

When to call your doctor

You likely see your doctor on a regular basis for amyotrophic lateral sclerosis (ALS). But what if something happens in between visits? When should you reach out to your doctor, rather than wait for your next visit?

Staying healthy starts with knowing yourself. Learn how ALS affects you. The better you understand your body, the better you can take care of yourself. Tracking symptoms and health changes helps your doctor know how well your treatment is working. Even if it is working well, stay on top of how you feel. You may feel bad one day and good the next. But some changes can be signs of bigger issues.

Your doctor should be told about any new or worsening symptoms. So, what issues should you (or your caregiver) look for with ALS? Call your doctor right away if you:

- have an increase in your usual symptoms
- feel like your medicines are not helping
- fall
- have more problems breathing, or feel short of breath when you lie down
- choke, or feel it is getting harder to chew and swallow
- have new trouble talking
- feel it is getting harder to cough
- feel an urgent need to go to the bathroom (pee) or you go a lot
- are losing weight

- have new muscle discomfort
- have any sign of infection
- have trouble finding the right words, thinking clearly, or making plans

Talk with your doctor about what they want as well. Your doctor may want you to track or report issues or signs specific to you. Follow that advice. It is also important to ask about the best way to reach your doctors (primary care or specialist). Some offices use phone calls, others use e-mails or online portals.

Still have questions about tracking symptoms or health changes? Ask your program nurse!

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When to call your doctor

You likely see your doctor on a regular basis for your chronic inflammatory demyelinating polyneuropathy (CIDP). But what if something happens in between visits? When should you reach out to your doctor, rather than wait for your next visit?

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

Tracking symptoms and health changes helps your doctor know how well your treatment is working. Even if it is working well, stay on top of how you feel. You may feel bad one day and good the next. But some changes can be signs of bigger issues.

Your doctor should be told about any new or worsening symptoms. So, what issues should you look for with CIDP? Call your doctor right away if you:

- have pain that is not helped at home
- have numbness that has changed or gotten worse
- have concerns with your medicines
- had recent hospital stays or ER/urgent care visits that your doctor is not aware of
- have changes in your ability to pay for medicines
- had a recent fall or falls with injury

Talk with your doctor about what they want as well. Your doctor may want you to track or report issues or signs specific to you. Follow that advice. It is also important to ask about the best way to reach your doctors (primary care or specialist). Some offices use phone calls, others use e-mails or online portals.

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When to call your doctor

You likely see your doctor on a regular basis for cystic fibrosis (CF). But what if something happens in between visits? When should you reach out to your doctor, rather than wait for your next visit? It is important to ask about the best way to reach your doctors (primary care or specialist). Some doctor offices use phone calls, others use e-mails or online portals.

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

Tracking your symptoms and health changes helps your doctor know how well your treatments are working. Even if they are working well, stay on top of how you feel. You may feel bad one day and good the next. But some changes can be signs of bigger issues.

Your doctor should be told about any new or worsening symptoms. So, what issues should you look for with CF? Call your doctor right away if you have:

- any sign of lung infection, like fever, increased cough, or weakness
- trouble catching your breath and chest pain or tightness
- trouble clearing your lungs or more mucus than normal
- blood in your mucus or coughing up blood
- uncontrolled abdominal/belly cramping or throwing up

Your doctor may have some questions about your symptoms. Your doctor may also want you to track or report issues or signs specific to you. Follow that advice.

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When to call your doctor

You likely see your doctor on a regular basis for Gaucher disease. But what if something happens in between visits? When should you reach out to your doctor, rather than wait for your next visit?

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

Tracking symptoms and health changes helps your doctor know how well your treatment is working. Even if it is working well, stay on top of how you feel. You may feel bad one day and good the next. But some changes can be signs of bigger issues.

Your doctor should be told about any new or worsening symptoms. So, what issues should you look for with Gaucher?

- Bone pain (talk to your Gaucher specialist about if your pain is related to Gaucher or some other cause)
- Pain or increased swelling in your belly (abdomen)
- Gaining or losing weight (more than a few pounds)
- Easy bruising or bleeding that is not from injury or hard to stop
- Feeling tired (fatigue)
- Shortness of breath or chest pain
- Fever or chills

Talk with your doctor about what they want as well. Your doctor may want you to track or report issues or signs specific to you. Follow that advice. It is also important to ask about the best way to reach your doctors (primary care or specialist). Some offices use phone calls, others use e-mails or online portals.

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When to call your doctor

You likely see your doctor on a regular basis for hemophilia. But what if something happens in between visits? When should you reach out to your doctor, rather than wait for your next visit?

