

Managing pain with ALS

Sometimes, living with a chronic illness means dealing with pain. Not all pain is the same, however. Sometimes pain is related to your illness. Sometimes it is not. It is important to know the difference. Learning the causes of pain and how to manage lower levels of pain can keep you out of the hospital and doctor's office.

A lot of things can cause pain. Headaches, infection, and muscle spasms are common causes. First, talk with your doctor about your pain. This will help your doctor find the cause of your pain and treat it the right way.

Amyotrophic lateral sclerosis (ALS) itself is not painful. However, muscle weakness and not being able to change position can lead to pain. ALS can also cause muscle cramps and spasms. Tightness in the shoulders can cause discomfort. Sitting for hours can also be uncomfortable.

Range-of-motion exercise and stretching can help with weakness and discomfort. So can special seating. Acupuncture and massage may help control pain from cramps and spasms. Pain relief medicines can also help. Talk to your doctor about how to best treat your pain. Also talk about how much pain is too much, and when to seek urgent care.

You can also try different things to manage pain at home:

- Be smart with your medicine. Talk to your doctor about what to do when you have pain and make a plan. Take medicine only for as long as prescribed.

- Take stress off your joints. Diet and exercise can help you reach a healthy weight. Your doctor may suggest a physical therapist or dietician for more help.

You might not be able to get rid of all pain. What is important is reducing the effect pain has in your life. Work with your doctor to set goals and make plans that work for you.

February is American Heart Month!

Do you know if you are at risk for a heart condition? Visit the American Heart Association website at heart.org to learn more, including how social inequality can lead to health issues like heart disease.

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Managing pain with CIDP

Sometimes, living with a chronic illness means dealing with pain. Not all pain is the same, however. Sometimes pain is related to your illness. Sometimes it is not. It is important to know the difference. Learning the causes of pain and how to manage lower levels of pain can keep you out of the hospital and doctor's office.

A lot of things can cause pain. Hard exercise, common headache, infection, and muscle strains are common causes. First, talk with your doctor about your pain. This will help your doctor find the cause of your pain and treat it the right way.

Chronic inflammatory demyelinating polyneuropathy (CIDP) affects nerves and can cause numbness, or you may be sensitive to touch. This is called neuropathic pain. It may be more common in the legs, arms, back, and shoulder blades than other places on the body. People with CIDP can have many other reasons to have pain, just like others who don't have CIDP.

You can help prevent pain through a healthy lifestyle. You can try different things to manage pain at home:

- Be smart with your medicine. Talk to your doctor about what to do when you have pain and make a plan. Take medicine only for as long as prescribed.
- Take stress off your joints. Regular exercise that fits your needs can make bones and muscles strong. Diet and exercise can also help you reach a healthy weight.

- Heat packs can soothe sore muscles. Cold packs or ice (used for 5 to 10 minutes at a time) can ease swelling.
- Make sure you get good sleep. This can help reduce the impact of pain.

You might not be able to get rid of all pain. What is important is reducing the effect pain has in your life. Some with CIDP are helped by physical therapy. Acupuncture, yoga, and tai chi may be other options to try. Work with your doctor to set goals and make plans that work for you.

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Managing pain with cystic fibrosis

Sometimes, living with a chronic illness means dealing with pain. Not all pain is the same, however. Sometimes pain is related to your illness. Sometimes it is not. It is important to know the difference. Learning the causes of pain and how to manage lower levels of pain can keep you out of the hospital and doctor's office.

A lot of things can cause pain. Hard exercise, headaches, infection, and joint pains are common causes. First, talk with your doctor about your pain. This will help your doctor find the cause of your pain and treat it the right way.

With cystic fibrosis (CF), you may feel pain in your chest, stomach and even your bones. Chest pain may give you the most discomfort. This type of pain may be caused by germs in your lungs, swelling, mucous plugging and non-stop coughing. Pain can also be felt in your bones, joints, and muscles. With CF, it is possible over time your bones can get weak and thin. This is called osteoporosis. With osteoporosis, if you experience a fall this can lead to broken bones and pain.

Talk to your doctor about treatments to manage your pain. Clearing mucus from your airways can help to reduce pain in your lungs. Your doctor may suggest treatments such as airway clearance techniques (ACT) to help with this.

