

ALS

Spring 2025

What are your goals for 2025?

Everyone can create goals they want to reach. But putting these plans into action is not always easy. Believing that you can is often the first step.

Many of you are doing this already. You have goals, you make a plan, and you stick to it. You schedule your doctor's visits well ahead of time. You take your medicines on time. You tackle challenges with confidence. If you have a problem, you keep trying until you work through it. If this is you, you deserve a pat on the back. Keep up the good work!

However, you may be new to goal setting. Start by asking yourself, "**What are my goals for the year?**" Ask your doctor the same question if you are not sure what your health or treatment goals should be. Or tell your doctor if you are struggling with a health goal you need to tackle. It's also good to think about goals that aren't related to your condition. Do you want to lose weight? Make more time for friends and family? Find a new job or earn a degree? Everyone is different—what matters is that the goal is something you want for yourself.

Once you have a few goals in mind, make a plan. How will you reach them? Try these tips to stay focused and positive:

- Take a real interest in what you plan to do.
- Do not dwell on setbacks.
- Look at problems as something to be mastered.
- Ask your care team and loved ones for support along the way.





Making lifestyle changes that last

Making lasting changes to your life can be hard. Do you want to exercise more? Are you trying to eat a healthier diet? Every January people spend time making New Year's resolutions. But by the middle of the year you realize that not enough progress has been made. With your condition you may have talked to your doctor about lifestyle changes. But, you may not know how to start making these changes or how to make them last.

Here are some steps that you can walk through to make a new change. First, **contemplation**. Think about what you want to change. This might mean asking questions like: why is it important for you to change? Second, **preparation**. You will need to prepare to make the change. You can do this by planning and goal setting. Third, **action**. This is where you carry out your plan. Every big change starts with bite-sized steps. So, remember to start small and be patient. Smart phone apps can be very helpful to set reminders and stay consistent. Fourth, **maintenance**. You have gotten used to your changes and have kept them up for more than 6 months.

Here are some tips to make your changes last:

- Start small.
- Set goals.
- Get support and ask for help.
- Track your progress.
- Celebrate progress.

Remember to be kind with yourself. If you slip up, don't give up. Just get back on track. Also remind yourself why you wanted to make this change in the first place. Over time you will continue to improve and make this change a part of your life. It is also important to talk to your doctor about any problems you have. Your doctor and care team may have helpful suggestions about how to stick to your lifestyle change(s).

Signs of heart attack & stroke

A stroke or heart attack can be very scary. Less blood flow to the heart is known as a heart attack. A stroke happens when oxygen levels in the brain are too low. It is important to know the signs of both heart attacks and strokes. Knowing these signs might save your life or the life of a loved one. More people survive strokes now than ever before, but it is still good to be prepared. Here are some signs of stroke and heart attack:

Stroke (Think "F.A.S.T.")	Heart Attacks
Face drooping	Chest pain
Arm weakness	Feeling weak or faint
Speech difficulty	Pain in the jaw, neck, or back
Time to call 911	Shortness of breath

Some other signs of stroke are numbress in your face, arms or legs, sudden confusion, or trouble walking or seeing. Women have mostly the same heart attack signs as men. But there may be some that are unique to them. Some women feel upper back pressure that feels like a rope being tied around them. Women can also feel shortness of breath, vomiting, or jaw pain. If you see any of the signs of a stroke or heart attack, call 911 right away.

Most heart attacks and strokes may be prevented. So, it is important to take care of your heart and overall health. High blood pressure, diabetes, smoking, and high body weight are all common risk factors for strokes and heart attacks. There are many things that you can do to take better care of your heart. Getting the right amount of sleep and exercise can be great places to start. Eating a healthy diet is important to maintain a healthy heart and body. A healthy, balanced diet is one filled with vegetables, fruits, whole grains, and nuts, for example.

It is also important to have regular visits with your doctor. At these visits, have your blood pressure, blood sugar, and lipids checked. These tests can give your doctor a sense of your overall heart health and risk level. Knowing your risk level will help you to take control of your health.

Staying active for ALS

When you have amyotrophic lateral sclerosis (ALS), the goals of exercise may be different. Staying active is still a must for good health. It can boost your mood, give you more energy, and help you sleep better at night. Be sure to talk with your doctor about what kinds of exercise are best for you.

So, what should those with ALS know when planning to exercise? There is a lot you can do, but keep these things in mind:

- Stretching is a great way to keep your limbs mobile. Try range of motion exercises to help keep your muscles and joints limber. When muscles are weak, it can be hard to move a limb to stretch muscles and joints. You may need to ask a caregiver to help.
- An exercise program may result in small gains in strength. Once a program is started, it is important to stick to it.
- Train your breathing to keep your lungs strong. You can practice by taking in very deep breaths.
- Make sure you are safe and supported during exercise. Do not put yourself at risk for a fall. Do what you can while seated or from the floor.
- A physical therapist can suggest helpful exercises. They can also tell if special equipment, like a splint or brace, might help mobility.

Cramps and spasms are also common with ALS. Sometimes these words are used for the same problem. With ALS, the nerves that control movement don't work correctly. Cramps and spasms can be painful, but there are things you can do to help control them. Try these tips:

- Drink plenty of water-before, during, and after activity.
- Take time to stretch. Focus on the muscles that often cramp.
- If you have poor circulation, keep the affected area warm.
- Massage your muscles before and after activity.
- Try both heat and cold on the affected area (no more than 20 minutes at a time).
- Do what activity you can, at the pace you can.
- Rest when you need to.

Still have questions about exercise and staying active? Reach out to your program nurse!

Nutrition—eating healthy for ALS

Eating well is a key part of your total health. What and how you eat affects many things, like healing, energy, immune health, and sleep.

No food or diet can cure amyotrophic lateral sclerosis (ALS), but being well nourished is good for those with ALS. The first step is talking with your doctor about a plan for your diet. A dietitian may help create a meal plan based on your needs and goals. Here are some tips to help you make the right choices when eating:

- Be smart about drinks—some are better for you than others (water beats sugary soda).
- Salt: too much can be bad for your heart health.
- Try blended foods, soups, and smoothies. These foods can help those with issues chewing/ swallowing to get the nutrients they need.
- Utensils and cups with special grips help you eat and drink with less strain.
- To maintain your weight:
 - Focus on getting enough calories and protein. Add shakes, smoothies, and supplements.
 Add olive oil, cheese, or avocado to food after cooking. Try adding nut butters into shakes.
 - Shorten mealtimes so you don't get tired.
 - Take medicines one at a time with pudding, applesauce, or yogurt.
- At some point as ALS gets worse, eating normally will no longer be safe. As it gets harder to chew and swallow, your risk of choking rises. Talk with your doctor and make a plan for feeding tube placement. Feeding tubes can also make it easier for you to get the nutrients and calories you need.

Still have questions about healthy eating? Ask your program nurse online or give them a call today!

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Care Connections[®]

Crohn's Disease

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Remember to be kind with yourself. If you slip up, don't give up. Just get back on track. Also remind yourself why you wanted to make this change in the first place. Over time you will continue to improve and make this change a part of your life. It is also important to talk to your doctor about any problems you have. Your doctor and care team may have helpful suggestions about how to stick to your lifestyle change(s).

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Most heart attacks and strokes may be prevented. So, it is important to take care of your heart and overall health. High blood pressure, diabetes, smoking, and high body weight are all common risk factors for strokes and heart attacks. There are many things that you can do to take better care of your heart. Getting the right amount of sleep and exercise can be great places to start. Eating a healthy diet is important to maintain a healthy heart and body. A healthy, balanced diet is one filled with vegetables, fruits, whole grains, and nuts, for example.

It is also important to have regular visits with your doctor. At these visits, have your blood pressure, blood sugar, and lipids checked. These tests can give your doctor a sense of your overall heart health and risk level. Knowing your risk level will help you to take control of your health.

Exercise for Crohn's disease

Staying active is a must for good health. Regular exercise can make your muscles, joints, and bones stronger. It can boost your mood, give you more energy, and help you sleep better at night. It can even lower your risk for illnesses like diabetes and heart disease.

When you have Crohn's disease, how you exercise will depend on many factors. Your age, experience, and interests all play a part. First, be sure to talk with your doctor about what kinds of exercise are best for you.

So, what should those with Crohn's know when planning to exercise? There is a lot you can do, but keep these things in mind:

- Stay hydrated: Drink water before, during, and after exercise.
- Let your body rest. Hold off on exercising if you are not feeling well or having a flare-up with your Crohn's. Flares may limit your exercise routines. Speak with your doctor about what to do when this happens.
- Plan exercises around bathroom breaks. You may need to take short breaks during exercise.

Staying active is more than an exercise routine. Try to make active choices each day to keep yourself fit and healthy. Here are a few ideas:

- Take the stairs instead of the elevator.
- Go for daily walks (ask a friend to join you!).
- Don't sit for too long—stand up and move around every half hour.

You can find more examples of exercises to try through the Crohn's and Colitis Foundation at **www.crohnscolitisfoundation.org**.

Still have questions about exercise and staying active? Give your program nurse a call!

Nutrition—eating healthy for Crohn's disease

Eating well is a key part of your total health. What and how you eat affects many things, like healing, energy, immune health, and sleep.

No food or diet can cure illness. Eating well can improve your overall health, however. Sometimes, it can also help to lessen some symptoms of illness.

The first step is talking with your doctor about a plan for your diet. Here are some tips to help you make the right choices when eating:

- Be smart about drinks—some are better for you than others (water beats soda).
- Watch out for these foods and ingredients:
 - Salt (too much can be bad for your heart health)
 - Animal fats like butter and tropical oils like coconut and palm (limit to less than 10% of your calories per day; choose olive and canola oil instead)
 - Sugars (limit to less than 10% of your calories per day)

Here are some important diet and nutrition points you should think about with Crohn's disease:

- Eat more plant-based foods (fruits and vegetables). Vegetables such as squash, cooked carrots, and green beans are great options. Watch out, though. During a flare you may have trouble digesting high-fiber foods such as fruits, vegetables, and whole grains.
- Do you struggle with dairy? Many people with Crohn's disease are lactose intolerant. This means that you may have trouble digesting dairy. You can try lactose-free dairy products, soy milk, or almond milk.
- Avoid trigger foods. There may be some foods that worsen your Crohn's symptoms. These may include spicy foods, caffeine, and alcohol.
- Work with a dietitian. A dietitian can help create a meal plan based on your needs and goals. You can discuss this more with your doctor or dietitian.

Still have questions about healthy eating? Ask your program nurse online or give them a call today!

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Cystic Fibrosis

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Remember to be kind with yourself. If you slip up, don't give up. Just get back on track. Also remind yourself why you wanted to make this change in the first place. Over time you will continue to improve and make this change a part of your life. It is also important to talk to your doctor about any problems you have. Your doctor and care team may have helpful suggestions about how to stick to your lifestyle change(s).

Signs of heart attack & stroke

A stroke or heart attack can be very scary. Less blood flow to the heart is known as a heart attack. A stroke happens when oxygen levels in the brain are too low. It is important to know the signs of both heart attacks and strokes. Knowing these signs might save your life or the life of a loved one. More people survive strokes now than ever before, but it is still good to be prepared. Here are some signs of stroke and heart attack:

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Most heart attacks and strokes may be prevented. So, it is important to take care of your heart and overall health. High blood pressure, diabetes, smoking, and high body weight are all common risk factors for strokes and heart attacks. There are many things that you can do to take better care of your heart. Getting the right amount of sleep and exercise can be great places to start. Eating a healthy diet is important to maintain a healthy heart and body. A healthy, balanced diet is one filled with vegetables, fruits, whole grains, and nuts, for example.