Staying healthy starts with knowing yourself. Learn how hemophilia affects you. The better you understand your body, the better you can take care of yourself. Tracking symptoms and health changes helps your doctor know how well your treatment is working. Your doctor may want to try other treatments, like gene therapy treatments. These treatments are newly approved by the FDA for adult males. You and your doctor can choose together which treatment is best for you.

Even if treatment is working well, stay on top of how you feel. You may feel bad one day and good the next. But some changes can be signs of bigger issues.

Your doctor should be told about any new or worsening symptoms. So, what issues should you look for with hemophilia?

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

Talk with your doctor about what they want as well. Your doctor may want you to track or report issues or signs specific to you. Follow that advice. It is also important to ask about the best way to reach your doctors (primary care or specialist). Some offices use phone calls, others use e-mails or online portals.

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When to call your doctor

You likely see your doctor on a regular basis for lupus. But what if something happens in between visits? When should you reach out to your doctor, rather than wait for your next visit?

Staying healthy starts with knowing yourself. Learn how lupus affects you. The better you understand your body, the better you can take care of yourself. Tracking symptoms and health changes helps your doctor know how well your treatment is working. Even if it is working well, stay on top of how you feel. You may feel bad one day and good the next. But some changes can be signs of bigger issues.

Your doctor should be told about any new or worsening symptoms. So, what issues should you look for with lupus? There are some key changes you should always talk about with your doctor. These include:

- signs of a flare (such as fever more than 100 degrees not due to an infection)
- feeling more tired or weak than usual
- new or worsening joint pain
- new breathing problems
- new or worsening skin rash
- worsening kidney problems (such as swelling, dizziness, dark or “foamy” urine)
- any plans for pregnancy

Your doctor may want you to track or report issues or signs specific to you. Follow that advice. It is also important to ask about the best way to reach your doctors (primary care or specialist). Some offices use phone calls, others use e-mails or online portals.

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When to call your doctor

You likely see your doctor on a regular basis for multiple sclerosis (MS). But what if something happens in between visits? When should you reach out to your doctor, rather than wait for your next visit?

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

Tracking symptoms and health changes helps your doctor know how well your treatment is working. Even if it is working well, stay on top of how you feel. You may feel bad one day and good the next. But some changes can be signs of bigger issues.

Your doctor should be told about any new or worsening symptoms. So, what issues should you look for with MS? Call your doctor right away if you have:

- a decline in thinking/memory
- increased fatigue
- problems with walking
- eye problems
- a fall with injury
- depression or other mood changes

- signs of infection
- bladder or bowel problems
- pain or spasms
- plans to become pregnant

Your doctor may want you to track or report issues or signs specific to you. Follow that advice. It is also important to ask about the best way to reach your doctors (primary care or specialist). Some offices use phone calls, others use e-mails or online portals.

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You likely see your doctor on a regular basis for myasthenia gravis (MG). But what if something happens in between visits? When should you reach out to your doctor, rather than wait for your next visit?

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

Tracking symptoms and health changes helps your doctor know how well your treatment is working. Even if it is working well, stay on top of how you feel. You may feel bad one day and good the next. But some changes can be signs of bigger issues.

Your doctor should be told about any new or worsening symptoms. So, what issues should you look for with MG? Call your doctor right away if you have:

- new or worsening blurry vision, double vision, or drooping eyelids
- trouble breathing
- problems holding your head up
- issues with chewing, swallowing, or speaking
- signs of pneumonia (chest pain, fever, shortness of breath, coughing up mucus)
- depression
- new muscle weakness in your face, arms, hands, fingers, eyelids, or legs

Talk with your doctor about what they want as well. Your doctor may want you to track or report issues or signs specific to you. Follow that advice. It is also important to ask about the best way to reach your doctors (primary care or specialist). Some offices use phone calls, others use e-mails or online portals.

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When to call your doctor

You likely see your doctor on a regular basis for your myositis. But what if something happens in between visits? When should you reach out to your doctor, rather than wait for your next visit?

Staying healthy starts with knowing yourself. Learn how myositis affects you. Symptoms of myositis are not the same for every person. The better you understand your body, the better you can take care of yourself.

Tracking symptoms and health changes helps your doctor know how well your treatment is working. Even if it is working well, stay on top of how you feel. You may feel bad one day and good the next. But some changes can be signs of bigger issues.

Your doctor should be told about any new or worsening symptoms. So, what issues should you look for with myositis? Call your doctor right away if you have:

- worsening muscle weakness
- new joint swelling
- worsening skin rash
- signs of infection
- depression
- recent hospital stays or ER/urgent care visits that your doctor is not aware of
- recent fall or falls with injury

Talk with your doctor about what they want as well. Your doctor may want you to track or report issues or signs specific to you. Follow that advice. It is also important to ask about the best way to reach your doctors (primary care or specialist). Some offices use phone calls, others use e-mails or online portals.