You can also try different things to manage pain at home:

- Be smart with your medicine. Talk to your doctor about what to do when you have pain and make a plan. Take pain medicines only for as long as prescribed.

- Take stress off your joints. Regular exercise and stretching that fits your needs can make bones and muscles strong. Exercise can also help improve your lung function.

You might not be able to get rid of all pain. What is important is reducing the effect pain has in your life. Work with your doctor to set goals and make plans that work for you.

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Managing pain with Gaucher

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A lot of things can cause pain. Hard exercise, headaches, infection, and muscle strains are common causes. First, talk with your doctor about your pain. This will help your doctor find the cause of your pain and treat it the right way.

For those with Gaucher disease, you might have bone pain. This pain is caused by a loss of blood supply to bone tissue. It can lead to weak or broken bones. It can also lead to bone crisis, a serious illness that can last weeks, months or even years. Symptoms include broken bones, swelling, sharp pains, dull aches, and fever.

The best way to prevent bone pain is to stick to your treatment plan to control your Gaucher. If you do have pain, write down your symptoms. This will help your doctor figure out the cause of your pain and how to treat it. Also talk about how much pain is too much, and when to seek urgent care.

You can also try different things to manage pain at home:

- Take your medicine for Gaucher as prescribed by your doctor.
- Be smart with your medicine. Talk to your doctor about what to do when you have pain and make a plan. Take medicine only for as long as prescribed.

- Take stress off your joints. Regular weight-bearing exercise that fits your needs can make bones and muscles strong. Calcium and vitamin D can also make bones strong. Diet and exercise can also help you reach a healthy weight.
- Make sure you get good sleep. This can help reduce the impact of pain.

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Managing pain with hemophilia

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A lot of things can cause pain. Hard exercise, common headache, infection, and muscle strains are common causes. First, talk with your doctor about your pain. This will help your doctor find the cause of your pain and treat it the right way. Also talk about how much pain is too much, and when to seek urgent care.

With hemophilia, you may have pain from joint bleeds. Common signs of joint bleeds are tingling, warmth, tightness, swelling, and pain when moving the joint. If not treated quickly, bleeds can cause joint damage over time. This damage can lead to arthritis and other painful issues in the joint.

Quick, effective treatment is the best way to stop joint damage from a bleed. For a joint bleed, you will usually need to take enough factor to raise your level to 40% after you hurt a joint or first suspect a bleed. While the joint heals, your doctor might want you to take extra factor to keep from having another bleed.

For arthritis from repeated joint bleeds, talk to your doctor. They may suggest treatment with medicine. Other options include therapy and joint surgery.

You can also try different things to manage pain at home:

- Be smart with your medicine. Talk to your doctor about what to do when you have pain and make a plan. Take medicine only for as long as prescribed.
- Take stress off your joints. Regular exercise that fits your needs can make bones and muscles strong. Diet and exercise can also help you reach a healthy weight.

You might not be able to get rid of all pain. What is important is reducing the effect pain has in your life. Work with your doctor to set goals and make plans that work for you.

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Managing pain with lupus

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A lot of things can cause pain. Hard exercise, headaches, infection, and muscle strains are common causes. First, talk with your doctor about your pain. This will help your doctor find the cause of your pain and treat it the right way.

With systemic lupus erythematosus (lupus) you may have aches and pains in your joints, tendons, and muscles. It also causes muscle weakness. The inflammation of lupus can attack your joints and cause pain, redness, stiffness, and swelling. This usually affects joints like fingers, wrists, and knees. Sometimes joint pain is a sign of a lupus flare. Other times it can be caused by a type of arthritis that may occur with lupus.

You can help manage pain through a healthy lifestyle. You can also try different things to manage pain at home:

- Take your medicine for lupus as prescribed by your doctor.
- Be smart with your medicine. Talk to your doctor about what to do when you have pain and make a plan. Take medicine only for as long as prescribed.
- Take stress off your joints. Regular exercise that fits your needs can make bones and muscles strong. Diet and exercise can also help you reach a healthy weight.