It is also important to have regular visits with your doctor. At these visits, have your blood pressure, blood sugar, and lipids checked. These tests can give your doctor a sense of your overall heart health and risk level. Knowing your risk level will help you to take control of your health.

Exercise for cystic fibrosis

Staying active is a must for good health. Regular exercise can make your muscles, joints, and bones stronger. It can boost your mood, give you more energy, and help you sleep better at night. It can even lower your risk for illnesses like diabetes and heart disease.

Exercise can help you feel better with your cystic fibrosis (CF). It can help clear mucus from your lungs, improve your lung function, and help your bones.

When you have CF, the best way to exercise will depend on many factors. Your age, experience, and interests all play a part. First, be sure to talk with your doctor about what kinds of exercises are best for you.

So, what should those with CF know when planning to exercise? There is a lot you can do, but keep these things in mind:

- Stay hydrated. Drink water before, during, and after exercise.
- Try weight-bearing exercises. You can use free weights or bands. Body weight exercises like pushups are also helpful. They can help you keep your bones healthy.
- Talk to your doctor about working with a physical therapist (health care provider to help you stretch and move). They can help you make an exercise program to fit your life.
- If you are sick, ask your doctor whether you should continue to exercise.

Staying active is more than an exercise routine. Try to make active choices each day to keep yourself fit and healthy. Here are a few ideas:

- Take the stairs instead of the elevator.
- Go for daily walks (ask a friend to join you!).
- Don't sit for too long—stand up and move around every half hour.

You can find resources on the Cystic Fibrosis Foundation website to help you create an exercise plan that works for you: **www.cff.org**.

Still have questions about exercise and staying active? Give your program nurse a call!

Nutrition—eating healthy for cystic fibrosis

Eating well is a key part of your total health. What and how you eat affects many things, like healing, energy, immune health, and sleep.

No food or diet can cure illness. Eating well can improve your overall health, however. For people with cystic fibrosis (CF) this is very important. Eating healthy and maintaining the weight goal your doctor sets can help keep your lungs healthy.

The first step is talking with your doctor about a plan for your diet. Here are some important diet and nutrition points you should think about with cystic fibrosis (CF):

- Eat a balanced diet. With your CF you may have trouble getting nutrients from food. You can eat foods such as fruits, vegetables, whole grains, lean proteins, and healthy fats. You can also take high-calorie supplements to boost calories.
- Track your BMI. You can work with your doctor to set goals for your weight. The CF Foundation recommends that women have a body mass index (BMI) of at least 22 and men a BMI of at least 23.
- Pancreatic enzyme supplements: You may have trouble digesting fat, protein, carbs, and other nutrients. Pancreatic enzyme supplements may be needed to help break down food and get more nutrients.
- Work with a dietitian to make a meal plan based on your needs.
- Screen for diabetes: Your doctor and health care team may also screen you for diabetes each year starting at age 10.

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CIDP

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Exercise for CIDP

Staying active is a must for good health. Regular exercise can make your muscles, joints, and bones stronger. It can boost your mood, give you more energy, and help you sleep better at night. It can even lower your risk for illnesses like diabetes and heart disease.

With chronic inflammatory demyelinating polyneuropathy (CIDP), how you exercise will depend on many factors. Your age, experience, and interests all play a part. First, be sure to talk with your doctor about what kinds of exercise are best for you.

So, what should those with CIDP know when planning to exercise? There is a lot you can do, but keep these things in mind:

- With CIDP, you may have difficulty with walking, and climbing stairs.
- You may have trouble with balance and using your hands to grasp objects.
- You're at increased risk of osteoporosis if you take steroids for CIDP. Weight-bearing exercises, like walking, can help improve bone strength.
- Exercise can help you reduce joint strain and promote movement, reduce pain, and help keep your immune system strong.
- It is important to choose a program planned for you that will not go past your limits. Your doctor may suggest physical therapy to help you get started with a plan.

Different types of exercises you can do include:

- Strength-training—making muscles stronger helps to strengthen bones. Examples: lifting weights or using resistance bands.
- Aerobic (or "cardio")—raise the heart rate. Examples: fast walking, running, dancing, or swimming.
- Flexibility—stretch muscles and promote range of motion. Some can also improve balance and help prevent falls. Examples: yoga, tai chi, Pilates.

Staying active is more than an exercise routine. Try to make active choices each day to keep yourself fit and healthy. Here are a few ideas:

- Take the stairs instead of the elevator if you're able to do so safely.
- Go for daily walks (ask a friend to join you!).
- Don't sit for too long—stand up and move around every half hour.

Nutrition—eating healthy for CIDP

Eating well is a key part of your total health. What and how you eat affects many things, like healing, energy, immune health, and sleep. No food or diet can cure illness. Eating well can improve your overall health, however.

The first step is talking with your doctor about a plan for your diet. A dietitian can also help create a meal plan based on your needs and goals. Here are some tips to help you make the right choices when eating:

- Be smart about drinks—some are better for you than others (water beats soda).
- Watch out for these foods and ingredients:
 - Salt (too much can be bad for your heart health)
 - Animal fats like butter, cheese, ice cream, red meat, and tropical oils like coconut and palm (limit to less than 10% of your calories per day; choose olive and canola oil instead)
 - Sugars (limit to less than 10% of your calories per day)

Here are some other important diet and nutrition points you should think about with chronic inflammatory demyelinating polyneuropathy (CIDP):

- Eat a variety of foods and strive to maintain a healthy weight.
- Include plenty of fruits and vegetables. These are high in vitamins and minerals and are a good source of antioxidants. This may help fight inflammation.
- Also include essential fats that are high in omega-3 fatty acids. Certain fatty fish, such as tuna and salmon, are good sources. Or take a fish oil supplement.
- If you take steroids to treat your CIDP, you are at greater risk for osteoporosis. Eat foods with lots of calcium for bone health. Include leafy greens, dairy foods, and whole-grain cereals.

Still have questions about healthy eating? Ask your program nurse online or give them a call today!

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Care Connections[®]

Gaucher

Spring 2025

What are your goals for 2025?

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Many of you are doing this already. You have goals, you make a plan, and you stick to it. You schedule your doctor's visits well ahead of time. You take your medicines on time. You tackle challenges with confidence. If you have a problem, you keep trying until you work through it. If this is you, you deserve a pat on the back. Keep up the good work!

However, you may be new to goal setting. Start by asking yourself, "**What are my goals for the year?**" Ask your doctor the same question if you are not sure what your health or treatment goals should be. Or tell your doctor if you are struggling with a health goal you need to tackle. It's also good to think about goals that aren't related to your condition. Do you want to lose weight? Make more time for friends and family? Find a new job or earn a degree? Everyone is different—what matters is that the goal is something you want for yourself.

Once you have a few goals in mind, make a plan. How will you reach them? Try these tips to stay focused and positive:

- Take a real interest in what you plan to do.
- Do not dwell on setbacks.
- Look at problems as something to be mastered.
- Ask your care team and loved ones for support along the way.





Making lifestyle changes that last

Making lasting changes to your life can be hard. Do you want to exercise more? Are you trying to eat a healthier diet? Every January people spend time making New Year's resolutions. But by the middle of the year you realize that not enough progress has been made. With your condition you may have talked to your doctor about lifestyle changes. But, you may not know how to start making these changes or how to make them last.

Here are some steps that you can walk through to make a new change. First, **contemplation**. Think about what you want to change. This might mean asking questions like: why is it important for you to change? Second, **preparation**. You will need to prepare to make the change. You can do this by planning and goal setting. Third, **action**. This is where you carry out your plan. Every big change starts with bite-sized steps. So, remember to start small and be patient. Smart phone apps can be very helpful to set reminders and stay consistent. Fourth, **maintenance**. You have gotten used to your changes and have kept them up for more than 6 months.

Here are some tips to make your changes last:

- Start small.
- Set goals.
- Get support and ask for help.
- Track your progress.
- Celebrate progress.

Remember to be kind with yourself. If you slip up, don't give up. Just get back on track. Also remind yourself why you wanted to make this change in the first place. Over time you will continue to improve and make this change a part of your life. It is also important to talk to your doctor about any problems you have. Your doctor and care team may have helpful suggestions about how to stick to your lifestyle change(s).

Signs of heart attack & stroke

A stroke or heart attack can be very scary. Less blood flow to the heart is known as a heart attack. A stroke happens when oxygen levels in the brain are too low. It is important to know the signs of both heart attacks and strokes. Knowing these signs might save your life or the life of a loved one. More people survive strokes now than ever before, but it is still good to be prepared. Here are some signs of stroke and heart attack:

Stroke (Think "F.A.S.T.")	Heart Attacks
Face drooping	Chest pain
Arm weakness	Feeling weak or faint
Speech difficulty	Pain in the jaw, neck, or back
Time to call 911	Shortness of breath

Some other signs of stroke are numbress in your face, arms or legs, sudden confusion, or trouble walking or seeing. Women have mostly the same heart attack signs as men. But there may be some that are unique to them. Some women feel upper back pressure that feels like a rope being tied around them. Women can also feel shortness of breath, vomiting, or jaw pain. If you see any of the signs of a stroke or heart attack, call 911 right away.

Most heart attacks and strokes may be prevented. So, it is important to take care of your heart and overall health. High blood pressure, diabetes, smoking, and high body weight are all common risk factors for strokes and heart attacks. There are many things that you can do to take better care of your heart. Getting the right amount of sleep and exercise can be great places to start. Eating a healthy diet is important to maintain a healthy heart and body. A healthy, balanced diet is one filled with vegetables, fruits, whole grains, and nuts, for example.

It is also important to have regular visits with your doctor. At these visits, have your blood pressure, blood sugar, and lipids checked. These tests can give your doctor a sense of your overall heart health and risk level. Knowing your risk level will help you to take control of your health.

Exercise for Gaucher disease

Staying active is a must for good health. Regular exercise can make your muscles, joints, and bones stronger. It can boost your mood, give you more energy, and help you sleep better at night. It can even lower your risk for illnesses like diabetes and heart disease.

When you have Gaucher disease, how you exercise will depend on many factors. Your age, experience, ability, and interests all play a part. First, be sure to talk with your doctor about what kinds of exercise are best for you.

So, what should those with Gaucher know when planning to exercise? There is a lot you can do, but keep these things in mind:

- If your spleen is bigger than normal, or your platelet count is low, avoid contact sports. This will lower your chances for a bleed.
- Weight-bearing exercise is great for bone health. There are many types. Try using free weights or bands, or do body weight exercises like stretching. Talk to your doctor or physical therapist about what kind of exercise routine is right for you.
- Gaucher can cause serious bone health issues. If you have had a knee or hip replacement, skip high-impact sports. This includes jogging or downhill skiing, for example.
- Swimming makes muscles strong and flexible without straining your joints. It is also good exercise for your heart.

Staying active is more than an exercise routine. Try to make active choices each day to keep yourself fit and healthy. Here are a few ideas:

- If able, take the stairs instead of the elevator and go for daily walks. If you want, ask a friend to join you!
- Don't sit still for too long—move around every half hour.

Still have questions about exercise and staying active? Give your program nurse a call!

Nutrition—eating healthy for Gaucher

Eating well is a key part of your total health. What and how you eat affects many things, like healing, energy, immune health, and sleep.