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You likely see your doctor on a regular basis for Parkinson's disease (PD). But what if something happens in between visits? When should you reach out to your doctor, rather than wait for your next visit?

Staying healthy starts with knowing yourself. Learn how PD affects you. The better you understand your body, the better you can take care of yourself. Tracking symptoms and health changes helps your doctor know how well your treatment is working. Even if it is working well, stay on top of how you feel. You may feel bad one day and good the next. But some changes can be signs of bigger issues.

Your doctor should be told about any new or worsening symptoms. So, what issues should you look for with PD? Call your doctor right away to report things such as:

- a fall with injury
- new problems with sleeping
- new problems with speech or swallowing
- bothersome hallucinations
- walking and rigidity that is getting worse
- a bad reaction to a medicine (talk to your doctor before starting any new meds)
- your medicine seems to stop working before it's time for your next dose
- pain that you can't fix at home
- signs of depression

Your doctor may want you to track or report issues or signs specific to you. Follow that advice. It is also important to ask about the best way to reach your doctors (primary care or specialist). Some offices use phone calls, others use e-mails or online portals.

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When to call your doctor

You likely see your doctor on a regular basis for rheumatoid arthritis (RA). But what if something happens in between visits? When should you reach out to your doctor, rather than wait for your next visit?

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

Tracking symptoms and health changes helps your doctor know how well your treatment is working. Even if it is working well, stay on top of how you feel. You may feel bad one day and good the next. But some changes can be signs of bigger issues.

Your doctor should be told about any new or worsening symptoms. So, what issues should you look for with RA? Call your doctor right away if you have:

- an RA flare (new pain, new swelling, new warmth/redness, or pain in joints)
- new symptoms (low fever, tiredness)
- signs of infection
- trouble staying on your RA medicine
- depression

Talk with your doctor about what they want as well. Your doctor may want you to track or report issues or signs specific to you. Follow that advice. It is also important to ask about the best way to reach your doctors (primary care or specialist). Some offices use phone calls, others use e-mails or online portals.

Still have questions about tracking symptoms or health changes? Ask your program nurse!

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When to call your doctor

You likely see your doctor on a regular basis for scleroderma. But what if something happens in between visits? When should you reach out to your doctor, rather than wait for your next visit?

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

Tracking symptoms and health changes helps your doctor know how well your treatment is working. Even if it is working well, stay on top of how you feel. You may feel bad one day and good the next. But some changes can be signs of bigger issues.

Your doctor should be told about any new or worsening symptoms. So, what issues should you look for with scleroderma? Call your doctor right away to report:

- worsening skin changes (it becomes hard and tight or shiny on your face or legs)
- worsening in fingers or toes that turn blue when you are cold
- a change in heartburn or burping up sour liquid in your throat
- new shortness of breath
- uncontrolled pain
- depression

Talk with your doctor about what tests you should have on a regular basis. Your doctor may want you to track issues or signs specific to you. Follow that advice. It is also important to ask about the best way to reach your doctors (primary care or specialist). Some offices use phone calls, others use e-mails or online portals.

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Gene-editing therapy for sickle cell disease

In December, the Food and Drug Administration (FDA) approved two new treatments for sickle cell disease (SCD). The treatments are called Casgevy (exagamglogene autotemcel) and Lyfgenia (lovotibeglogene autotemcel). Both treatments, approved for people 12 years and older, are a new type of “gene therapy.” Let’s talk about these treatments and whether they might be right for you.

How does gene therapy work? First, you need to know what causes SCD. There are certain genes in your DNA that tell your body how to make hemoglobin, a building block of red blood cells. With SCD, certain genes don’t make hemoglobin the right way. They make red blood cells that are sickled and restrict blood flow.

How do gene therapies for SCD work? By either adding a functional gene that helps your body to make more normal red blood cells or changing an existing gene to make native fetal hemoglobin. To do this, a sample of your own stem cells is taken from you and treated with gene therapy. Then the stem cells are put back in your body. It is a one-time, single-dose infusion.

These are still new treatments and may or may not be right for you. If you have questions about gene therapy, talk to your doctor. You and your doctor can choose together the best treatment for your SCD.

Still have questions about your treatment plan? Ask your program nurse!

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When to call your doctor

You likely see your doctor on a regular basis for epilepsy. But what if something happens in between visits? When should you reach out to your doctor, rather than wait for your next visit?

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

Tracking symptoms and health changes helps your doctor know how well your treatment is working. Even if it is working well, stay on top of how you feel. You may feel bad one day and good the next. But some changes can be signs of bigger issues.

