

## Apps and online tools for ALS

The ways we manage our care are changing. There are many apps and tools out there for helping with long-term illness. They can manage medicine and insurance, track symptoms, and store medical info. Many can also be used to talk with your care team. Ask your doctors and program nurse which online tools they use.

What apps or online tools should you try? For those with amyotrophic lateral sclerosis (ALS), there are several options. All can be found either through the Apple and Android app stores, or through the website links below. A good place you can also start is the ALS Association.

### Apps:

- **MyID – Medical ID Profile**—a free app used for keeping all your medical info in one place.
- **Manage My Pain**—good for any and all chronic pain, this free app helps you keep detailed track of your pain, as well as treatment, triggers, and more.
- **Sleep Score**—a free app for better sleep. It takes data about your sleep and gives advice to help you fall asleep, stay asleep, and wake up at the right time.

For those in the later stages of ALS who struggle to speak, your doctor is likely to consult a speech-language pathologist to get the best help and care for you. Text-to-speech technology has come a long way. These computer programs (and now apps) allow you to type without needing your hands.

They then turn what you type into audio, or speech. These apps can help those who have issues moving their hands and fingers. To learn more, go to the ALS Association website at [www.als.org](http://www.als.org) and search for “Augmentative and Alternative Communication.”

Remember: apps and websites have limits. These tools aren’t meant to replace your doctor or care team. But they can make your life and care easier to manage. For new problems or conditions, you should still see your doctor in-person or via a telehealth visit. Screenings and lab tests will also need to be done in-person.

Have questions? Reach out to your program nurse. Ask them which apps or tools are available to you through your health plan.

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## Apps and online tools for Crohn's disease

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What apps or online tools should you try? For those with Crohn's disease, there are several options. They can be found either through the Apple and Android app stores, or through the website links below. Another place you can also start is the Crohn's and Colitis Foundation website.

### Apps:

- **MyID – Medical ID Profile**—a free app used for keeping all your medical info in one place.
- **Manage My Pain**—good for any and all chronic pain, this free app helps you keep detailed track of your pain, as well as treatment, triggers, and more.
- **Sleep Score**—a free app for better sleep. It takes data about your sleep and gives advice to help you fall asleep, stay asleep, and wake up at the right time.
- **IBD Healthline**—an app that provides access to a community of people with IBD, daily tips, and health news.
- **We Can't Wait**—the Crohn's & Colitis Foundation's restroom finder app. It helps those with IBD find restrooms when out in public. It can help those who may experience a sudden, urgent need to go.

## Online tools:

CrohnsAndColitis.com keeps a tools & support page on their website. It has many resources to help you manage your illness. These include restroom request cards, online locators to help you find a doctor, and worksheets for planning your next doctor's visit. Go to the "Tools & Support" tab on [www.crohnsandcolitis.com](http://www.crohnsandcolitis.com) to learn more.

Remember: apps and websites have limits. These tools aren't meant to replace your doctor or care team. But they can make your life and care easier to manage. For new problems or conditions, you should still see your doctor in-person or via a telehealth visit. Screenings and lab tests will also need to be done in-person.

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### Apps and online tools for cystic fibrosis

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What apps or online tools should you try? For those with cystic fibrosis (CF), there are several options. They can be found either through the Apple and Android app stores, or through the website links below. Another good place you can start is the Cystic Fibrosis Foundation (CFF) website.

#### Apps:

- **MyID – Medical ID Profile**—a free app used for keeping all your medical info in one place.
- **Manage My Pain**—good for any and all chronic pain, this free app helps you keep detailed track of your pain, as well as treatment, triggers, and more.
- **Sleep Score**—a free app for better sleep. It takes data about your sleep and gives advice to help you fall asleep, stay asleep, and wake up at the right time.

#### Online tools:

The Compass page of the CFF website is a great resource. Need help with insurance and financial issues? Have questions about your legal rights? Need help planning your daily care, or for emergencies? Go to the “Support” section of the CFF website at [www.cff.org](http://www.cff.org) to learn more.