No food or diet can cure Gaucher disease. Eating well can improve your overall health, however. The first step is talking with your doctor about a plan for your diet. Here are some tips to help you make the right choices when eating:

- Children with Gaucher might have trouble growing. They may face delayed skeletal growth or delayed start of puberty. With proper treatment for Gaucher and nutrition, growth and puberty usually catch up in the late teens.
- Those with Gaucher have a higher risk of osteopenia. This is a loss of bone mass that causes weak bones, so make sure to get enough calcium and vitamin D in your diet.
- Be smart about drinks—some are better for you than others (water beats sugary soda).
- Watch out for these foods and ingredients:
 - Salt (too much can be bad for your heart health)
 - Animal fats like butter and tropical oils like coconut and palm (limit to less than 10% of your calories per day; choose olive and canola oil instead)
 - Sugars (limit to less than 10% of your calories per day)
- Diets like the DASH diet help to control weight and high blood pressure. DASH (Dietary Approaches to Stop Hypertension) is a plant-focused, well-rounded diet. It uses fruits, vegetables, lean meat, fish, poultry, nuts, whole grains and healthy fats to balance your nutrition. Check out www.dashdiet.org for more info.

Still have questions about healthy eating? Ask your program nurse online or give them a call today!

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Hereditary Angioedema

Spring 2025

What are your goals for 2025?

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Once you have a few goals in mind, make a plan. How will you reach them? Try these tips to stay focused and positive:

- Take a real interest in what you plan to do.
- Do not dwell on setbacks.
- Look at problems as something to be mastered.
- Ask your care team and loved ones for support along the way.





Making lifestyle changes that last

Making lasting changes to your life can be hard. Do you want to exercise more? Are you trying to eat a healthier diet? Every January people spend time making New Year's resolutions. But by the middle of the year you realize that not enough progress has been made. With your condition you may have talked to your doctor about lifestyle changes. But, you may not know how to start making these changes or how to make them last.

Here are some steps that you can walk through to make a new change. First, **contemplation**. Think about what you want to change. This might mean asking questions like: why is it important for you to change? Second, **preparation**. You will need to prepare to make the change. You can do this by planning and goal setting. Third, **action**. This is where you carry out your plan. Every big change starts with bite-sized steps. So, remember to start small and be patient. Smart phone apps can be very helpful to set reminders and stay consistent. Fourth, **maintenance**. You have gotten used to your changes and have kept them up for more than 6 months.

Here are some tips to make your changes last:

- Start small.
- Set goals.
- Get support and ask for help.
- Track your progress.
- Celebrate progress.

Remember to be kind with yourself. If you slip up, don't give up. Just get back on track. Also remind yourself why you wanted to make this change in the first place. Over time you will continue to improve and make this change a part of your life. It is also important to talk to your doctor about any problems you have. Your doctor and care team may have helpful suggestions about how to stick to your lifestyle change(s).

Signs of heart attack & stroke

A stroke or heart attack can be very scary. Less blood flow to the heart is known as a heart attack. A stroke happens when oxygen levels in the brain are too low. It is important to know the signs of both heart attacks and strokes. Knowing these signs might save your life or the life of a loved one. More people survive strokes now than ever before, but it is still good to be prepared. Here are some signs of stroke and heart attack:

Stroke (Think "F.A.S.T.")	Heart Attacks
Face drooping	Chest pain
Arm weakness	Feeling weak or faint
Speech difficulty	Pain in the jaw, neck, or back
Time to call 911	Shortness of breath

Some other signs of stroke are numbress in your face, arms or legs, sudden confusion, or trouble walking or seeing. Women have mostly the same heart attack signs as men. But there may be some that are unique to them. Some women feel upper back pressure that feels like a rope being tied around them. Women can also feel shortness of breath, vomiting, or jaw pain. If you see any of the signs of a stroke or heart attack, call 911 right away.

Most heart attacks and strokes may be prevented. So, it is important to take care of your heart and overall health. High blood pressure, diabetes, smoking, and high body weight are all common risk factors for strokes and heart attacks. There are many things that you can do to take better care of your heart. Getting the right amount of sleep and exercise can be great places to start. Eating a healthy diet is important to maintain a healthy heart and body. A healthy, balanced diet is one filled with vegetables, fruits, whole grains, and nuts, for example.

It is also important to have regular visits with your doctor. At these visits, have your blood pressure, blood sugar, and lipids checked. These tests can give your doctor a sense of your overall heart health and risk level. Knowing your risk level will help you to take control of your health.

Exercise for HAE

Staying active is a must for good health. Regular exercise can make your muscles, joints, and bones stronger. It can boost your mood, give you more energy, and help you sleep better at night. It can even lower your risk for illnesses like diabetes and heart disease.

When you have hereditary angioedema (HAE), how you exercise will depend on many factors. Your age, experience, and interests all play a part. First, be sure to talk with your doctor about what kinds of exercise are best for you.

Exercise can help you manage stress, a common HAE trigger. So, what should those with HAE know when planning to exercise? There is a lot you can do, but keep these things in mind:

- Stick to your HAE medicine.
- With the right medicines, many people can exercise without triggering HAE attacks. Make sure to watch for any attack symptoms. Be ready with HAE rescue medicine, if needed.
- Low impact exercise like yoga may be less likely to set off your HAE.

Staying active is more than an exercise routine. Try to make active choices each day to keep yourself fit and healthy. Here are a few ideas:

- Take the stairs instead of the elevator.
- Go for daily walks (ask a friend to join you).
- Don't sit for too long—stand up and move around every half hour.

Still have questions about exercise and staying active? Give your program nurse a call!

Nutrition—eating healthy for HAE

Eating well is a key part of your total health. What and how you eat affects many things, like healing, energy, immune health, and sleep.

No food or diet can cure hereditary angioedema (HAE). Eating well can improve your overall health. However dietary changes have not been proven to reduce HAE symptoms specifically.

The first step is talking with your doctor about a plan for your diet. Here are some tips to help you make the right choices when eating:

- Be smart about drinks—some are better for you than others (water beats sugary soda).
- Watch out for these foods and ingredients:
 - Salt (too much can be bad for your heart health)
 - Animal fats like butter and tropical oils like coconut and palm (limit to less than 10% of your calories per day; choose olive and canola oil instead)
 - Sugars (limit to less than 10% of your calories per day)
- Diets like the DASH diet help to control weight and high blood pressure. DASH (Dietary Approaches to Stop Hypertension) is a plant-focused, well-rounded diet. It uses fruits, vegetables, lean meat, fish, poultry, nuts, whole grains and healthy fats to balance your nutrition. Check out **www.dashdiet.org** for more info.
- The Mediterranean diet is also good. It can keep blood pressure and cholesterol in check. It can also lower your risk of heart disease. This diet is focused on plant-based foods (fruits, vegetables, beans, nuts) and healthy fats like olive oil.

Still have questions about healthy eating? Ask your program nurse online or give them a call today!

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HIV

Spring 2025

What are your goals for 2025?

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Once you have a few goals in mind, make a plan. How will you reach them? Try these tips to stay focused and positive:

- Take a real interest in what you plan to do.
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Making lifestyle changes that last

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Here are some steps that you can walk through to make a new change. First, **contemplation**. Think about what you want to change. This might mean asking questions like: why is it important for you to change? Second, **preparation**. You will need to prepare to make the change. You can do this by planning and goal setting. Third, **action**. This is where you carry out your plan. Every big change starts with bite-sized steps. So, remember to start small and be patient. Smart phone apps can be very helpful to set reminders and stay consistent. Fourth, **maintenance**. You have gotten used to your changes and have kept them up for more than 6 months.

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Remember to be kind with yourself. If you slip up, don't give up. Just get back on track. Also remind yourself why you wanted to make this change in the first place. Over time you will continue to improve and make this change a part of your life. It is also important to talk to your doctor about any problems you have. Your doctor and care team may have helpful suggestions about how to stick to your lifestyle change(s).

Signs of heart attack & stroke

A stroke or heart attack can be very scary. Less blood flow to the heart is known as a heart attack. A stroke happens when oxygen levels in the brain are too low. It is important to know the signs of both heart attacks and strokes. Knowing these signs might save your life or the life of a loved one. More people survive strokes now than ever before, but it is still good to be prepared. Here are some signs of stroke and heart attack:

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Most heart attacks and strokes may be prevented. So, it is important to take care of your heart and overall health. High blood pressure, diabetes, smoking, and high body weight are all common risk factors for strokes and heart attacks. There are many things that you can do to take better care of your heart. Getting the right amount of sleep and exercise can be great places to start. Eating a healthy diet is important to maintain a healthy heart and body. A healthy, balanced diet is one filled with vegetables, fruits, whole grains, and nuts, for example.

It is also important to have regular visits with your doctor. At these visits, have your blood pressure, blood sugar, and lipids checked. These tests can give your doctor a sense of your overall heart health and risk level. Knowing your risk level will help you to take control of your health.

Exercise for HIV

Staying active is a must for good health. Regular exercise can make your muscles, joints, and bones stronger. It can boost your mood, give you more energy, and help you sleep better at night. It can even lower your risk for illnesses like diabetes, high cholesterol, weight gain, high blood pressure, and heart disease.

When you have human immunodeficiency virus (HIV), how you exercise will depend on many factors. Your age, experience, and interests all play a part. First, be sure to talk with your doctor about what kinds of exercise are best for you.

So, what should those with HIV know when planning to exercise? There is a lot you can do, but keep these things in mind:

- Try to exercise about 150 minutes every week. This can be 30 minutes each day, five times every week. Examples are walking, running, and biking.
- Strength exercises are great to do twice a week. Push-ups and sit-ups are good ones to try.
- Social activities are great sources of exercise. You may take a dance class or play on a sports team. They also help you meet with others.

Staying active is more than an exercise routine. Try to make active choices each day to keep yourself fit and healthy. Here are a few ideas:

- Take the stairs instead of the elevator.
- Go for daily walks. Ask a friend to join you!
- Don't sit for too long—stand up and move around every half hour.

Take control of your health and fitness. Balance exercise and rest. Still have questions about exercise and staying active? Give your program nurse a call!

Nutrition—eating healthy for HIV

Eating well is a key part of your total health. How you eat affects many things, like healing, energy, immune health, and sleep.

No food or diet can cure human immunodeficiency virus (HIV). Eating well can improve your overall health, however.

The first step is talking with your doctor about a plan for your diet. Here are some tips to help you make the right choices when eating:

- Be smart about drinks—some are better for you than others (water beats soda).
- Watch out for these foods and ingredients:
 - Salt (too much can be bad for your heart health)
 - Animal fats like butter and tropical oils like coconut and palm (limit to less than 10% of your calories per day; choose olive and canola oil instead)
 - Sugars (limit to less than 10% of your calories per day)

Here are some important diet and nutrition points you should think about with HIV:

- Eat a balanced diet high in vitamins, minerals, and other essential nutrients. This can help support the immune system. These foods include fruits, vegetables, whole grains, lean proteins, and healthy fats.
- Some HIV medicines may reduce your appetite. Talk to your doctor if you notice a change in how hungry you are.
- In general, avoid processed and sugary foods. Try to eat whole and unprocessed foods instead.
- Work with a dietitian. A dietitian can make a meal plan based on your needs and goals. This can help you manage other issues like your weight, diabetes, or high blood pressure.

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Hemophilia

Spring 2025

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Exercise for hemophilia

Staying active is a must for good health. Regular exercise can make your muscles, joints, and bones stronger. It can boost your mood, give you more energy, and help you sleep better at night. It can even lower your risk for illnesses like diabetes and heart disease.

When you have hemophilia, how you exercise will depend on many factors. Your age, experience, and interests all play a part. First, be sure to talk with your doctor about what kinds of exercise are best for you.

