologist. Have an action plan for both your daily treatment and seizures. Also, get good sleep and manage problems like behavior issues and migraines to help control seizures.

If you still struggle to control seizures, you should visit an epilepsy Center of Excellence (COE).

For some with epilepsy, you may want to make lifestyle changes for safety. Not sure what you need or where to start? Talk with your doctor. Your doctor can assess if assistive aids or tools are right for you, or if your treatment needs to be adjusted.

Some common home safety options are shower seats and handheld shower heads. Cook with an electric stove (avoid gas) and only use the rear burners. Or use a microwave. Don't lock the bathroom door and bathe with just a few inches of water.

Some people with epilepsy also find help from having a service dog. Service dogs can be trained to respond to a seizure. Medical alert bracelets or I.D.s are also a good idea to have on you at all times.

You can also ask your program nurse for more safety tips. To get started, give your nurse a call today.

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### Tools and aids that make life easier

Some people living with Crohn's may need to have surgery if their disease gets worse. Along with the surgery an opening or ostomy may be a part of the surgery. Your doctor will discuss this with you if this is necessary. An ostomy changes the way food leaves your body. An ostomy allows stool to pass through an opening or stoma created during surgery into a bag that you wear on your stomach. Your ostomy device or stoma can come in one piece or in two pieces. An ostomy can help you stay healthy and feel less pain.

Your doctor can help you to learn how to care for your stoma. It is also important to take care of the skin around your stoma. The fit of your stoma matters. A stoma nurse can help you find the right fit. They can also teach you how to avoid leaks and odor while using a stoma. You should also keep emergency numbers for stoma supplies with you. These can include numbers for your home health agency, doctor's office, and insurance. This will help you to always have the ostomy supplies that you need.

You can also ask your doctor about an occupational or physical therapist. Such therapists can help you see where you struggle or are at risk. They can also help you choose the most helpful aids for any given task. Therapists can train you to use these aids and get the most out of them.

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Your doctor can help you to learn how to care for your stoma. It is also important to take care of the skin around your stoma. The fit of your stoma matters. A stoma nurse can help you find the right fit. They can also teach you how to avoid leaks and odor while using a stoma. You should also keep emergency numbers for stoma supplies with you. These can include numbers for your home health agency, doctor's office, and insurance. This will help you to always have the ostomy supplies that you need.

You can also ask your doctor about an occupational or physical therapist. Such therapists can help you see where you struggle or are at risk. They can also help you choose the most helpful aids for any given task. Therapists can train you to use these aids and get the most out of them.

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## Tools and aids that make life easier

Living with HIV, it is vital to take your HIV medicines as prescribed by your doctor. It can be very hard to remember when to take your medicines. You also need to stay on top of your doctor visits. You can use text messages and mobile apps to give you reminders. You can also use these tools to remember when to get regular tests. Pill boxes and calendars can also help you take your medicines.



Do you find it hard to exercise? You need to exercise to stay healthy with your HIV. You can use mobile apps to help you exercise more. They can help you find new exercise and track your progress. Exercise can also help you stay healthy with other health conditions you may have.

They can help you record any changes with your HIV treatment. They can also help you to tell your doctor when you have a change in your disease. You can also use them to record worried about something that is new or different.

Talk about assistive tools with your program nurse. To get started, give your nurse a call today.

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### Time to think about back-to-school planning

Do you have a child with hereditary angioedema (HAE) who is school-aged? To give your child the support they need at school, think about setting up a 504 plan. This is a plan you set up with your child's school. It can help a student with health issues or special needs.

Here is how a 504 plan works:

- Defines the support and services your child will get at school
- Lists each person tasked with helping your child and carrying out the plan
- Must be reviewed each year and renewed every 3 years.

Not sure how to get started? Your program nurse can help you learn more about 504 plans. It is important to make sure you have the plan in place BEFORE the school year starts. This way, your child can get help right away. To learn more, go to [www.understood.org](http://www.understood.org), which also has resources for helping you and your child manage a virtual school.

The HAE Association also has resources for parents to learn about 504 plans. To learn more, go to the "For Parents" section of [haea.org](http://haea.org).

What else can you do to prepare your child for school? If your child ever has a problem at school, they should know who to call and how to reach them. These people are emergency contacts. Make sure the teachers and school nurse have a copy of these names and numbers. If your child is old enough, let them have a copy of an Action Plan that outlines their overall care too.

Have more questions? Call your program nurse today. Your nurse can also help you make an Action Plan for your child's care.

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