Remember: apps and websites have limits. These tools aren't meant to replace your doctor or care team. But they can make your life and care easier to manage. For new problems or conditions, you should still see your doctor in-person or via a telehealth visit. Screenings and lab tests will also need to be done in-person.

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## Apps and online tools for CIDP

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What apps or online tools should you try? For those with chronic inflammatory demyelinating polyneuropathy (CIDP), there are several options. All can be found either through the Apple and Android app stores, or through the website links below. A good place you can also start is the GBS/CIDP Foundation International ([www.gbs-cidp.org](http://www.gbs-cidp.org)).

### Apps:

- **MyID – Medical ID Profile**—a free app used for keeping all your medical info in one place.
- **Manage My Pain**—good for any and all chronic pain, this free app helps you keep detailed track of your pain, as well as treatment, triggers, and more.
- **Sleep Score**—a free app for better sleep. It takes data about your sleep and gives advice to help you fall asleep, stay asleep, and wake up at the right time.

### Online tools:

The GBS/CIDP Foundation International website keeps an up-to-date resources page for those who need help with their care. It includes lists for patient services, infusion options, support groups, and more. Some other sites that provide links to additional resources include: [www.knowingpn.com/cidp/resources](http://www.knowingpn.com/cidp/resources) (an informational site sponsored by Takeda

Pharmaceuticals) and <https://shiningthroughcidp.com/> (a site sponsored by argenx).

Remember: apps and websites have limits. These tools aren't meant to replace your doctor or care team. But they can make your life and care easier to manage. For new problems or conditions, you should still see your doctor in-person or via a telehealth visit. Screenings and lab tests will also need to be done in-person.

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## Apps and online tools for Gaucher disease

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What apps or online tools should you try? For those with Gaucher disease, there are several options. All can be found either through the Apple and Android app stores, or through the website links below. A good place you can also start is the National Gaucher Foundation.

### Apps:

- **MyID – Medical ID Profile**—a free app used for keeping all your medical info in one place.
- **Manage My Pain**—good for any and all chronic pain, this free app helps you keep detailed track of your pain, as well as treatment, triggers, and more.
- **Sleep Score**—a free app for better sleep. It takes data about your sleep and gives advice to help you fall asleep, stay asleep, and wake up at the right time.

### Online tools:

The National Gaucher Foundation has a resource page called the “Knowledge Center.” It has information for building a care team, finding a support group, finding financial help or advocacy groups, and more. Go to [www.gaucherdisease.org](http://www.gaucherdisease.org) to see what they offer.

Remember: apps and websites have limits. These tools aren't meant to replace your doctor or care team. But they can make your life and care easier to manage. For new problems or conditions, you should still see your doctor in-person or via a telehealth visit. Screenings and lab tests will also need to be done in-person.

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## Apps and online tools for HAE

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What apps or online tools should you try? For those with hereditary angioedema (HAE), there are several options. All can be found either through the Apple and Android app stores, or through the website links below. A good place you can also start is the US Hereditary Angioedema Association at [www.haea.org](http://www.haea.org).

### Apps:

- **HAE TrackR**—an app through the US Hereditary Angioedema Association. It can help people track attacks and remind you when it's time to take your prophylactic (medicine used to stop symptoms before they start) treatments.
- **MyID – Medical ID Profile**—a free app used for keeping all your medical info in one place.
- **Manage My Pain**—good for any and all chronic pain, this free app helps you keep detailed track of your pain, as well as treatment, triggers, and more.
- **Sleep Score**—a free app for better sleep. It takes data about your sleep and gives advice to help you fall asleep, stay asleep, and wake up at the right time.

## Online tools:

Discover HAE also keeps a resource page on their website. It has helpful info for learning about HAE, talking with your doctor, treatment plans, emergency cards, and more. Go to [www.discoverhae.com](http://www.discoverhae.com) and under the “Get Involved” tab click the “HAE Resources” tab.

Remember: apps and websites have limits. These tools aren’t meant to replace your doctor or care team. But they can make your life and care easier to manage. For new problems or conditions, you should still see your doctor in-person or via a telehealth visit. Screenings and lab tests will also need to be done in-person.