So, what should those with hemophilia know when planning to exercise? There is a lot you can do, but keep these things in mind:

- With your doctor, make an activity plan. Include any impacts on your factor dose. You can also speak with a trained physical therapist connected to a hemophilia treatment center (HTC).
- Stick to your doctor's hemophilia drug treatment.
- Check your personal history—do you have any muscle or joint issues from a past bleed?
- Choose your activities with care. Sports where you could fall or run into others are high-risk.

Staying active is more than an exercise routine. Try to make active choices each day to keep yourself fit and healthy. Here are a few ideas:

- Take the stairs instead of the elevator.
- Go for daily walks (ask a friend to join you!).
- Don't sit for too long—stand up and move around every half hour.

Still have questions about exercise and staying active? Give your program nurse a call!

Nutrition—eating healthy for hemophilia

Eating well is a key part of your total health. What and how you eat affects many things, like healing, energy, immune health, and sleep.

No food or diet can cure hemophilia. Eating well can improve your overall health, however. The first step is talking with your doctor about a plan for your diet. Here are some tips to help you make the right choices when eating:

- Avoid too much vitamin E, which could increase bleeding. Talk with your doctor before you start taking any supplements.
- Keep iron levels up. Try lean red meat, liver, poultry, leafy vegetables, beans, and raisins.
- Maintain a healthy weight. High body weight can put extra strain on joints and cause bleeds.
- Be smart about drinks—some are better for you than others (water beats sugary soda).
- Watch out for these foods and ingredients:
 - Salt (too much can be bad for your heart health)
 - Animal fats like butter and tropical oils like coconut and palm (limit to less than 10% of your calories per day; choose olive and canola oil instead)
 - Sugars (limit to less than 10% of your calories per day)
- Diets like the DASH diet help to control weight and high blood pressure. DASH (Dietary Approaches to Stop Hypertension) is a plant-focused, well-rounded diet. It uses fruits, vegetables, lean meat, fish, poultry, nuts, whole grains and healthy fats to balance your nutrition. Check out www.dashdiet.org for more info.

Still have questions about healthy eating? Ask your program nurse online or give them a call today!

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Myasthenia Gravis

Spring 2025

What are your goals for 2025?

Everyone can create goals they want to reach. But putting these plans into action is not always easy. Believing that you can is often the first step.

Many of you are doing this already. You have goals, you make a plan, and you stick to it. You schedule your doctor's visits well ahead of time. You take your medicines on time. You tackle challenges with confidence. If you have a problem, you keep trying until you work through it. If this is you, you deserve a pat on the back. Keep up the good work!

However, you may be new to goal setting. Start by asking yourself, "**What are my goals for the year?**" Ask your doctor the same question if you are not sure what your health or treatment goals should be. Or tell your doctor if you are struggling with a health goal you need to tackle. It's also good to think about goals that aren't related to your condition. Do you want to lose weight? Make more time for friends and family? Find a new job or earn a degree? Everyone is different—what matters is that the goal is something you want for yourself.

Once you have a few goals in mind, make a plan. How will you reach them? Try these tips to stay focused and positive:

- Take a real interest in what you plan to do.
- Do not dwell on setbacks.
- Look at problems as something to be mastered.
- Ask your care team and loved ones for support along the way.





Making lifestyle changes that last

Making lasting changes to your life can be hard. Do you want to exercise more? Are you trying to eat a healthier diet? Every January people spend time making New Year's resolutions. But by the middle of the year you realize that not enough progress has been made. With your condition you may have talked to your doctor about lifestyle changes. But, you may not know how to start making these changes or how to make them last.

Here are some steps that you can walk through to make a new change. First, **contemplation**. Think about what you want to change. This might mean asking questions like: why is it important for you to change? Second, **preparation**. You will need to prepare to make the change. You can do this by planning and goal setting. Third, **action**. This is where you carry out your plan. Every big change starts with bite-sized steps. So, remember to start small and be patient. Smart phone apps can be very helpful to set reminders and stay consistent. Fourth, **maintenance**. You have gotten used to your changes and have kept them up for more than 6 months.

Here are some tips to make your changes last:

- Start small.
- Set goals.
- Get support and ask for help.
- Track your progress.
- Celebrate progress.

Remember to be kind with yourself. If you slip up, don't give up. Just get back on track. Also remind yourself why you wanted to make this change in the first place. Over time you will continue to improve and make this change a part of your life. It is also important to talk to your doctor about any problems you have. Your doctor and care team may have helpful suggestions about how to stick to your lifestyle change(s).

Signs of heart attack & stroke

A stroke or heart attack can be very scary. Less blood flow to the heart is known as a heart attack. A stroke happens when oxygen levels in the brain are too low. It is important to know the signs of both heart attacks and strokes. Knowing these signs might save your life or the life of a loved one. More people survive strokes now than ever before, but it is still good to be prepared. Here are some signs of stroke and heart attack:

Stroke (Think "F.A.S.T.")	Heart Attacks
Face drooping	Chest pain
Arm weakness	Feeling weak or faint
Speech difficulty	Pain in the jaw, neck, or back
Time to call 911	Shortness of breath

Some other signs of stroke are numbress in your face, arms or legs, sudden confusion, or trouble walking or seeing. Women have mostly the same heart attack signs as men. But there may be some that are unique to them. Some women feel upper back pressure that feels like a rope being tied around them. Women can also feel shortness of breath, vomiting, or jaw pain. If you see any of the signs of a stroke or heart attack, call 911 right away.

Most heart attacks and strokes may be prevented. So, it is important to take care of your heart and overall health. High blood pressure, diabetes, smoking, and high body weight are all common risk factors for strokes and heart attacks. There are many things that you can do to take better care of your heart. Getting the right amount of sleep and exercise can be great places to start. Eating a healthy diet is important to maintain a healthy heart and body. A healthy, balanced diet is one filled with vegetables, fruits, whole grains, and nuts, for example.

It is also important to have regular visits with your doctor. At these visits, have your blood pressure, blood sugar, and lipids checked. These tests can give your doctor a sense of your overall heart health and risk level. Knowing your risk level will help you to take control of your health.

Exercise for myasthenia gravis

Staying active is a must for good health. Regular exercise can make your muscles, joints, and bones stronger. It can boost your mood, give you more energy, and help you sleep better at night. It can even lower your risk for illnesses like diabetes and heart disease.

When you have myasthenia gravis (MG), how you exercise will depend on many factors. Your age, experience, and interests all play a part. First, be sure to talk with your doctor about what kinds of exercise are best for you.

So, what should those with MG know when planning to exercise? Keep in mind:

- Your MG should be stable before starting any exercise program.
- Exercise can have these benefits for people with MG:
 - Can help you have better balance and lower your risk of having a fall.
 - Helps strengthen breathing muscles.
 - Can help you recover after a thymectomy. Talk to you doctor about exercise if you plan to have this type of surgery to treat your MG.

Types of exercise may include:

- Strength training—makes muscles and bones stronger. Two types are:
 - Weight-bearing—you support your weight against gravity. Examples: stair climbing, tai chi, walking.
 - Resistance—you use a force against yourself. Examples: lifting weights, stretch bands.
- Aerobic ("cardio")—raises your heart rate. Examples: jogging, fast walking, dancing, swimming, riding a stationary bike.
- Flexibility—stretches muscles, promotes range of motion. Examples: yoga, Pilates.

Staying active is more than an exercise routine. Try to make active choices each day to keep yourself fit and healthy. Here are a few ideas:

- Take the stairs instead of the elevator if you're able to do so safely.
- Go for daily walks (ask a friend to join you!).
- Don't sit for too long—stand up and move around every half hour.

Nutrition—eating healthy for myasthenia gravis

Eating well is a key part of your total health. What and how you eat affects many things, like healing, energy, immune health, and sleep. No food or diet can cure illness. Eating well can improve your overall health, however.

The first step is talking with your doctor about a plan for your diet. Here are some tips to help you make the right choices when eating:

- Watch out for these foods and ingredients:
 - Salt (too much can be bad for your heart health). In general, avoid frozen meals, canned soups, smoked and cured meats, and salty snacks.
 - Animal fats like butter and tropical oils like coconut and palm (limit to less than 10% of your calories per day; choose olive and canola oil instead)
 - Sugars (limit to <10% of your calories per day); choose water over soda.

Here are some diet and nutrition points to think about with myasthenia gravis (MG):

- Eat a variety of foods and strive to maintain a healthy weight.
- If you have trouble swallowing or choking, ask your doctor if seeing a dietitian might be needed. Working with a speech therapist might also be helpful.
- The Mediterranean diet may be one to check out (visit **myastheniagravis.org** and look up Mediterranean diet). This diet includes plenty of plant-based foods (fruits, vegetables, beans, nuts) and healthy fats like olive oil.
- If you take steroids such as prednisone, you're at higher risk of bone loss (osteoporosis) and fractures. Ask your doctor about how often you should have bone density testing. Be sure to eat foods with lots of calcium for bone health.

Still have questions about healthy eating? Ask your program nurse online or give them a call today!

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Multiple Sclerosis

Spring 2025

What are your goals for 2025?

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However, you may be new to goal setting. Start by asking yourself, "**What are my goals for the year?**" Ask your doctor the same question if you are not sure what your health or treatment goals should be. Or tell your doctor if you are struggling with a health goal you need to tackle. It's also good to think about goals that aren't related to your condition. Do you want to lose weight? Make more time for friends and family? Find a new job or earn a degree? Everyone is different—what matters is that the goal is something you want for yourself.

Once you have a few goals in mind, make a plan. How will you reach them? Try these tips to stay focused and positive:

- Take a real interest in what you plan to do.
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- Look at problems as something to be mastered.
- Ask your care team and loved ones for support along the way.





Making lifestyle changes that last

Making lasting changes to your life can be hard. Do you want to exercise more? Are you trying to eat a healthier diet? Every January people spend time making New Year's resolutions. But by the middle of the year you realize that not enough progress has been made. With your condition you may have talked to your doctor about lifestyle changes. But, you may not know how to start making these changes or how to make them last.

Here are some steps that you can walk through to make a new change. First, **contemplation**. Think about what you want to change. This might mean asking questions like: why is it important for you to change? Second, **preparation**. You will need to prepare to make the change. You can do this by planning and goal setting. Third, **action**. This is where you carry out your plan. Every big change starts with bite-sized steps. So, remember to start small and be patient. Smart phone apps can be very helpful to set reminders and stay consistent. Fourth, **maintenance**. You have gotten used to your changes and have kept them up for more than 6 months.

Here are some tips to make your changes last:

- Start small.
- Set goals.
- Get support and ask for help.
- Track your progress.
- Celebrate progress.

Remember to be kind with yourself. If you slip up, don't give up. Just get back on track. Also remind yourself why you wanted to make this change in the first place. Over time you will continue to improve and make this change a part of your life. It is also important to talk to your doctor about any problems you have. Your doctor and care team may have helpful suggestions about how to stick to your lifestyle change(s).

Signs of heart attack & stroke

A stroke or heart attack can be very scary. Less blood flow to the heart is known as a heart attack. A stroke happens when oxygen levels in the brain are too low. It is important to know the signs of both heart attacks and strokes. Knowing these signs might save your life or the life of a loved one. More people survive strokes now than ever before, but it is still good to be prepared. Here are some signs of stroke and heart attack:

Stroke (Think "F.A.S.T.")	Heart Attacks
Face drooping	Chest pain
Arm weakness	Feeling weak or faint
Speech difficulty	Pain in the jaw, neck, or back
Time to call 911	Shortness of breath

Some other signs of stroke are numbress in your face, arms or legs, sudden confusion, or trouble walking or seeing. Women have mostly the same heart attack signs as men. But there may be some that are unique to them. Some women feel upper back pressure that feels like a rope being tied around them. Women can also feel shortness of breath, vomiting, or jaw pain. If you see any of the signs of a stroke or heart attack, call 911 right away.