- Physical and/or occupational therapy might also be good options for you. Ask your doctor about other options to try such as acupuncture, yoga, or tai chi.
- Make sure to balance exercise with rest.
- Make sure you get good sleep. This can help reduce the impact of pain.

You might not be able to get rid of all pain. What is important is reducing the effect pain has in your life. Work with your doctor to set goals and make plans that work for you.

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Managing pain with multiple sclerosis

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A lot of things can cause pain. Strenuous exercise, headaches, infection, and muscle strains are common causes. First, talk with your doctor about your pain. This will help your doctor find the cause of your pain and treat it appropriately.

With multiple sclerosis (MS), you may have pain related to many things including nerve damage. Nerve pain can vary a lot. The pain might be acute. You might feel an electric shock like stabbing pain on the face, head, scalp, or spine. A shooting pain can happen in your eye. Or, you might have chronic pain—more of an ongoing burning or aching feeling. It can happen in your lower back, arms, or legs. Pain can also be linked with spasm.

You can help prevent pain through a healthy lifestyle. You can try different things to manage pain at home:

- Take your medicine for MS as prescribed.
- Be smart with your medicine. Talk to your doctor about what to do when you have pain and make a plan. Take medicine only for as long as prescribed.
- Take stress off your joints. Regular exercise that fits your needs can make bones and muscles strong. Be sure to balance exercise with rest.

- Be careful with your diet to maintain a healthy weight.
- Ask your doctor about physical therapy, massage, or ultrasound options.
- Make sure you get good sleep. This can help reduce the impact of pain.

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Managing pain with myasthenia gravis

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A lot of things can cause pain. Hard exercise, headaches, infection, and muscle strains are common causes. First, talk with your doctor about your pain. This will help your doctor find the cause of your pain and treat it the right way.

Myasthenia gravis (MG) does not typically cause pain. However, some people with MG may have pain related to muscle weakness. This may cause muscle aches and cramps. Pain in the neck is most common. Any muscle group can be affected, though, including hips or shoulders. Falls from muscle weakness may cause injury that results in pain. There are also many other reasons you may have pain not related to your MG.

You can help prevent pain through a healthy lifestyle. You can try different things to manage pain at home:

- Be smart with your medicine. Ask your doctor about what to do when you have pain. You may have to try a series of medicines to find the best answer. Take medicine only for as long as prescribed.
- Take stress off your joints. Regular exercise that fits your needs can make bones and muscles strong.

- Balance exercise with rest. Rest usually helps your muscles regain their strength.
- Be careful about your diet to help reach and maintain a healthy weight.
- Ask your doctor about home treatments such as cold packs or muscle creams.
- Make sure you get good sleep. This can help reduce the impact of pain.

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Managing pain with myositis

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A lot of things can cause pain. Hard exercise, headaches, infection, and muscle strains are common causes. First, talk with your doctor about your pain. This will help your doctor find the cause of your pain and treat it the right way.

With active myositis, you may have pain from muscle inflammation or arthritis. Joint pain is common, often in the hands. Muscle weakness is also common and can range from mild to severe. Some forms of myositis do not cause muscle pain. You may have less range of motion and shoulder pain from tight ligaments. When myositis affects the neck, you might have trouble swallowing. You might have trouble holding your head up.

You can also try different things to manage pain at home:

- Take your medicine for myositis as your doctor has prescribed.
- Talk to your doctor about what to do when you have pain and make a plan.
- You may have to try a series of medicines to find the best answer. Take medicine only for as long as prescribed.
- Take stress off your joints. Regular exercise that fits your needs can make bones and muscles strong. Balance exercise with rest.
- Diet and exercise can also help you reach a healthy weight.

- Heat packs can help soothe sore muscles.
- Make sure you get good sleep. This can help reduce the impact of pain.

You might not be able to get rid of all pain. What is important is reducing the effect pain has in your life. Not all pain you may have is related to your myositis. Work with your doctor to set goals and make plans that work for you.

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Managing pain with Parkinson's disease

Sometimes, living with a chronic illness means dealing with pain. Not all pain is the same, however. Sometimes pain is related to your illness. Sometimes it is not. It is important to know the difference. Learning the causes of pain and how to manage lower levels of pain can keep you out of the hospital and doctor's office.

