

When should I call my doctor?

You likely see your doctor on a regular basis for your amyotrophic lateral sclerosis (ALS). But what happens in between your visits? Have you and your doctor talked about what to do if you notice a health change? When is it worth reaching out to your doctor, rather than waiting for your next visit?

Staying healthy starts with knowing yourself. The better you understand your body, the better you can take care of yourself.

Tracking symptoms and changes in your health also helps your doctor know how well your treatment is working. So, what are the signs or changes you should look for with ALS?

- New or worse weakness in arms or legs that affects daily activities
- Problems walking or standing that cause walking to become unsafe (from falls)
- Problems chewing and swallowing, or trouble from extra saliva
- Trouble speaking or breathing
- Trouble sleeping

Talk with your doctor about their expectations as well. Your doctor may want you to track issues or signs specific to your health. Your doctor may have already outlined those things they want you to report back to them. Follow that advice. It is also important to find out the best way to talk to your doctors (primary care provider or ALS neurologist). Some offices use phone calls, others e-mails or online patient portals. Ask your doctor's office how they would like you to reach out.



Even if treatment is working, stay on top of how you feel. Keep up the conversation with your doctor. You may feel bad one day, and good the next. But some changes can be signs that your disease is progressing. Those changes need to be caught early, so your doctor can help you right away.

Need help tracking symptoms or changes in your health? Call your program nurse. Your nurse can help you make an Action Plan to track health changes and treatment.

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When should I call my doctor?

You likely see your doctor on a regular basis for your chronic inflammatory demyelinating polyneuropathy (CIDP). But what happens in between your visits? Have you and your doctor talked about what to do if you notice a health change? When is it worth reaching out to your doctor, rather than waiting for your next visit?

Staying healthy starts with knowing yourself. The better you understand your body, the better you can take care of yourself. Tracking symptoms and changes in your health also helps your doctor know how well your treatment is working. With CIDP, your condition may not change all that much over time. For some of you, it may even be in remission. But for some, there can be ups and downs (becoming stronger or weaker). Many of these ups and downs are related to changes in medications for CIDP. If these occur, consult your doctor.

Some changes you might notice are side effects of your CIDP medications. Most side effects are very rare, but you might notice:

- breathing problems
- fever or chills
- confusion, dizziness, or extreme sleepiness
- rash or itching
- bluish-colored skin on your lips, fingers, or toes
- unusual bleeding or bruising

Talk with your doctor about their expectations as well. Your doctor may want you to track issues or signs specific to your health. Your doctor may have already outlined those things they want you to report back to them. Follow that advice. It is also important to find out the best way to talk to your doctors (primary care provider or CIDP neurologist). Some offices use phone calls, others e-mails or online patient portals. Ask your doctor's office how they would like you to reach out.

Even if treatment is working, stay on top of how you feel. Keep up the conversation with your doctor. You may feel bad one day, and good the next. But some changes can be signs that your disease is progressing. Those changes need to be caught early, so your doctor can help you right away.

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You likely see your doctor on a regular basis for your cystic fibrosis (CF). But what happens in between your visits? Have you and your doctor talked about what to do if you notice a health change? When is it worth reaching out to your doctor, rather than waiting for your next visit?

Staying healthy starts with knowing yourself. The better you understand your body, the better you can take care of yourself.

Tracking symptoms and changes in your health also helps your doctor know how well your treatment is working. So, what are the signs or changes you should look for with CF?

- An increase of coughing with thick mucus (sputum)
- Worse wheezing
- Repeated lung infections
- Big changes in bowel habits
- Frequent sinusitis

Talk with your doctor about their expectations as well. Your doctor may want you to track issues or signs specific to your health. Your doctor may have already outlined those things they want you to report back to them. Follow that advice. It is also important to find out the best way to talk to your doctors (primary care provider or specialist). Some offices use phone calls, others e-mails or online patient portals. Ask your doctor's office how they would like you to reach out.