Most heart attacks and strokes may be prevented. So, it is important to take care of your heart and overall health. High blood pressure, diabetes, smoking, and high body weight are all common risk factors for strokes and heart attacks. There are many things that you can do to take better care of your heart. Getting the right amount of sleep and exercise can be great places to start. Eating a healthy diet is important to maintain a healthy heart and body. A healthy, balanced diet is one filled with vegetables, fruits, whole grains, and nuts, for example.

It is also important to have regular visits with your doctor. At these visits, have your blood pressure, blood sugar, and lipids checked. These tests can give your doctor a sense of your overall heart health and risk level. Knowing your risk level will help you to take control of your health.

Exercise for multiple sclerosis

Staying active is a must for good health. Regular exercise can make your muscles, joints, and bones stronger. It can boost your mood, give you more energy, and help you sleep better at night. It can help you feel better and think more clearly. It can even lower your risk for health issues like diabetes, thin bones, and heart disease.

When you have multiple sclerosis (MS), how you exercise will depend on many factors. Your age, abilities, and interests all play a part. Staying active has many benefits. First, be sure to talk with your doctor about what kinds of exercise are best for you.

So, what should those with MS know when planning to exercise?

- Exercise can help you build muscle strength. This can make it easier to do simple daily tasks. It can help you to feel less tired and lower your risk for a fall.
- Plan to exercise most when you feel best and rest when your MS is most active.
- Getting too hot can make MS symptoms worse. Here are things that can help:
 - Try swimming in a non-heated pool (water temperature around 82° F to 84° F).
 - Work out in an air-conditioned space.
 - Wear a cooling vest.
 - Make sure to stay hydrated; cold water can help your body stay cool.
 - Exercise in the morning when body and outdoor temperatures are lower.
- Stretch before and after exercise.
- Your doctor might advise physical therapy to get you started with a fitness plan.

Types of exercise may include:

- Strength training—Two types are:
 - Weight-bearing—you support your weight against gravity. Examples: walking, household chores.
 - Resistance—you use a force against yourself. Examples: lifting weights, using stretch bands.
- Aerobic ("cardio")—raises your heart rate. Examples: stationary bike, dancing, swimming.
- Flexibility—stretch muscles and promote range of motion. Examples: yoga, Pilates.

The National MS Society (**www.nationalmssociety.org**) offers exercise tips and videos. Still have questions about exercise and staying active? Give your program nurse a call!

Nutrition—eating healthy for multiple sclerosis

Eating well is a key part of your total health. What and how you eat affects many things, like healing, energy, immune health, and sleep. No food or diet can cure illness. Eating well can improve your overall health, however.

Here are some tips to help you make the right choices when eating:

- Watch out for these foods and ingredients:
 - Salt (too much can be bad for your heart health)
 - Animal fats like butter and tropical oils like coconut and palm (limit to less than 10% of your calories per day; choose olive and canola oil instead)
 - Sugars (limit to <10% of your calories per day)—choose water over soda

Ask your doctor about any special diet needs you may have because of your multiple sclerosis (MS). A dietitian can also help create a meal plan based on your needs and goals. Here are some tips to keep in mind when making diet choices:

- Strive to keep a steady and healthy body weight. This can help decrease the risk of MS activity and related disability.
- Obesity leads to greater risk for high blood pressure, high cholesterol, and diabetes. These can lead to other conditions such as heart disease and stroke.
- Most MS experts agree that a healthy diet affects the long-term health of the nervous system. The MS Society suggests that those with MS:
 - Prepare meals at home as much as possible.
 - Include colorful fresh fruits and vegetables daily.
 - Choose whole grains over refined grains.
 - Avoid or limit processed foods as much as possible.
- Diet affects the bacteria that live in the gut. This in turn affects the immune system. This may play a role in MS, although its exact effect is unknown.
- Be sure to include foods with plenty of vitamins, fatty acids, and amino acids. These all have direct effects on the immune system and the brain.

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Myositis

Spring 2025

What are your goals for 2025?

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However, you may be new to goal setting. Start by asking yourself, "**What are my goals for the year?**" Ask your doctor the same question if you are not sure what your health or treatment goals should be. Or tell your doctor if you are struggling with a health goal you need to tackle. It's also good to think about goals that aren't related to your condition. Do you want to lose weight? Make more time for friends and family? Find a new job or earn a degree? Everyone is different—what matters is that the goal is something you want for yourself.

Once you have a few goals in mind, make a plan. How will you reach them? Try these tips to stay focused and positive:

- Take a real interest in what you plan to do.
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Making lifestyle changes that last

Making lasting changes to your life can be hard. Do you want to exercise more? Are you trying to eat a healthier diet? Every January people spend time making New Year's resolutions. But by the middle of the year you realize that not enough progress has been made. With your condition you may have talked to your doctor about lifestyle changes. But, you may not know how to start making these changes or how to make them last.

Here are some steps that you can walk through to make a new change. First, **contemplation**. Think about what you want to change. This might mean asking questions like: why is it important for you to change? Second, **preparation**. You will need to prepare to make the change. You can do this by planning and goal setting. Third, **action**. This is where you carry out your plan. Every big change starts with bite-sized steps. So, remember to start small and be patient. Smart phone apps can be very helpful to set reminders and stay consistent. Fourth, **maintenance**. You have gotten used to your changes and have kept them up for more than 6 months.

Here are some tips to make your changes last:

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- Track your progress.
- Celebrate progress.

Remember to be kind with yourself. If you slip up, don't give up. Just get back on track. Also remind yourself why you wanted to make this change in the first place. Over time you will continue to improve and make this change a part of your life. It is also important to talk to your doctor about any problems you have. Your doctor and care team may have helpful suggestions about how to stick to your lifestyle change(s).

Signs of heart attack & stroke

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It is also important to have regular visits with your doctor. At these visits, have your blood pressure, blood sugar, and lipids checked. These tests can give your doctor a sense of your overall heart health and risk level. Knowing your risk level will help you to take control of your health.

Exercise for myositis

Staying active is a must for good health. Regular exercise can make your muscles, joints, and bones stronger. It can boost your mood, give you more energy, and help you sleep better at night. It can even lower your risk for illnesses like diabetes and heart disease.

When you have myositis, how you exercise will depend on many factors. Your age, experience, and interests all play a part. First, be sure to talk with your doctor about what kinds of exercise are best for you.

So, what should those with myositis know when planning to exercise? Keep in mind:

- With myositis, there may be some days when you aren't able to exercise. But when your myositis is under control, exercise has many great benefits.
- It may help you to have less fatigue and be more able to join in on social activities.
- Exercise strengthens your muscles. This can help reduce your risk of falling.
- It helps strengthen bones. This is important because medicines you may take to treat myositis, like prednisone, can give you a higher chance for osteoporosis.
- Staying active helps you maintain a healthy weight.
- It can help keep your immune system strong and help prevent infections.

Types of exercise you may choose may include:

- Strength training—makes muscles and bones stronger. Two types are:
 - Weight-bearing—you support your weight against gravity. Examples: stair climbing and walking.
 - Resistance—you use a force or weight against yourself. Example: lifting weights.
- Aerobic ("cardio")—raises your heart rate. Examples: running, dancing, swimming.
- Flexibility—stretches muscles, promotes range of motion. Examples: yoga, Pilates.

Staying active is more than an exercise routine. Try to make active choices each day to keep yourself fit and healthy. Here are a few ideas:

- Take the stairs instead of the elevator.
- Go for daily walks (ask a friend to join you!).
- Don't sit for too long—stand up and move around every half hour.

Nutrition—eating healthy for myositis

Eating well is a key part of your total health. What and how you eat affects many things, like healing, energy, immune health, and sleep. No food or diet can cure illness. Eating well can improve your overall health, however.

First, talk with your doctor about a plan for your diet. Here are some tips to help you:

- Be smart about drinks avoid drinking sugary soda, drink water instead.
- Watch out for these foods and ingredients:
 - Salt (too much can be bad for your heart health)
 - Animal fats like butter and tropical oils like coconut and palm (limit to less than 10% of your calories per day; choose olive and canola oil instead)

Here are some important diet and nutrition points you should think about with myositis:

- In general, avoid processed and fast foods, and high fructose corn syrup. Instead, opt for a wide variety of brightly colored fresh fruits and vegetables.
- Diabetes is a risk if you take steroids to treat myositis. Limit sugar to less than 10% of your calories per day. Keep your blood sugar levels in a normal range.
- The Myositis Association suggests the Mediterranean diet as a good option. (For details, visit **myositis.org** and search for Mediterranean diet.) This diet includes:
 - plenty of plant-based foods and healthy fats like olive oil.
 - whole grains, such as brown rice and bulgur wheat. Limit foods made with white flour and sugar (bread, pasta, and most packaged snack foods).
 - avocados and nuts, such as walnuts, cashews, and almonds.
 - fish to add omega-3 fatty acids in your diet. Include salmon, sardines, herring, or black cod.
 or take a fish oil supplement.
 - more vegetable protein and less meat (beans, soy, cheese, and yogurt) if you drink alcohol, red wine is preferable.
 - chocolate (in moderation). Choose the type with 70% cocoa or more.

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Spring 2025

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Making lifestyle changes that last

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Here are some steps that you can walk through to make a new change. First, **contemplation**. Think about what you want to change. This might mean asking questions like: why is it important for you to change? Second, **preparation**. You will need to prepare to make the change. You can do this by planning and goal setting. Third, **action**. This is where you carry out your plan. Every big change starts with bite-sized steps. So, remember to start small and be patient. Smart phone apps can be very helpful to set reminders and stay consistent. Fourth, **maintenance**. You have gotten used to your changes and have kept them up for more than 6 months.

Here are some tips to make your changes last:

- Start small.
- Set goals.
- Get support and ask for help.
- Track your progress.
- Celebrate progress.

Remember to be kind with yourself. If you slip up, don't give up. Just get back on track. Also remind yourself why you wanted to make this change in the first place. Over time you will continue to improve and make this change a part of your life. It is also important to talk to your doctor about any problems you have. Your doctor and care team may have helpful suggestions about how to stick to your lifestyle change(s).

Signs of heart attack & stroke

A stroke or heart attack can be very scary. Less blood flow to the heart is known as a heart attack. A stroke happens when oxygen levels in the brain are too low. It is important to know the signs of both heart attacks and strokes. Knowing these signs might save your life or the life of a loved one. More people survive strokes now than ever before, but it is still good to be prepared. Here are some signs of stroke and heart attack:

Stroke (Think "F.A.S.T.")	Heart Attacks
Face drooping	Chest pain
Arm weakness	Feeling weak or faint
Speech difficulty	Pain in the jaw, neck, or back
Time to call 911	Shortness of breath

Some other signs of stroke are numbress in your face, arms or legs, sudden confusion, or trouble walking or seeing. Women have mostly the same heart attack signs as men. But there may be some that are unique to them. Some women feel upper back pressure that feels like a rope being tied around them. Women can also feel shortness of breath, vomiting, or jaw pain. If you see any of the signs of a stroke or heart attack, call 911 right away.