A lot of things can cause pain. Hard exercise, common headache, infection, and muscle strains are common causes. First, talk with your doctor about your pain. This will help your doctor find the cause of your pain and treat it the right way. With Parkinson's disease (PD), you may have pain for many reasons. The type and site of pain can vary. It is often related to rigidity (stiffness and decreased movement). Many with PD have muscle cramps and tightness in the neck, spine, or arms. Shoulder pain is also common. Painful curling of the feet, toes, or hands may occur from muscle spasms. In those with PD, pain may also result from arthritis or nerve injury.

You can also try different things to manage pain at home:

- Be smart with your medicine. Always take PD medicines as prescribed.
- Work with your doctor to find out what to take when you have pain. You may have to try a series of medicines to find the best answer.
- Take stress off your joints. Regular exercise that fits your needs can make bones and muscles strong. Diet and exercise can also help you reach a healthy weight.
- Stretching and strengthening can help the joints to relax and become more flexible. Yoga and tai chi can make muscles more flexible.
- Always remember to balance exercise with rest.

- Use heat and cold packs. Heat packs can soothe sore muscles. Cold packs or ice (used for 5 to 10 minutes at a time) can ease swelling.
- Make sure you get good sleep. This can help reduce the impact of pain.

You might not be able to get rid of all pain. What is important is reducing the effect pain has in your life. Work with your doctor to set goals and make plans that work for you. Ask your doctor about massage, acupuncture, and ultrasound.

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Managing pain with rheumatoid arthritis

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A lot of things can cause pain. Hard exercise, common headache, infection, and muscle strains are common causes. First, talk with your doctor about your pain. This will help your doctor find the cause of your pain and treat it the right way.

With rheumatoid arthritis (RA) you may feel pain. RA can cause your body to attack your joints. This may cause swelling and stiffness. Over time this swelling can lead to joint damage and sharp pain. Your pain may increase during a flare. This is when your RA symptoms get worse.

The best way to manage joint pain is to follow your RA treatment plan. If you do have pain, write down your symptoms and bring them to your doctor. This will help your doctor figure out the cause of your pain and how to better treat it. Your doctor may suggest medicines and physical therapy to help with your pain.

You can also try different things to manage pain at home:

- Take your medicine for RA as prescribed by your doctor.
- Be smart with your medicine. Talk to your doctor about what to do when you have pain and make a plan. Take medicine only for as long as prescribed.

- Take stress off your joints. Regular exercise that fits your needs can make bones and muscles strong. Diet and exercise can also help you reach a healthy weight.
- Make sure you get good sleep. This can help reduce the impact of pain.

You might not be able to get rid of all pain. What is important is reducing the effect pain has in your life. Work with your doctor to set goals and make plans that work for you.

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Managing pain with scleroderma

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A lot of things can cause pain. Hard exercise, common headache, infection, and muscle strains are common causes. First, talk with your doctor about your pain. This will help your doctor find the cause of your pain and treat it the right way.

With scleroderma, you may have pain from swollen or puffy hands, stiff joints, and skin problems like calluses and ulcers. You might also have stomach pain from diarrhea or constipation. The best way to prevent pain from scleroderma is to keep your illness under control as best as possible. Talk to your doctor and have a plan for what to take when you have pain. You may have to try a series of medicines to find what works for you. Help to prevent pain through a healthy lifestyle.

You can also try different things to manage pain at home:

- Be smart with your medicine. Talk to your doctor about what to do when you have pain and make a plan. Take medicine only for as long as prescribed.
- Take stress off your joints. Regular exercise that fits your needs can make bones and muscles strong and keep you more mobile. Diet and exercise can also help you reach a healthy weight.
- Stretching exercises for the hand and face may be particularly helpful.
- Use heat and cold packs. Heat packs can soothe sore muscles. Cold packs or ice (used for 5 to 10 minutes at a time) can ease swelling.

- Make sure you get good sleep. This can help reduce the impact of pain.

You might not be able to get rid of all pain. What is important is reducing the effect pain has in your life. Work with your doctor to set goals and make plans that work for you.