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You likely see your doctor on a regular basis for your Gaucher disease. But what happens in between your visits? Have you and your doctor talked about what to do if you notice a health change? When is it worth reaching out to your doctor, rather than waiting for your next visit?

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Tracking symptoms and changes in your health also helps your doctor know how well your treatment is working. So, what are the signs or changes you should look for with Gaucher?

- Bone pain
- Pain or swelling in your belly (abdomen)
- Loss of hunger
- Gaining or losing weight
- Easy bruising
- Feeling tired (fatigue)

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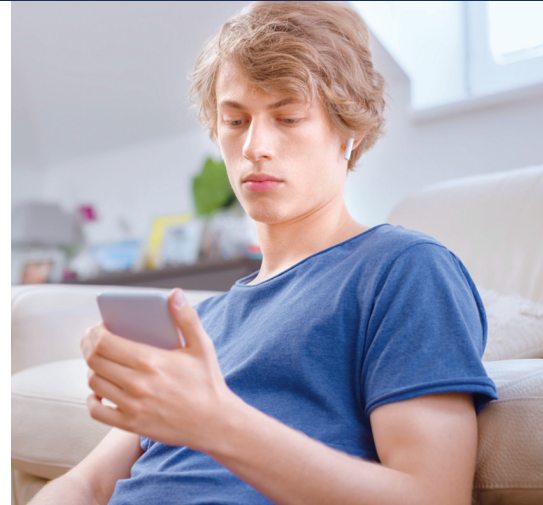
You likely see your doctor on a regular basis for your hemophilia. But what happens in between your visits? Have you and your doctor talked about what to do if you notice a health change? When is it worth reaching out to your doctor, rather than waiting for your next visit?

Staying healthy starts with knowing yourself. The better you understand your body, the better you can take care of yourself.

Tracking symptoms and changes in your health also helps your doctor know how well your treatment is working. So, what are the signs or changes you should look for with hemophilia?

- More frequent bleeds
- Bleeds that take longer to respond to treatment
- Pain or swelling in your joints
- Blood in urine or stool
- Problems infusing at home
- Needing more factor than normal

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You likely see your doctor on a regular basis for your lupus. But what happens in between your visits? Have you and your doctor talked about what to do if you notice a health change? When is it worth reaching out to your doctor, rather than waiting for your next visit?

Staying healthy starts with knowing yourself. The better you understand your body, the better you can take care of yourself.

Tracking symptoms and changes in your health also helps your doctor know how well your treatment is working. Lupus can affect skin, joints, lungs, nervous system, kidneys, and other organs.

Symptoms may come and go. When you have a new symptom, or your symptoms get worse, it may be a “lupus flare.” Signs of a flare include:

- growing tired (fatigued) more easily
- new or worse rash
- ongoing fever that is not due to an infection
- pain and swelling of joints
- mental fog
- sores or ulcers in the mouth or nose
- chest pain or feeling short of breath

Talk with your doctor about their expectations as well. Your doctor may want you to track issues or signs specific to your health. Your doctor may have already outlined those things they want you to report back to them. Follow that advice. Tell your doctor right away if your flares happen more often, you have signs of an infection, or your medicine doesn't seem to help. Your treatment can be changed if needed.

Even if treatment is working, stay on top of how you feel. Keep up the conversation with your doctor. You may feel bad one day, and good the next. But some changes can be signs that your disease is progressing. Those changes need to be caught early, so your doctor can help you right away.

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When should I call my doctor?

You likely see your doctor on a regular basis for your multiple sclerosis (MS). But what happens in between your visits? Have you and your doctor talked about what to do if you notice a health change? When is it worth reaching out to your doctor, rather than waiting for your next visit?

Staying healthy starts with knowing yourself. The better you understand your body, the better you can take care of yourself.

Tracking symptoms and changes in your health also helps your doctor know how well your treatment is working. So, what are the signs or changes you should look for with MS?