Most heart attacks and strokes may be prevented. So, it is important to take care of your heart and overall health. High blood pressure, diabetes, smoking, and high body weight are all common risk factors for strokes and heart attacks. There are many things that you can do to take better care of your heart. Getting the right amount of sleep and exercise can be great places to start. Eating a healthy diet is important to maintain a healthy heart and body. A healthy, balanced diet is one filled with vegetables, fruits, whole grains, and nuts, for example.

It is also important to have regular visits with your doctor. At these visits, have your blood pressure, blood sugar, and lipids checked. These tests can give your doctor a sense of your overall heart health and risk level. Knowing your risk level will help you to take control of your health.

Exercise for Parkinson's disease

Staying active is a must for good health. Regular exercise can make your muscles, joints, and bones stronger. It can boost your mood, improve walking, give you more energy, help you sleep better at night, and maybe reduce falls. It can even lower your risk for illnesses like diabetes and heart disease.

When you have Parkinson's disease (PD), how you exercise will depend on many factors. Your age, experience, and interests all play a part. First, be sure to talk with your doctor about what kinds of exercise are best for you.

So, what should those with PD know when planning to exercise? Keep in mind:

- With PD, it can be hard to move around. Staying active, though, is one of the best things you can do to treat your PD and to stay well.
- Exercise can reduce the motor symptoms of PD by improving signals between the brain and nerves. This makes it easier for you to move and less likely to fall.
- It can also help slow memory loss.
- Staying active can help your digestion and help you maintain a healthy weight.
- Ask your doctor if working with a physical therapist would be right for you.

There are lots of types of exercises to consider:

- Strength training—makes muscles and bones stronger. Two types are:
 - Weight-bearing—you support your weight against gravity. Examples: stair climbing and walking.
 - Resistance—you use a force against yourself. Example: lifting weights.
- Aerobic ("cardio")—raises your heart rate. Examples: running, dancing, swimming.
- Flexibility—stretches muscles and promote range of motion. Examples: yoga, Pilates.

Staying active is more than an exercise routine. Try to make active choices each day to keep yourself fit and healthy. Here are a few ideas:

- Take the stairs instead of the elevator if you're able to do so safely.
- Go for daily walks (ask a friend to join you!).
- Don't sit for too long—stand up and move around every half hour.

Still have questions about staying active? Give your program nurse a call! Check out the Parkinson's Foundation website **www.parkinson.org** to find exercise classes in your area.

Nutrition—eating healthy for Parkinson's disease

Eating well is a key part of your total health. What and how you eat affects many things, like healing, energy, immune health, and sleep. No food or diet can cure illness. Eating well can improve your overall health, however.

The first step is talking with your doctor about a plan for your diet. Here are some tips to help you make the right choices when eating:

- Be smart about drinks—some are better for you than others (water beats soda).
- Watch out for these foods and ingredients:
 - Salt (too much can be bad for your heart health)
 - Animal fats like butter and tropical oils like coconut and palm (limit to less than 10% of your calories per day; choose olive and canola oil instead)
 - Sugars (limit to less than 10% of your calories per day)

Here are some diet and nutrition points to think about with Parkinson's disease (PD):

- There is no PD-specific diet. Instead strive to include a variety of whole grains, vegetables, fruits, and protein-rich foods.
- Include nuts, olive oil, fish, and eggs to the diet, for their healthy fats—these promote brain health.
- Drink enough water and eat fiber-rich foods to help prevent constipation.
- Avoid any foods that you find hard to swallow. For some, choose moist soft foods such as mashed potatoes, pasta, creamy soups, yogurt, custard, or pudding.
- Your doctor may suggest you see a speech therapist. They can teach you chewing tricks, like tucking your chin to your chest, to help you swallow better.
- Talk to your doctor about the best time to take PD medicines, such as levodopa. Protein-rich foods can interfere with how levodopa works. Ask if it's best to take meds on an empty stomach or with a small low-protein snack, such as crackers.

Still have questions about healthy eating? Ask your program nurse today!

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Rheumatoid Arthritis

Spring 2025

What are your goals for 2025?

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Many of you are doing this already. You have goals, you make a plan, and you stick to it. You schedule your doctor's visits well ahead of time. You take your medicines on time. You tackle challenges with confidence. If you have a problem, you keep trying until you work through it. If this is you, you deserve a pat on the back. Keep up the good work!

However, you may be new to goal setting. Start by asking yourself, "**What are my goals for the year?**" Ask your doctor the same question if you are not sure what your health or treatment goals should be. Or tell your doctor if you are struggling with a health goal you need to tackle. It's also good to think about goals that aren't related to your condition. Do you want to lose weight? Make more time for friends and family? Find a new job or earn a degree? Everyone is different—what matters is that the goal is something you want for yourself.

Once you have a few goals in mind, make a plan. How will you reach them? Try these tips to stay focused and positive:

- Take a real interest in what you plan to do.
- Do not dwell on setbacks.
- Look at problems as something to be mastered.
- Ask your care team and loved ones for support along the way.





Making lifestyle changes that last

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Here are some steps that you can walk through to make a new change. First, **contemplation**. Think about what you want to change. This might mean asking questions like: why is it important for you to change? Second, **preparation**. You will need to prepare to make the change. You can do this by planning and goal setting. Third, **action**. This is where you carry out your plan. Every big change starts with bite-sized steps. So, remember to start small and be patient. Smart phone apps can be very helpful to set reminders and stay consistent. Fourth, **maintenance**. You have gotten used to your changes and have kept them up for more than 6 months.

Here are some tips to make your changes last:

- Start small.
- Set goals.
- Get support and ask for help.
- Track your progress.
- Celebrate progress.

Remember to be kind with yourself. If you slip up, don't give up. Just get back on track. Also remind yourself why you wanted to make this change in the first place. Over time you will continue to improve and make this change a part of your life. It is also important to talk to your doctor about any problems you have. Your doctor and care team may have helpful suggestions about how to stick to your lifestyle change(s).

Signs of heart attack & stroke

A stroke or heart attack can be very scary. Less blood flow to the heart is known as a heart attack. A stroke happens when oxygen levels in the brain are too low. It is important to know the signs of both heart attacks and strokes. Knowing these signs might save your life or the life of a loved one. More people survive strokes now than ever before, but it is still good to be prepared. Here are some signs of stroke and heart attack:

Stroke (Think "F.A.S.T.")	Heart Attacks
Face drooping	Chest pain
Arm weakness	Feeling weak or faint
Speech difficulty	Pain in the jaw, neck, or back
Time to call 911	Shortness of breath

Some other signs of stroke are numbress in your face, arms or legs, sudden confusion, or trouble walking or seeing. Women have mostly the same heart attack signs as men. But there may be some that are unique to them. Some women feel upper back pressure that feels like a rope being tied around them. Women can also feel shortness of breath, vomiting, or jaw pain. If you see any of the signs of a stroke or heart attack, call 911 right away.

Most heart attacks and strokes may be prevented. So, it is important to take care of your heart and overall health. High blood pressure, diabetes, smoking, and high body weight are all common risk factors for strokes and heart attacks. There are many things that you can do to take better care of your heart. Getting the right amount of sleep and exercise can be great places to start. Eating a healthy diet is important to maintain a healthy heart and body. A healthy, balanced diet is one filled with vegetables, fruits, whole grains, and nuts, for example.

It is also important to have regular visits with your doctor. At these visits, have your blood pressure, blood sugar, and lipids checked. These tests can give your doctor a sense of your overall heart health and risk level. Knowing your risk level will help you to take control of your health.

Exercise for RA

Staying active is a must for good health. Regular exercise can make your muscles, joints, and bones stronger. It can boost your mood, give you more energy, and help you sleep better at night. It can even lower your risk for illnesses like diabetes and heart disease.

When you have rheumatoid arthritis (RA), how you exercise will depend on many factors. Your age, experience, and interests all play a part. First, be sure to talk with your doctor about what kinds of exercise are best for you.

So, what should those with RA know when planning to exercise? There is a lot you can do, but keep these things in mind:

- Listen to your body. Exercise when you are in remission or free from your RA symptoms.
- Stay hydrated. Drink water before, during, and after exercise. This can help your joints move better during exercise.
- Use assistive devices if needed. These are tools that can help you do daily activities.
- Talk to your doctor about wearing the right footwear or other devices. This can help to reduce stress on your joints.
- You can find more examples of exercises to try on the Arthritis Foundation website: **www.arthritis.org**.

Staying active is more than an exercise routine. Try to make active choices each day to keep yourself fit and healthy. Here are a few ideas:

- Take the stairs instead of the elevator.
- Go for daily walks (ask a friend to join you!).
- Don't sit for too long—stand up and move around every half hour.

Still have questions about exercise and staying active? Give your program nurse a call!

Nutrition—eating healthy for RA

Eating well is a key part of your total health. What and how you eat affects many things, like healing, energy, immune health, and sleep.

No food or diet can cure illness. Eating well can improve your overall health, however. Sometimes, it can also help to lessen some symptoms of illness.

The first step is talking with your doctor about a plan for your diet. Here are some tips to help you make the right choices when eating:

- Be smart about drinks—some are better for you than others (water beats soda).
- Watch out for these foods and ingredients:
 - Salt (too much can be bad for your heart health)
 - Animal fats like butter and tropical oils like coconut and palm (limit to less than 10% of your calories per day; choose olive and canola oil instead)
 - Sugars (limit to less than 10% of your calories per day)

Here are some important diet and nutrition points to think about with rheumatoid arthritis (RA):

- Eat a balanced diet. Some foods may make swelling better or worse. You should eat foods such as fruits, vegetables, whole grains, lean proteins, and healthy fats. These foods are rich in antioxidants and other nutrients.
- Limit processed foods. Processed foods such as fast food, sugary snacks, and white bread are high in sugar and unhealthy fats. These foods can worsen inflammation and lead to weight gain.
- Work with a dietitian to make a meal plan based on your needs and goals. They can also help you learn more about how to maintain a healthy diet and manage RA symptoms.
- Work with your doctor to be screened for high blood pressure, diabetes, and other disorders.

Still have questions about healthy eating? Ask your program nurse online or give them a call today!

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Sickle Cell Disease

Spring 2025

What are your goals for 2025?

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Many of you are doing this already. You have goals, you make a plan, and you stick to it. You schedule your doctor's visits well ahead of time. You take your medicines on time. You tackle challenges with confidence. If you have a problem, you keep trying until you work through it. If this is you, you deserve a pat on the back. Keep up the good work!

However, you may be new to goal setting. Start by asking yourself, "**What are my goals for the year?**" Ask your doctor the same question if you are not sure what your health or treatment goals should be. Or tell your doctor if you are struggling with a health goal you need to tackle. It's also good to think about goals that aren't related to your condition. Do you want to lose weight? Make more time for friends and family? Find a new job or earn a degree? Everyone is different—what matters is that the goal is something you want for yourself.

Once you have a few goals in mind, make a plan. How will you reach them? Try these tips to stay focused and positive:

- Take a real interest in what you plan to do.
- Do not dwell on setbacks.
- Look at problems as something to be mastered.
- Ask your care team and loved ones for support along the way.





Making lifestyle changes that last

Making lasting changes to your life can be hard. Do you want to exercise more? Are you trying to eat a healthier diet? Every January people spend time making New Year's resolutions. But by the middle of the year you realize that not enough progress has been made. With your condition you may have talked to your doctor about lifestyle changes. But, you may not know how to start making these changes or how to make them last.