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Hydroxyurea: what you should know

Have you talked with your doctor about taking hydroxyurea? Maybe you are thinking about it, or maybe you take it already. Let's talk about what you should know before starting treatment.

What is hydroxyurea? It is a medicine used to treat sickle cell disease. Among other things it does, it works by making your red blood cells bigger and less sickle-shaped. It is also used to treat cancer. However, those with sickle cell take a much lower dose. So, those taking hydroxyurea for sickle cell have fewer side effects.

As a sickle cell medicine, hydroxyurea can help to prevent pain crises and acute chest syndrome. It can also mean fewer blood transfusions and hospital visits. It is approved for both children and adults.

Hydroxyurea is taken in the form of a pill. It must be taken every day, so don't forget. You can use a calendar, pill box, or phone alarm to help you remember.

If you think you are having side-effects, do not stop taking your medicine. Talk to your doctor first. Your doctor can adjust your dose as needed. You will also need regular blood count tests while on hydroxyurea. These tests will tell your doctor if your treatment is working. It may take time to find the right dose for you.

Still have questions? You can always reach out to your program nurse.

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EEG: what you should know

If you have epilepsy, there is a good chance you know about EEGs. An EEG may have been used to help diagnose your epilepsy. But there is also a chance you still have questions. How do they work? Why are they needed? Let's talk about some EEG basics.

An electroencephalograph (EEG) is a machine. It measures electrical signals in your brain. It looks for patterns that are common in people with epilepsy. It records brain waves while you are attached to the machine. If you have a seizure during the EEG, it will record that too.

To trigger a seizure, you may be asked to stay up all night, breathe deeply, or look at flashing light. You may need more than one EEG to get a good seizure recording. You will be safe during this time. The doctor can use what they learn from the EEG to plan your treatment.

Your doctor may use other tools as well. A video EEG will film you during an EEG. This helps the doctor see and hear how you react during a seizure. The video can be compared to the EEG results.

Your doctor may also want you to get an MRI (magnetic resonance imaging) brain scan. This scan is used to look at the brain for physical issues. Both the EEG and MRI are tools that help your doctor decide how best to treat you.

Still have questions? Reach out to your program nurse!

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Managing pain with Crohn's disease

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A lot of things can cause pain. Hard exercise, common headache, infection, and muscle strains are common causes. First, talk with your doctor about your pain. This will help your doctor find the cause of your pain and treat it the right way.

With Crohn's disease, pain is a common issue. Crohn's can cause inflammation in your body. Inflammation causes redness, swelling, and pain. When this happens in your gut, it can lead to belly pain and loose watery poop. Infections may also cause pain. Pain can come from the gallbladder or kidney stones or blockages in the gut. The pain can be sharp, cramping, or an ongoing ache.

The best way to manage belly pain is to follow your Crohn's treatment plan. Keep your doctor up to date if you feel any pain. Write down the location of your pain and how long it lasts. Your doctor may talk to you about treatments and lifestyle changes to help with your pain.

You can also try different things to manage pain at home:

- Be smart with your medicine. Talk to your doctor about what to do when you have pain and make a plan. Take your medicine only for as long as prescribed.

- Take stress off your joints. Regular exercise that fits your needs can make bones and muscles strong. Diet and exercise can also help you reach a healthy weight.
- Make sure you get good sleep. This can help reduce the impact of pain.

You might not be able to get rid of all pain. What is important is reducing the effect pain has in your life. Work with your doctor to set goals and make plans that work for you.

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Managing pain with ulcerative colitis

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A lot of things can cause pain. Hard exercise, common headache, infection, and muscle strains are common causes. First, talk with your doctor about your pain. This will help your doctor find the cause of your pain and treat it the right way.

With ulcerative colitis (UC), pain is a common issue. UC can cause inflammation in your body. Inflammation causes redness, swelling, and pain. When this happens in your gut, it can lead to belly pain and loose watery poop. Infections may also cause pain. Pain can come from the gallbladder or kidney stones or blockages in the gut. The pain can be sharp, cramping, or an ongoing ache.

The best way to manage belly pain is to follow your UC treatment plan. Keep your doctor up to date if you feel any pain. Write down the location of your pain and how long it lasts. Your doctor may talk to you about treatments and lifestyle changes to help with your pain.