Most people with MS have symptoms that come and go over time. This varies greatly from person to person. Some with MS have sudden worsening of symptoms, known as “flares.” Contact your doctor if your symptoms get worse quickly, or new ones occur. These symptoms may mean that a change in treatment is needed before your next visit:

- blurry vision or pain around the eyes
- problems with balance
- severe tiredness (fatigue)
- rapid changes in feeling (tingling, numbness, or pain)
- sudden severe problems with bladder or bowel control

Talk with your doctor about their expectations as well. Your doctor may want you to track issues or signs specific to your health. Your doctor may have already outlined those things they want you to report back to them. Follow that advice.

Even if treatment is working, stay on top of how you feel. Keep up the conversation with your doctor. You may feel bad one day, and good the next. But some changes can be signs that your disease is progressing. Those changes need to be caught early, so your doctor can help you right away.

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You likely see your doctor on a regular basis for your myasthenia gravis (MG). But what happens in between your visits? Have you and your doctor talked about what to do if you notice a health change? When is it worth reaching out to your doctor, rather than waiting for your next visit?

Staying healthy starts with knowing yourself. The better you understand your body, the better you can take care of yourself.

Tracking symptoms and changes in your health also helps your doctor know how well your treatment is working. So, what are the signs or changes you should look for with MG?

- Eyelid droop
- Feelings of weakness
- Trouble swallowing
- Shortness of breath

Trouble breathing can be a sign of a flare-up or an MG crisis. How can you tell you're having trouble? The one-breath count test is a tool you can use. Here's what to do:

1. Sit in a comfortable chair with your back straight and your feet on the floor.
2. Take a deep breath.
3. Count out loud as far as you can on one breath (one number per second).
4. Record the number you reach before you need to take a second breath.
5. If you can't count to at least 20, contact your doctor right away.

Talk with your doctor about their expectations as well. Your doctor may want you to track issues or signs specific to your health. Your doctor may have already outlined those things they want you to report back to them. Follow that advice.

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Staying healthy starts with knowing yourself. The better you understand your body, the better you can take care of yourself.

Tracking symptoms and changes in your health also helps your doctor know how well your treatment is working. So, what are the signs or changes you should look for with myositis?

Symptoms can vary greatly in people with myositis. Some of the more serious ones to watch for that may indicate your condition is getting worse include:

- Muscle pain and weakness
- Skin rashes
- Signs of infection—you may be at high risk from some medicines
- Shortness of breath, cough, wheezing (signs of lung problems)
- Trouble swallowing

Talk with your doctor about their expectations as well. Your doctor may want you to track issues or signs specific to your type of myositis. Your doctor may have already outlined those things they want you to report back to them. Follow that advice. It is also important to find out the best way to talk to your doctors (primary care provider or myositis specialist). Some offices use phone calls, others e-mails or online patient portals. Ask your doctor's office how they would like you to reach out.

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Tracking symptoms and changes in your health also helps your doctor know how well your treatment is working. So, what are the signs or changes you should look for with PD?

Many people with PD notice changes in symptoms over time when their medicine begins to lose its effect. Symptoms may seem much worse and movement can become more difficult. This is known as "wearing off" time. If this happens and your doctor does not already know, talk to them right away. Sometimes a change in your medications, or how you take them, can help with these symptoms.

Talk with your doctor about their expectations as well. Your doctor may want you to track issues or signs specific to your health. Your doctor may have already outlined those things they want you to report back to them. Follow that advice. It is also important to find out the best way to talk to your doctors (primary care provider or specialist). Some offices use phone calls, others e-mails or online patient portals. Ask your doctor's office how they would like you to reach out.



Even if treatment is working, stay on top of how you feel. Keep up the conversation with your doctor. You may feel bad one day, and good the next. But some changes can be signs that your disease is progressing. Those changes need to be caught early, so your doctor can help you right away.

Need help tracking symptoms or changes in your health? Call your program nurse. Your nurse can help you make an Action Plan to track health changes and treatment.

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You likely see your doctor on a regular basis for your rheumatoid arthritis (RA). But what happens in between your visits? Have you and your doctor talked about what to do if you notice a health change? When is it worth reaching out to your doctor, rather than waiting for your next visit?