Here are some steps that you can walk through to make a new change. First, **contemplation**. Think about what you want to change. This might mean asking questions like: why is it important for you to change? Second, **preparation**. You will need to prepare to make the change. You can do this by planning and goal setting. Third, **action**. This is where you carry out your plan. Every big change starts with bite-sized steps. So, remember to start small and be patient. Smart phone apps can be very helpful to set reminders and stay consistent. Fourth, **maintenance**. You have gotten used to your changes and have kept them up for more than 6 months.

Here are some tips to make your changes last:

- Start small.
- Set goals.
- Get support and ask for help.
- Track your progress.
- Celebrate progress.

Remember to be kind with yourself. If you slip up, don't give up. Just get back on track. Also remind yourself why you wanted to make this change in the first place. Over time you will continue to improve and make this change a part of your life. It is also important to talk to your doctor about any problems you have. Your doctor and care team may have helpful suggestions about how to stick to your lifestyle change(s).

Signs of heart attack & stroke

A stroke or heart attack can be very scary. Less blood flow to the heart is known as a heart attack. A stroke happens when oxygen levels in the brain are too low. It is important to know the signs of both heart attacks and strokes. Knowing these signs might save your life or the life of a loved one. More people survive strokes now than ever before, but it is still good to be prepared. Here are some signs of stroke and heart attack:

Stroke (Think "F.A.S.T.")	Heart Attacks
Face drooping	Chest pain
Arm weakness	Feeling weak or faint
Speech difficulty	Pain in the jaw, neck, or back
Time to call 911	Shortness of breath

Some other signs of stroke are numbress in your face, arms or legs, sudden confusion, or trouble walking or seeing. Women have mostly the same heart attack signs as men. But there may be some that are unique to them. Some women feel upper back pressure that feels like a rope being tied around them. Women can also feel shortness of breath, vomiting, or jaw pain. If you see any of the signs of a stroke or heart attack, call 911 right away.

Most heart attacks and strokes may be prevented. So, it is important to take care of your heart and overall health. High blood pressure, diabetes, smoking, and high body weight are all common risk factors for strokes and heart attacks. There are many things that you can do to take better care of your heart. Getting the right amount of sleep and exercise can be great places to start. Eating a healthy diet is important to maintain a healthy heart and body. A healthy, balanced diet is one filled with vegetables, fruits, whole grains, and nuts, for example.

It is also important to have regular visits with your doctor. At these visits, have your blood pressure, blood sugar, and lipids checked. These tests can give your doctor a sense of your overall heart health and risk level. Knowing your risk level will help you to take control of your health.

Exercise for sickle cell disease

Staying active is a must for good health. Regular exercise can make your muscles, joints, and bones stronger. It can boost your mood, give you more energy, and help you sleep better at night. It can even lower your risk for illnesses like diabetes and heart disease.

When you have sickle cell disease, how you exercise will depend on many factors. Your age, experience, and interests all play a part. First, be sure to talk with your doctor about what kinds of exercise are best for you.

So, what should those with sickle cell know when planning to exercise? There is a lot you can do, but keep these things in mind:

- Start slowly. Pick a pace that is comfortable and safe with your pain crisis trigger.
- Don't get too hot or cold. When you can, exercise in an air-conditioned area. Avoid quick changes in temperature, such as swimming in cold water.
- If you do swim, dry off, shower in warm water, and dress quickly. This can help you stay warm and avoid triggering a pain crisis.
- Drink lots of water before, during, and after exercise.
- Do not hike at high altitudes or swim a long time under water. This can cause red blood cells to sickle.
- Those with an enlarged spleen should avoid contact sports.
- Rest during and between exercise routines.
- Stick to your medicines that treat your sickle cell disease.

Staying active is more than an exercise routine. Try to make active choices each day to keep yourself fit and healthy. Here are a few ideas:

- Take the stairs instead of the elevator.
- Go for daily walks (ask a friend to join you!).
- Don't sit for too long—stand up and move around every half hour.

Still have questions about exercise and staying active? Give your program nurse a call!

Nutrition—eating healthy for sickle cell disease

Eating well is a key part of your total health. What and how you eat affects many things, like healing, energy, immune health, and sleep.

No food or diet can cure sickle cell disease. Eating well can improve your overall health, however. The first step is talking with your doctor about a plan for your diet. Here are some tips to help you make the right choices when eating:

- Be smart about drinks—some are better for you than others (water beats sugary soda).
- Drink plenty of water. Staying hydrated can help prevent blood cells from sickling. Ask your doctor how much water you should drink each day.
- Watch out for these foods and ingredients:
 - Salt (too much can be bad for your heart health)
 - Animal fats like butter and tropical oils like coconut and palm (limit to less than 10% of your calories per day; choose olive and canola oil instead)
 - Sugars (limit to less than 10% of your calories per day)
- Diets like the DASH diet help to control weight and high blood pressure. DASH (Dietary Approaches to Stop Hypertension) is a plant-focused, well-rounded diet. It uses fruits, vegetables, lean meat, fish, poultry, nuts, whole grains and healthy fats to balance your nutrition. Check out www.dashdiet.org for more info.

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Care Connections[®]

Scleroderma

Spring 2025

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Signs of heart attack & stroke

A stroke or heart attack can be very scary. Less blood flow to the heart is known as a heart attack. A stroke happens when oxygen levels in the brain are too low. It is important to know the signs of both heart attacks and strokes. Knowing these signs might save your life or the life of a loved one. More people survive strokes now than ever before, but it is still good to be prepared. Here are some signs of stroke and heart attack:

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Most heart attacks and strokes may be prevented. So, it is important to take care of your heart and overall health. High blood pressure, diabetes, smoking, and high body weight are all common risk factors for strokes and heart attacks. There are many things that you can do to take better care of your heart. Getting the right amount of sleep and exercise can be great places to start. Eating a healthy diet is important to maintain a healthy heart and body. A healthy, balanced diet is one filled with vegetables, fruits, whole grains, and nuts, for example.

It is also important to have regular visits with your doctor. At these visits, have your blood pressure, blood sugar, and lipids checked. These tests can give your doctor a sense of your overall heart health and risk level. Knowing your risk level will help you to take control of your health.

Exercise for scleroderma

Staying active is a must for good health. Regular exercise can make your muscles, joints, and bones stronger. It can boost your mood, give you more energy, and help you sleep better. It can even lower your risk for illnesses like high blood pressure and heart disease.

When you have scleroderma, how you exercise will depend on many factors. Your age, abilities, and interests all play a part. First, be sure to talk with your doctor about what kinds of exercise are best for you.

What should those with scleroderma know when planning to exercise? Keep in mind:

- Daily stretching exercises of the hands and face can be especially helpful. These can help preserve grip strength and motion in the hands and improve facial flexibility for oral care.
- Exercise can help keep you maintain a normal weight. This can help reduce the risk of conditions that could make scleroderma worse (such as heart disease, diabetes).
- Staying active helps to keep the immune system strong to avoid infections.

Types of exercise to discuss with your doctor or physical therapist include:

- Strength training—Two types are:
 - Weight-bearing—you support your weight against gravity. Examples: stair climbing and walking.
 - Resistance—you use a force against yourself. Example: lifting weights, using stretch bands.
- Aerobic ("cardio")—raises your heart rate. Examples: walking, dancing, swimming.
- Flexibility—stretches muscles, promotes range of motion. Examples: yoga, Pilates.

Staying active is more than an exercise routine. Try to make active choices each day to keep yourself fit and healthy. Here are a few ideas:

- Take the stairs instead of the elevator if you're able to do so safely.
- Go for daily walks (ask a friend to join you!).
- Don't sit for too long—stand up and move around every half hour.

The National Scleroderma Foundation (**www.scleroderma.org**) offers tips on exercise. Still have questions about exercise and staying active? Give your program nurse a call!

Nutrition—eating healthy for scleroderma

Eating well is a key part of your total health. What and how you eat affects many things, like healing, energy, immune health, and sleep. No food or diet can cure illness. Eating well can improve your overall health, however.

The first step is talking with your doctor about a plan for your diet. Here are some general tips to help you make the right choices when eating:

- Be smart about drinks—some are better for you than others (water beats soda).
- Watch out for these foods and ingredients:
 - Salt (too much can be bad for your heart health)
 - Animal fats like butter and tropical oils like coconut and palm (limit to less than 10% of your calories per day; choose olive and canola oil instead)
 - Sugars (limit to less than 10% of your calories per day)

There's no specific "scleroderma diet." You should simply strive to eat a balanced diet.

- Include foods that provide energy, protein, vitamins, and minerals. With scleroderma, you are at increased risk of malnutrition. This may occur if you are not able to eat enough healthy foods. Or it can result from poor absorption of nutrients from the gastrointestinal (GI) tract. Ask your doctor about any concerns you may have. Your doctor may suggest you see a dietitian.
- Scleroderma can lead to heartburn and acid reflux. Eating small frequent meals can help this problem and increase nutrient intake.
- Choose brightly colored fruits and vegetables to increase antioxidant intake. These can help fight inflammation.
- Include fatty fish, ground flaxseeds and walnuts for their omega-3 fatty acids. Nuts, seeds and extra virgin olive oil are also good choices for this.
- Try blending fresh fruits and vegetables into smoothies. This can help if you have problems chewing or swallowing. Other good choices include soft, moist foods such as cottage cheese, scrambled eggs, or yogurt.

Still have questions about healthy eating? Ask your program nurse today!

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Care Connections[®]

Lupus

Spring 2025

What are your goals for 2025?

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Many of you are doing this already. You have goals, you make a plan, and you stick to it. You schedule your doctor's visits well ahead of time. You take your medicines on time. You tackle challenges with confidence. If you have a problem, you keep trying until you work through it. If this is you, you deserve a pat on the back. Keep up the good work!

However, you may be new to goal setting. Start by asking yourself, "**What are my goals for the year?**" Ask your doctor the same question if you are not sure what your health or treatment goals should be. Or tell your doctor if you are struggling with a health goal you need to tackle. It's also good to think about goals that aren't related to your condition. Do you want to lose weight? Make more time for friends and family? Find a new job or earn a degree? Everyone is different—what matters is that the goal is something you want for yourself.

Once you have a few goals in mind, make a plan. How will you reach them? Try these tips to stay focused and positive:

- Take a real interest in what you plan to do.
- Do not dwell on setbacks.
- Look at problems as something to be mastered.
- Ask your care team and loved ones for support along the way.





Making lifestyle changes that last

Making lasting changes to your life can be hard. Do you want to exercise more? Are you trying to eat a healthier diet? Every January people spend time making New Year's resolutions. But by the middle of the year you realize that not enough progress has been made. With your condition you may have talked to your doctor about lifestyle changes. But, you may not know how to start making these changes or how to make them last.

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Here are some tips to make your changes last:

- Start small.
- Set goals.
- Get support and ask for help.
- Track your progress.
- Celebrate progress.

Remember to be kind with yourself. If you slip up, don't give up. Just get back on track. Also remind yourself why you wanted to make this change in the first place. Over time you will continue to improve and make this change a part of your life. It is also important to talk to your doctor about any problems you have. Your doctor and care team may have helpful suggestions about how to stick to your lifestyle change(s).

Signs of heart attack & stroke

A stroke or heart attack can be very scary. Less blood flow to the heart is known as a heart attack. A stroke happens when oxygen levels in the brain are too low. It is important to know the signs of both heart attacks and strokes. Knowing these signs might save your life or the life of a loved one. More people survive strokes now than ever before, but it is still good to be prepared. Here are some signs of stroke and heart attack:

Stroke (Think "F.A.S.T.")	Heart Attacks
Face drooping	Chest pain
Arm weakness	Feeling weak or faint
Speech difficulty	Pain in the jaw, neck, or back
Time to call 911	Shortness of breath

Some other signs of stroke are numbress in your face, arms or legs, sudden confusion, or trouble walking or seeing. Women have mostly the same heart attack signs as men. But there may be some that are unique to them. Some women feel upper back pressure that feels like a rope being tied around them. Women can also feel shortness of breath, vomiting, or jaw pain. If you see any of the signs of a stroke or heart attack, call 911 right away.