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## Apps and online tools for HIV

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What apps or online tools should you try? For those with human immunodeficiency virus (HIV), there are several options. They can be found either through the Apple and Android app stores, or through the website links below.

### Apps:

- **MyID – Medical ID Profile**—a free app used for keeping all your medical info in one place.
- **Manage My Pain**—good for any and all chronic pain, this free app helps you keep detailed track of your pain, as well as treatment, triggers, and more.
- **Sleep Score**—a free app for better sleep. It takes data about your sleep and gives advice to help you fall asleep, stay asleep, and wake up at the right time.

### Online tools:

- **HIV.gov** has a tool called the HIV testing sites and care services locator. It allows you to search for testing services, housing, health centers, and other services near to you. You can find it here: [locator.hiv.gov](https://locator.hiv.gov). You can also receive help through the Ryan White HIV/AIDS Program, run by

the Health Resources and Services Administration (HRSA). Go to [ryanwhite.hrsa.gov](https://ryanwhite.hrsa.gov) or ask your program nurse to learn more.

- **myHIVteam** is a social network for people living with HIV, offering a platform to connect, share experiences, and find support.

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### Apps and online tools for hemophilia

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What apps or online tools should you try? For those with hemophilia, there are several options. All can be found either through the Apple and Android app stores, or through the website links below. A good place to start is the National Bleeding Disorders Foundation at [www.bleeding.org](http://www.bleeding.org).

**Apps:** There are a range of hemophilia management options for members to try. Members should talk to their doctor about what program is right for them. Here are a few popular options that can help you track treatment and bleeds and share info with your treatment center or provider:

- **Robust Health**
- **MicroHealth Hemophilia**
- **HemMobile**
- **Hemocraft**—a video game modeled after Minecraft. It helps teach kids with bleeding disorders about being prepared and sticking to their treatment plan. It can be downloaded through the website at [www.hemocraft.com](http://www.hemocraft.com).

Other health management apps:

- **MyID – Medical ID Profile**—a free app used for keeping all your medical info in one place.

- **Manage My Pain**—good for any and all chronic pain, this free app helps you keep detailed track of your pain, as well as treatment, triggers, and more.
- **Sleep Score**—a free app for better sleep. It takes data about your sleep and gives advice to help you fall asleep, stay asleep, and wake up at the right time.

Remember: apps and websites have limits. These tools aren't meant to replace your doctor or care team. But they can make your life and care easier to manage. For new problems or conditions, you should still see your doctor in-person or via a telehealth visit. Screenings and lab tests will also need to be done in-person.

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## Apps and online tools for myasthenia gravis

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What apps or online tools should you try? For those with myasthenia gravis (MG), there are several options. All can be found either through the Apple and Android app stores, or through the website link below. A good place to start is the Myasthenia Gravis Foundation of America (MGFA).

### Apps:

- **MyID – Medical ID Profile**—a free app used for keeping all your medical info in one place.
- **Manage My Pain**—good for any and all chronic pain, this free app helps you keep detailed track of your pain, as well as treatment, triggers, and more.
- **Sleep Score**—a free app for better sleep. It takes data about your sleep and gives advice to help you fall asleep, stay asleep, and wake up at the right time.
- **MyMG**—a mobile app created by MGFA that can help you keep track of symptoms and take notes so you can have more informed talks with your health care team. This tool can chart how your symptoms change and affect your life over time. Survey results can be printed off the MGFA website.

### Online tools:

The MGFA website provides information on managing MG, finding support groups, trial medicines, finding a doctor, and more. Go to the “MGFA Online Community” section on [www.myasthenia.org](http://www.myasthenia.org).

MGFA also offers a Helpline (**1-833-647-8764**) to reach counselors who can help you connect with local support groups and find resources.

Remember: apps and websites have limits. These tools aren't meant to replace your doctor or care team. But they can make your life and care easier to manage. For new problems or conditions, you should still see your doctor in-person or via a telehealth visit. Screenings and lab tests will also need to be done in-person.