Your doctor should be told about any new or worsening symptoms. So, what issues should you look for with epilepsy? Some reasons to call your doctor are:

- You start having more seizures. Or your seizures last longer or get more intense.
- You notice signs of depression. Or you think you may be depressed.
- You have side effects from your medicine.
- You have an unplanned pregnancy.
- Migraine headaches are getting worse.

Talk with your doctors about what they want as well. Your doctor may want you to track or report issues or signs specific to you. Follow that advice. It is also important to ask about the best way to reach your doctors (primary care or specialist). Some offices use phone calls, others use e-mails or online portals.

Still have questions about tracking symptoms or health changes? Ask your program nurse!

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When to call your doctor

You likely see your doctor on a regular basis for Crohn's disease (CD). But what if something happens in between visits? When should you reach out to your doctor, rather than wait for your next visit?

Staying healthy starts with knowing yourself. Learn how CD affects you. The better you understand your body, the better you can take care of yourself. Tracking symptoms and health changes helps your doctor know how well your treatment is working. Even if it is working well, stay on top of how you feel. You may feel bad one day and good the next. But some changes can be signs of bigger issues.

Your doctor should be told about any new or worsening symptoms. So, what issues should you look for with CD? Call your doctor right away if you have:

- pain in your lower stomach (belly)
- frequent or urgent bathroom visits
- more diarrhea or loose watery poop than before
- cramps after you eat
- blood when you wipe after a bowel or gut movement
- night-time bowel movement
- new fatigue
- poor sleep

Talk with your doctor about what they want as well. Your doctor may want you to track or report issues or signs specific to you. Follow that advice. It is also important to ask about the best way to reach your doctors (primary care or specialist). Some offices use phone calls, others use e-mails or online portals.

Still have questions about tracking symptoms or health changes? Ask your program nurse!

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When to call your doctor

You likely see your doctor on a regular basis for ulcerative colitis (UC). But what if something happens in between visits? When should you reach out to your doctor, rather than wait for your next visit?

Staying healthy starts with knowing yourself. Learn how UC affects you. The better you understand your body, the better you can take care of yourself. Tracking symptoms and health changes helps your doctor know how well your treatment is working. Even if it is working well, stay on top of how you feel. You may feel bad one day and good the next. But some changes can be signs of bigger issues.

Your doctor should be told about any new or worsening symptoms. So, what issues should you look for with UC? Call your doctor right away if you have:

- pain in your lower stomach (belly)
- frequent or urgent bathroom visits
- more diarrhea or loose watery poop than before
- cramps after you eat
- blood when you wipe after a bowel or gut movement
- night-time bowel movement
- new onset fatigue
- poor sleep

Talk with your doctor about what they want as well. Your doctor may want you to track or report issues or signs specific to you. Follow that advice. It is also important to ask about the best way to reach your doctors (primary care or specialist). Some offices use phone calls, others use e-mails or online portals.

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When to call your doctor

You likely see your doctor or health care provider on a regular basis for human immunodeficiency virus (HIV). But what if something happens in between visits? When should you reach out to your provider, rather than wait for your next visit?

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

Tracking symptoms and health changes helps your doctor know how well your treatment is working. Even if it is working well, stay on top of how you feel. You may feel bad one day and good the next. But some changes can be signs of bigger issues.

Your doctor should be told about any new or worsening symptoms. So, what issues should you look for with HIV? Call your doctor right away if you have:

- problems taking your medicines regularly or with affording your medicines
- problems with keeping your follow up visits
- any new medical conditions or diseases
- any sign of infection
- a bad reaction to a drug
- uncontrolled pain
- depression

Talk with your doctor about what they want as well. Your doctor may want you to track or report issues or signs specific to you. Follow that advice. It is also important to ask about the best way to reach your providers (primary care or specialist). Some offices use phone calls, others use e-mails or online portals.

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When to call your doctor

You likely see your doctor on a regular basis for hereditary angioedema (HAE). But what if something happens in between visits? When should you reach out to your doctor, rather than wait for your next visit?

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

Tracking symptoms and health changes helps your doctor know how well your treatment is working. Even if it is working well, stay on top of how you feel. You may feel bad one day and good the next. But some changes can be signs of bigger issues.

Your doctor should be told about any new or worsening symptoms. So, what issues should you look for with HAE? You should call your doctor when:

- Attacks get worse or happen more often
- Attacks don't respond to treatment
- You are planning dental work/surgery
- You are pregnant or want to become pregnant
- You plan to travel
- You have any complications from HAE

Talk with your doctor about what they want as well. Your doctor may want you to track or report issues or signs specific to you. Follow that advice. It is also important to ask about the best way to reach your doctors (primary care or specialist). Some offices use phone calls, others use e-mails or online portals.

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