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Tracking symptoms and changes in your health also helps your doctor know how well your treatment is working. So, what are the signs or changes you should look for with RA?

- Symptoms of flare (stiffness, redness, warmth, swelling, pain)
- Nodules (small bumps under skin)
- Low fever
- Unusual tiredness
- Any sign of infection (fever, chills, redness, heat, muscle aches, and pain when urinating)

Talk with your doctor about their expectations as well. Your doctor may want you to track issues or signs specific to your health. Your doctor may have already outlined those things they want you to report back to them. Follow that advice. It is also important to find out the best way to talk to your doctors (primary care provider or specialist). Some offices use phone calls, others e-mails or online patient portals. Ask your doctor's office how they would like you to reach out.



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Tracking symptoms and changes in your health also helps your doctor know how well your treatment is working. So, what are the signs or changes you should look for with scleroderma?

- Your skin suddenly looks much worse.
- New skin ulcers on the fingertips.
- Your blood pressure gets too high (140/90 or higher, not caused by exercise). Check your blood pressure on a regular basis so you'll know what numbers are too high.
- Unplanned weight loss or eating problems like trouble swallowing or heartburn.
- Chest pain, problems breathing or a cough that won't go away.
- Problems with swallowing or reflux.

In some people, scleroderma only affects the skin. But in some, it can also harm blood vessels, internal organs (kidneys, heart), or the digestive system.

Talk with your doctor about their expectations as well. Your doctor may want you to track issues or signs specific to your type of scleroderma. Your doctor may have already outlined those things they want you to report back to them. Follow that advice.

Even if treatment is working, stay on top of how you feel. Keep up the conversation with your doctor. You may feel bad one day, and good the next. But some changes can be signs that your disease is progressing. Those changes need to be caught early, so your doctor can help you right away.

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You likely see your doctor on a regular basis for your sickle cell disease. But what happens in between your visits? Have you and your doctor talked about what to do if you notice a health change? When is it worth reaching out to your doctor, rather than waiting for your next visit?

Staying healthy starts with knowing yourself. The better you understand your body, the better you can take care of yourself.

Tracking symptoms and changes in your health also helps your doctor know how well your treatment is working. So, what are the signs or changes you should look for with sickle cell disease?

- Pain in the chest, belly, arms, and/or legs
- Trouble breathing
- Fever of 101° F or higher
- Pain and swelling in hands and feet
- Stroke signs (remember **FAST**: **F**acial drooping, **A**rm weakness, **S**peech problems and **T**ime to call 9-1-1)

Talk with your doctor about their expectations as well. Your doctor may want you to track issues or signs specific to your health. Your doctor may have already outlined those things they want you to report back to them. Follow that advice. It is also important to find out the best way to talk to your doctors (primary care provider or specialist). Some offices use phone calls, others e-mails or online patient portals. Ask your doctor's office how they would like you to reach out.



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When should I call my doctor?

You likely see your doctor on a regular basis for your epilepsy. But what happens in between your visits? Have you and your doctor talked about what to do if you notice a health change? When is it worth reaching out to your doctor, rather than waiting for your next visit?

Staying healthy starts with knowing yourself. The better you understand your body, the better you can take care of yourself.

Tracking symptoms and changes in your health also helps your doctor know how well your treatment is working. So, what are the signs or changes you should look for with epilepsy?

- Having seizures more often
- Changes in mood
- Seizures that are getting worse (more severe)
- Trouble sleeping
- Broken bones from falling
- A rash after starting a new anti-seizure medicine

Try tracking seizures on your calendar to see if they get more or less frequent. (You may also ask someone to video your seizures.) Your doctor will want to see your seizure calendar. This information helps doctors adjust your antiseizure medication. Talk with your doctor about their expectations.

Your doctor may have already outlined those things they want you to report. Follow that advice.

Even if treatment is working, stay on top of how you feel. Keep up the conversation with your doctor. You may feel bad one day, and good the next. But some changes can be signs that your disease is progressing. Those changes need to be caught early, so your doctor can help you right away. If you have side effects like dizziness or drowsiness, mark these symptoms on your calendar. If they are severe, call the doctor's office.