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## Apps and online tools for multiple sclerosis

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What apps or online tools should you try? For those with multiple sclerosis (MS), there are several options. All can be found either through the Apple and Android app stores, or through the website link below. A good place to start is the National MS Society.

### Apps:

- **MyID – Medical ID Profile**—a free app used for keeping all your medical info in one place.
- **Manage My Pain**—good for any and all chronic pain, this free app helps you keep detailed track of your pain, as well as treatment, triggers, and more.
- **Sleep Score**—a free app for better sleep. It takes data about your sleep and gives advice to help you fall asleep, stay asleep, and wake up at the right time.

### Online tools:

The National MS Society keeps a resource page on their website. It has an online library for learning more about MS, tools to connect to others through support groups, and info for those who need help managing their care. It can also help those with MS find local specialists, online programs, and other resources. To learn more, go to [www.nationalmssociety.org](http://www.nationalmssociety.org).

Remember: apps and websites have limits. These tools aren't meant to replace your doctor or care team. But they can make your life and care easier to manage. For new problems or conditions, you should still see your doctor in-person or via a telehealth visit. Screenings and lab tests will also need to be done in-person.

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What apps or online tools should you try? For those with myositis, there are several options. All can be found either through the Apple and Android app stores, or through the website links below. A good place to start is the Myositis Association.

### Apps:

- **MyID – Medical ID Profile**—a free app used for keeping all your medical info in one place.
- **Manage My Pain**—good for any and all chronic pain, this free app helps you keep detailed track of your pain, as well as treatment, triggers, and more.
- **Sleep Score**—a free app for better sleep. It takes data about your sleep and gives advice to help you fall asleep, stay asleep, and wake up at the right time.

### Online tools:

The Myositis Association keeps an online library on its website with many resources to learn about and manage myositis. It also has the **My Myositis Tracker tool** (free to download). This worksheet can help you plan treatment, track symptoms, and prepare for doctor's visits. Go to [www.myositis.org](http://www.myositis.org) and click the "Visit the Myositis Library" tab to learn more. Myositis Support and Understanding (MSU) is another myositis-focused website. This is a nonprofit group that

provides education, support, advocacy, and access to research and clinical trials. Go to <https://understandingmyositis.org/support/>.

Remember: apps and websites have limits. These tools aren't meant to replace your doctor or care team. But they can make your life and care easier to manage. For new problems or conditions, you should still see your doctor in-person or via a telehealth visit. Screenings and lab tests will also need to be done in-person.

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What apps or online tools should you try? For those with Parkinson's disease (PD), there are several options. All can be found either through the Apple and Android app stores. Two good places you can start are the Parkinson's Foundation and the Michael J. Fox Foundation websites linked below.

### Apps:

- **MyID – Medical ID Profile**—a free app used for keeping all your medical info in one place.
- **Manage My Pain**—good for any and all chronic pain, this free app helps you keep detailed track of your pain, as well as treatment, triggers, and more.
- **Sleep Score**—a free app for better sleep. It takes data about your sleep and gives advice to help you fall asleep, stay asleep, and wake up at the right time.

### Online tools:

The Michael J. Fox Foundation keeps a resource page called Parkinson's 360 on their website. The page covers many topics—info about medicine, mental health, managing insurance, and building a care team. Go to [www.michaeljfox.org](http://www.michaeljfox.org) and click the “Understanding Parkinson's” tab to learn

more. The Parkinson's Foundation offers support to people with PD as well as their care partners, family members, and healthcare professionals. Go to [www.parkinson.org/resources-support](http://www.parkinson.org/resources-support).

Remember: apps and websites have limits. These tools aren't meant to replace your doctor or care team. But they can make your life and care easier to manage. For new problems or conditions, you should still see your doctor in-person or via a telehealth visit. Screenings and lab tests will also need to be done in-person.

Have questions? Reach out to your program nurse. Ask them which apps or tools are available to you through your health plan.

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## Apps and online tools for rheumatoid arthritis

The ways we manage our care are changing. There are many apps and tools out there for helping with long-term illness. They can manage medicine and insurance, track symptoms, and store medical info. Many can also be used to talk with your care team. Ask your doctors and program nurse which online tools they suggest.