You can also try different things to manage pain at home:

- Be smart with your medicine. Talk to your doctor about what to do when you have pain and make a plan. Take medicine only for as long as prescribed.

- Take stress off your joints. Regular exercise that fits your needs can make bones and muscles strong. Diet and exercise can also help you reach a healthy weight.
- Make sure you get good sleep. This can help reduce the impact of pain.

You might not be able to get rid of all pain. What is important is reducing the effect pain has in your life. Work with your doctor to set goals and make plans that work for you.

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Managing pain with HIV

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A lot of things can cause pain. Hard exercise, common headache, infection, and muscle strains are common causes. First, talk with your doctor about your pain. This will help your doctor find the cause of your pain and treat it the right way.

Human immunodeficiency virus (HIV) does not usually cause pain. However, you may feel pain because of another health condition. There are many treatments that can help manage your pain. The treatment will depend on the type and location of your pain. For joint pain, cold packs can help to reduce swelling.

Listen to your body and adjust your physical activity to avoid any pain triggers. Physical and massage therapy may also help you control your pain. Talk to your doctor about your pain. Your doctor may suggest medicines and lifestyle changes to help with any pain.

You can also try different things to manage pain at home:

- Be smart with your medicine. Talk to your doctor about what to do when you have pain and make a plan. Take medicine only for as long as prescribed.

- Take stress off your joints. Regular exercise that fits your needs can make bones and muscles strong. Diet and exercise can also help you reach a healthy weight.
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A lot of things can cause pain. Hard exercise, common headache, infection, and muscle strains are common causes. First, talk with your doctor about your pain. This will help your doctor find the cause of your pain and treat it the right way.

With hereditary angioedema (HAE), swelling attacks are a common source of pain. Preventing swelling in the first place is the top goal for all HAE care. The best way to prevent pain is to keep your HAE under control. You can do this by following your treatment plan.

Do you have an HAE attack action plan? If not, talk to your doctor about making one. This will help you take steps to infuse quickly to treat acute attacks.

You can also try different things to manage pain at home:

- Take your HAE prophylaxis as prescribed by your doctor.
- Be smart with your medicine. Talk to your doctor about what to do when you have pain and make a plan. Take medicine only for as long as prescribed.

- Take stress off your joints. Regular exercise that fits your needs can make bones and muscles strong. Diet and exercise can also help you reach a healthy weight.

You might not be able to get rid of all pain. What is important is reducing the effect pain has in your life. Work with your doctor to set goals and make plans that work for you.

February is American Heart Month!

Do you know if you are at risk for a heart condition? Visit the American Heart Association website at heart.org to learn more, including how social inequality can lead to health issues like heart disease.

This CareConnections newsletter was reviewed for medical accuracy by Andrew Krueger, MD, FACP. The CareConnections newsletter and the Accordant website are for your information. The information given in this newsletter was correct to the best of our knowledge at the time of printing. References available upon request. We may talk about medicines, products or services offered by companies that are not a part of Accordant's services. We are not paid by these companies and we do not make promises about their medicines, products or services. Also, Accordant does not offer treatment, accept payment from or endorse other websites. The CareConnections newsletter and Accordant website do not replace your doctor's medical advice. Always talk to your doctor before making any changes in your medications or other treatment. Visit our website for the full Terms of Use. Your health plan benefits may or may not pay for the medicines, products or services that we talk about in CareConnections. Contact your health plan's customer service department to talk about your benefits. You may copy or print this newsletter for other people as long as you don't receive any kind of payment for it and the copyright notice is displayed. You may not change any article or remove the copyright notice. If you have comments or suggestions, send a letter to the address below or an email to editor@accordant.net. If we sent this newsletter to you in error, please accept our apology. Call the phone number listed above if you want Accordant to stop sending these newsletters to you. You can also write "remove from mailing list" on this newsletter and return it to us. Your privacy is important to us. Our employees are trained regarding the appropriate way to handle your private health information.

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♥ **CVS specialty** nurse care management

4050 PIEDMONT PARKWAY / SUITE 210
HIGH POINT, NC 27265

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