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When should I call my doctor?

You likely see your doctor on a regular basis for your Crohn's disease. But what happens in between your visits? Have you and your doctor talked about what to do if you notice a health change? When is it worth reaching out to your doctor, rather than waiting for your next visit?

Staying healthy starts with knowing yourself. The better you understand your body, the better you can take care of yourself.

Tracking symptoms and changes in your health also helps your doctor know how well your treatment is working. So, what are the signs or changes you should look for with Crohn's?

- Diarrhea or constipation
- Rectal bleeding
- Vomiting
- Chronically feeling tired (fatigue)
- Unexplained joint pain or skin ulcers
- Pain in the belly (abdomen)
- Signs of infections (fever, cough)
- Poor sleep
- Unintended weight loss

Talk with your doctor about their expectations as well. Your doctor may want you to track issues or signs specific to your health. Your doctor may have already outlined those things they want you to report back to them. Follow that advice.



Even if treatment is working, stay on top of how you feel. Keep up the conversation with your doctor. You may feel bad one day, and good the next. But some changes can be signs that your disease is progressing. Those changes need to be caught early, so your doctor can help you right away.

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When should I call my doctor?

You likely see your doctor on a regular basis for your ulcerative colitis (UC). But what happens in between your visits? Have you and your doctor talked about what to do if you notice a health change? When is it worth reaching out to your doctor, rather than waiting for your next visit?

Staying healthy starts with knowing yourself. The better you understand your body, the better you can take care of yourself.

Tracking symptoms and changes in your health also helps your doctor know how well your treatment is working. So, what are the signs or changes you should look for with UC:

- Diarrhea
- Cramps
- Low stomach pain
- Nighttime bowel movements
- Bloody stools
- Fatigue or low energy
- Joint pain
- Weight loss

Talk with your doctor about their expectations as well. Your doctor may want you to track issues or signs specific to your health. Your doctor may have already outlined those things they want you to report back to them. Follow that advice.



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When should I call my doctor?

You likely see your doctor on a regular basis for your human immunodeficiency virus (HIV). But what happens in between your visits? Have you and your doctor talked about what to do if you notice a health change? When is it worth reaching out to your doctor, rather than waiting for your next visit?

Staying healthy starts with knowing yourself. The better you understand your body, the better you can take care of yourself.

Tracking symptoms and changes in your health also helps your doctor know how well your treatment is working. Also, stay on top of general health issues that commonly affect those with HIV:

- Have you been screened for diabetes, lipids, and thyroid and kidney disease?
- If you are at risk, you should be screened for STIs (sexually transmitted infections).
- Be aware of mental health issues like depression.

Talk with your doctor about their expectations as well. Your doctor may want you to track issues or signs specific to your health. Your doctor may have already outlined those things they want you to report back to them. Follow that advice. It is also important to find out the best way to talk to your doctors (primary care provider or specialist). Some offices use phone calls, others e-mails or online patient portals. Ask your doctor's office how they would like you to reach out.



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You likely see your doctor on a regular basis for your hereditary angioedema (HAE). But what happens in between your visits? Have you and your doctor talked about what to do if you notice a health change? When is it worth reaching out to your doctor, rather than waiting for your next visit?

Staying healthy starts with knowing yourself. The better you understand your body, the better you can take care of yourself.

Tracking symptoms and changes in your health also helps your doctor know how well your treatment is working. So, what are the signs or changes you should look for with HAE?

- Severe swelling of the skin
- Trouble swallowing, speaking, or breathing
- Puffiness of the face
- Pain and swelling in the stomach
- Nausea, vomiting, or diarrhea

Talk with your doctor about their expectations as well. Your doctor may want you to track issues or signs specific to your health. Your doctor may have already outlined those things they want you to report back to them. Follow that advice. It is also important to find out the best way to talk to your doctors (primary care provider or specialist). Some offices use phone calls, others e-mails or online patient portals. Ask your doctor's office how they would like you to reach out.



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