What apps or online tools should you try? For those with rheumatoid arthritis (RA), there are several options. They can be found either through the Apple and Android app stores, or through the website links below. Another place you can also start is the Arthritis Foundation website.

### Apps:

- **MyID – Medical ID Profile**—a free app used for keeping all your medical info in one place.
- **Manage My Pain**—good for any and all chronic pain, this free app helps you keep detailed track of your pain, as well as treatment, triggers, and more.
- **Sleep Score**—a free app for better sleep. It takes data about your sleep and gives advice to help you fall asleep, stay asleep, and wake up at the right time.
- **MyRA**—an app that helps patients track their symptoms and overall health. It provides reminders for medicines and doctor visits.

### Online tools:

- **Your Exercise Solution (YES)** is an online tool through the Arthritis Foundation website. It helps those with RA make an exercise plan. The tool factors your fitness level as well as the areas currently giving you pain. Go to [www.arthritis.org](http://www.arthritis.org) to learn more.

- **CreakyJoints:** is an online community for people with all types of arthritis. It offers a variety of resources, including educational materials, and forums for support. It also has a medicine tracker app called ArthritisPower.
- **RA Foundation Helpline:** [www.arthritis.org](http://www.arthritis.org)

Remember: apps and websites have limits. These tools aren't meant to replace your doctor or care team. But they can make your life and care easier to manage. For new problems or conditions, you should still see your doctor in-person or via a telehealth visit. Screenings and lab tests will also need to be done in-person.

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## Apps and online tools for sickle cell disease

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What apps or online tools should you try? For those with sickle cell disease, there are several options. They can be found either through the Apple and Android app stores, or through the website links below. A good place to start is the Sickle Cell Disease Association of America.

### Apps:

- **MyID – Medical ID Profile**—a free app used for keeping all your medical info in one place.
- **Manage My Pain**—good for any and all chronic pain, this free app helps you keep detailed track of your pain, as well as treatment, triggers, and more.
- **Sleep Score**—a free app for better sleep. It takes data about your sleep and gives advice to help you fall asleep, stay asleep, and wake up at the right time.

### Online tools:

The Sickle Cell Disease Association of America keeps a resource page on their website. It has info about new research and studies, a Clinical Trial Finder, COVID-19 resources, fact sheets and articles for learning about sickle cell, and much more. Go to [www.sicklecelldisease.org](http://www.sicklecelldisease.org) and click “Links & Resources” under the “Sickle Cell Disease” tab.

Remember: apps and websites have limits. These tools aren't meant to replace your doctor or care team. But they can make your life and care easier to manage. For new problems or conditions, you should still see your doctor in-person or via a telehealth visit. Screenings and lab tests will also need to be done in-person.

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## Apps and online tools for scleroderma

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What apps or online tools should you try? For those with scleroderma, there are several options. All can be found either through the Apple and Android app stores, or through the website links below. A good place to start is the National Scleroderma Foundation ([www.scleroderma.org](http://www.scleroderma.org)).

### Apps:

- **MyID – Medical ID Profile**—a free app used for keeping all your medical info in one place.
- **Manage My Pain**—good for any and all chronic pain, this free app helps you keep detailed track of your pain, as well as treatment, triggers, and more.
- **Sleep Score**—a free app for better sleep. It takes data about your sleep and gives advice to help you fall asleep, stay asleep, and wake up at the right time.

### Online tools:

**Self-Manage Scleroderma** is an online self-management program. It is for those who don't live near a local chapter of the Scleroderma Foundation or an in-person support group. The program can help you learn about scleroderma and manage symptoms and treatment. Go to [www.selfmanagescleroderma.com](http://www.selfmanagescleroderma.com) to learn more.

Remember: apps and websites have limits. These tools aren't meant to replace your doctor or care team. But they can make your life and care easier to manage. For new problems or conditions, you should still see your doctor in-person or via a telehealth visit. Screenings and lab tests will also need to be done in-person.

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## Apps and online tools for lupus

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What apps or online tools should you try? For those with lupus, there are several options. All can be found either through the Apple and Android app stores, or through the website link below. A good place to start is the Lupus Foundation of America.

### Apps:

- **MyID – Medical ID Profile**—a free app used for keeping all your medical info in one place.
- **Manage My Pain**—good for any and all chronic pain, this free app helps you keep detailed track of your pain, as well as treatment, triggers, and more.
- **Sleep Score**—a free app for better sleep. It takes data about your sleep and gives advice to help you fall asleep, stay asleep, and wake up at the right time.

### Online tools:

The Lupus Foundation of America keeps a Support & Resources page on their website. It has tips for managing symptoms (such as how to avoid common triggers, prevent and manage flares, and prevent infections.) It offers help to find support groups and financial resources. It also has an

**Interactive Lupus Center** for those with lupus to learn more about their illness and its care through fun games and quizzes. Go to [www.lupus.org](http://www.lupus.org) to learn more.

Remember: apps and websites have limits. These tools aren't meant to replace your doctor or care team. But they can make your life and care easier to manage. For new problems or conditions, you should still see your doctor in-person or via a telehealth visit. Screenings and lab tests will also need to be done in-person.

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### Apps and online tools for epilepsy

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What apps or online tools should you try? For those with epilepsy, there are several options. All can be found either through the Apple and Android app stores, or through the website links below. A good place you can also start is the Epilepsy Foundation.

#### Apps:

- **Seizure Tracker**—a free app through [Seizuretracker.com](https://www.seizuretracker.com) and the app store. Easily log seizures and share reports with your providers.
- **MyID – Medical ID Profile**—a free app used for keeping all your medical info in one place.
- **Manage My Pain**—good for any and all chronic pain, this free app helps you keep detailed track of your pain, as well as treatment, triggers, and more.
- **Sleep Score**—a free app for better sleep. It takes data about your sleep and gives advice to help you fall asleep, stay asleep, and wake up at the right time.
- Calendar apps can also help you to remember to take your antiseizure drugs (ASDs).

#### Online tools:

The Epilepsy Foundation keeps a resource page on their website. It has many helpful links. This includes learning for those new to epilepsy, treatment factsheets, seizure tracking forms, and

plans for how to handle a seizure for your care team. Go to the “Living With Epilepsy” tab on [www.epilepsy.com](http://www.epilepsy.com) to learn more.

Remember: apps and websites have limits. These tools aren’t meant to replace your doctor or care team. But they can make your life and care easier to manage. For new problems or conditions, you should still see your doctor in-person or via a telehealth visit. Screenings and lab tests will also need to be done in-person.

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## Apps and online tools for ulcerative colitis

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What apps or online tools should you try? For those with ulcerative colitis (UC), there are several options. They can be found either through the Apple and Android app stores, or through the website links below. Another good place you can also start is the Crohn's and Colitis Foundation website.

### Apps:

- **MyID – Medical ID Profile**—a free app used for keeping all your medical info in one place.
- **Manage My Pain**—good for any and all chronic pain, this free app helps you keep detailed track of your pain, as well as treatment, triggers, and more.
- **Sleep Score**—a free app for better sleep. It takes data about your sleep and gives advice to help you fall asleep, stay asleep, and wake up at the right time.
- **IBD Healthline**—is an app that provides access to a community of people with IBD, daily tips, and health news.
- **We Can't Wait**—the Crohn's & Colitis Foundation's restroom finder app. It helps those with IBD find restrooms when out in public. It can help those who may experience a sudden, urgent need to go.

## Online tools:

CrohnsAndColitis.com keeps a tools & support page on their website. It has many resources to help you manage your illness. These include restroom request cards, online locators to help you find a doctor, and worksheets for planning your next doctor's visit. Go to the "Tools & Support" tab on [www.crohnsandcolitis.com/ulcerative-colitis](http://www.crohnsandcolitis.com/ulcerative-colitis) to learn more.

Remember: apps and websites have limits. These tools aren't meant to replace your doctor or care team. But they can make your life and care easier to manage. For new problems or conditions, you should still see your doctor in-person or via a telehealth visit. Screenings and lab tests will also need to be done in-person.

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