Most heart attacks and strokes may be prevented. So, it is important to take care of your heart and overall health. High blood pressure, diabetes, smoking, and high body weight are all common risk factors for strokes and heart attacks. There are many things that you can do to take better care of your heart. Getting the right amount of sleep and exercise can be great places to start. Eating a healthy diet is important to maintain a healthy heart and body. A healthy, balanced diet is one filled with vegetables, fruits, whole grains, and nuts, for example.

It is also important to have regular visits with your doctor. At these visits, have your blood pressure, blood sugar, and lipids checked. These tests can give your doctor a sense of your overall heart health and risk level. Knowing your risk level will help you to take control of your health.

Exercise for lupus

Staying active is a must for good health. Regular exercise can make your muscles, joints, and bones stronger. It can boost your mood, give you more energy, and help you sleep better at night. It can even lower your risk for illnesses like diabetes, high blood pressure, and heart disease.

When you have lupus, how you exercise will depend on many factors. Your age, abilities, and interests all play a part. First, be sure to talk with your doctor about what kinds of exercise are best for you.

So, what should those with lupus know when planning to exercise? Keep in mind:

- With lupus, exercise can be a challenge sometimes because of a flare (times when your lupus becomes very active).
- You may have problems with strength and endurance, joint pain, and fatigue.
- Letting your body rest until the flare is controlled may be best. But sometimes getting even a small amount of movement can help.
- Exercise can help you reduce joint strain, lower chances of flares, and reduce pain. It can help keep your immune system strong to prevent infections.
- Exercise can help you keep your weight in check. Extra weight can raise your risk of health problems like diabetes, high blood pressure, or cancer.

Types of exercise you can do include:

- Strength training—makes muscles and bones stronger. Two types are:
 - Weight-bearing—you support your weight against gravity. Examples: stair climbing and walking.
 - Resistance—you use a force against yourself. Example: lifting weights.
- Aerobic ("cardio")—raise your heart rate. Examples: bicycling, dancing, swimming.
- Flexibility—stretch muscles and promote range of motion. Examples: yoga, Pilates.

Staying active is more than an exercise routine. Try to make active choices each day to keep yourself fit and healthy. Here are a few ideas:

- Take the stairs instead of the elevator if you're able to do so safely.
- Go for daily walks (ask a friend to join you!).
- Don't sit for too long—stand up and move around every half hour.

Nutrition—eating healthy for lupus

Eating well is a key part of your total health. What and how you eat affects many things, like healing, energy, immune health, and sleep. No food or diet can cure illness. Eating well can improve your overall health, however.

First, talk with your doctor about a plan for your diet. Here are some tips to help you:

- Be smart about drinks—some are better for you than others (water beats soda).
- Watch out for these foods and ingredients:
 - Salt (too much can be bad for your heart health)
 - Animal fats like butter and tropical oils like coconut and palm (limit to less than 10% of your calories per day; choose olive and canola oil instead)
 - Sugars (limit to less than 10% of your calories per day)

Here are some important diet and nutrition points you should think about with lupus:

- Healthy eating can help manage other conditions like high blood pressure.
- There's no special "lupus diet." Just aim for a balanced diet with foods you enjoy. Include lots of fruits and vegetables. Choose whole grains, and healthy proteins, such as lean meats, poultry, beans, and eggs.
- Alfalfa may trigger lupus symptoms; you may want to avoid alfalfa sprouts. Talk to your doctor if any other foods seem to increase your lupus symptoms.
- Since lupus raises your risk for osteoporosis, eat foods with lots of calcium for bone health. Include leafy greens, dairy foods and whole-grain cereals. For heart health, eat foods with omega-3 fatty acids. These are found in fatty fish (salmon, mackerel, and sardines), nuts and seeds.
- If you don't eat any animal foods, you may want to take a vitamin B12 supplement. But supplements can interact with your lupus medicines. So talk with your doctor before you start taking any supplements.
- Limit alcohol to one drink or less a day. Alcohol can also interact with some medicines. So ask your doctor if you need to avoid alcohol.

Still have questions about healthy eating? Ask your program nurse today!

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Care Connections[®]

Epilepsy

Spring 2025

What are your goals for 2025?

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However, you may be new to goal setting. Start by asking yourself, "**What are my goals for the year?**" Ask your doctor the same question if you are not sure what your health or treatment goals should be. Or tell your doctor if you are struggling with a health goal you need to tackle. It's also good to think about goals that aren't related to your condition. Do you want to lose weight? Make more time for friends and family? Find a new job or earn a degree? Everyone is different—what matters is that the goal is something you want for yourself.

Once you have a few goals in mind, make a plan. How will you reach them? Try these tips to stay focused and positive:

- Take a real interest in what you plan to do.
- Do not dwell on setbacks.
- Look at problems as something to be mastered.
- Ask your care team and loved ones for support along the way.





Making lifestyle changes that last

Making lasting changes to your life can be hard. Do you want to exercise more? Are you trying to eat a healthier diet? Every January people spend time making New Year's resolutions. But by the middle of the year you realize that not enough progress has been made. With your condition you may have talked to your doctor about lifestyle changes. But, you may not know how to start making these changes or how to make them last.

Here are some steps that you can walk through to make a new change. First, **contemplation**. Think about what you want to change. This might mean asking questions like: why is it important for you to change? Second, **preparation**. You will need to prepare to make the change. You can do this by planning and goal setting. Third, **action**. This is where you carry out your plan. Every big change starts with bite-sized steps. So, remember to start small and be patient. Smart phone apps can be very helpful to set reminders and stay consistent. Fourth, **maintenance**. You have gotten used to your changes and have kept them up for more than 6 months.

Here are some tips to make your changes last:

- Start small.
- Set goals.
- Get support and ask for help.
- Track your progress.
- Celebrate progress.

Remember to be kind with yourself. If you slip up, don't give up. Just get back on track. Also remind yourself why you wanted to make this change in the first place. Over time you will continue to improve and make this change a part of your life. It is also important to talk to your doctor about any problems you have. Your doctor and care team may have helpful suggestions about how to stick to your lifestyle change(s).

Signs of heart attack & stroke

A stroke or heart attack can be very scary. Less blood flow to the heart is known as a heart attack. A stroke happens when oxygen levels in the brain are too low. It is important to know the signs of both heart attacks and strokes. Knowing these signs might save your life or the life of a loved one. More people survive strokes now than ever before, but it is still good to be prepared. Here are some signs of stroke and heart attack:

Stroke (Think "F.A.S.T.")	Heart Attacks
Face drooping	Chest pain
Arm weakness	Feeling weak or faint
Speech difficulty	Pain in the jaw, neck, or back
Time to call 911	Shortness of breath

Some other signs of stroke are numbress in your face, arms or legs, sudden confusion, or trouble walking or seeing. Women have mostly the same heart attack signs as men. But there may be some that are unique to them. Some women feel upper back pressure that feels like a rope being tied around them. Women can also feel shortness of breath, vomiting, or jaw pain. If you see any of the signs of a stroke or heart attack, call 911 right away.

Most heart attacks and strokes may be prevented. So, it is important to take care of your heart and overall health. High blood pressure, diabetes, smoking, and high body weight are all common risk factors for strokes and heart attacks. There are many things that you can do to take better care of your heart. Getting the right amount of sleep and exercise can be great places to start. Eating a healthy diet is important to maintain a healthy heart and body. A healthy, balanced diet is one filled with vegetables, fruits, whole grains, and nuts, for example.

It is also important to have regular visits with your doctor. At these visits, have your blood pressure, blood sugar, and lipids checked. These tests can give your doctor a sense of your overall heart health and risk level. Knowing your risk level will help you to take control of your health.

Exercise for epilepsy

Staying active is a must for good health. Regular exercise can make your muscles, joints, and bones stronger. It can boost your mood, give you more energy, and help you sleep better at night. It can even lower your risk for illnesses like diabetes and heart disease.

When you have epilepsy, how you exercise will depend on many factors. Your age, experience, and interests all play a part. Your seizure type and how often they occur will affect the type of exercise that is safe. Talk with your doctor about what kinds of exercise are best for you.

Regular exercise may also help to prevent seizures. So, what should those with epilepsy know when planning to exercise? There is a lot you can do, but keep these things in mind:

- Exercise with a friend. This can keep you motivated. They can also help if you have a seizure.
- Ask your doctor if you need a First Aid for Seizures wallet card with you during exercise.
- Swimming exercises are high risk for those with epilepsy. If you swim in a pool, alert the lifeguard that you have epilepsy. Never swim alone. If your seizures are uncontrolled, swimming may not be a good exercise for you.
- Avoid high risk sports like rock climbing, scuba diving, and contact sports.

Along with regular exercise, make active choices each day to keep yourself fit and healthy. Here are a few ideas:

- Take the stairs instead of the elevator.
- Go for daily walks (ask a friend to join you).
- Don't sit for too long—stand up and move around every half hour.

Still have questions about exercise and staying active? Give your program nurse a call!

Nutrition—healthy eating for people with epilepsy

Eating well is important for a healthy mind and body. What and how you eat affects your energy level, healing, immune health, and sleep.

No food or diet can cure epilepsy. Eating well can improve your overall health, however. The first step is talking with your doctor about a diet plan. Here are some tips to help you make the right choices when eating:

- Be smart about drinks—some are better for you than others (water beats sugary soda).
- Watch out for these foods and ingredients:
 - Salt (too much can be bad for your heart health)
 - Animal fats like butter
 - Tropical oils like coconut and palm (limit to less than 10% of your calories per day; choose olive and canola oil instead)

Here are some healthy eating points you should think about if you have epilepsy:

- Are you on a special diet for your epilepsy, such as the ketogenic (keto) diet? If so, follow it exactly as outlined by your dietitian and doctor over the advice of others.
- Have you not tried the keto diet yet? Are you still having seizures? Ask your doctor if the keto diet is right for you. This diet is very low in carbs and high in fats. It can reduce seizures in many people with epilepsy.
- Cut out foods with a high level of simple sugars.
- Eat whole, natural foods. These are foods with little or no processing, few ingredients, and high nutrients. Avoid processed foods with artificial ingredients.

Still have questions about healthy eating? Ask your program nurse online or give them a call!

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Ulcerative Colitis

Spring 2025

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Remember to be kind with yourself. If you slip up, don't give up. Just get back on track. Also remind yourself why you wanted to make this change in the first place. Over time you will continue to improve and make this change a part of your life. It is also important to talk to your doctor about any problems you have. Your doctor and care team may have helpful suggestions about how to stick to your lifestyle change(s).

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Most heart attacks and strokes may be prevented. So, it is important to take care of your heart and overall health. High blood pressure, diabetes, smoking, and high body weight are all common risk factors for strokes and heart attacks. There are many things that you can do to take better care of your heart. Getting the right amount of sleep and exercise can be great places to start. Eating a healthy diet is important to maintain a healthy heart and body. A healthy, balanced diet is one filled with vegetables, fruits, whole grains, and nuts, for example.

It is also important to have regular visits with your doctor. At these visits, have your blood pressure, blood sugar, and lipids checked. These tests can give your doctor a sense of your overall heart health and risk level. Knowing your risk level will help you to take control of your health.

Exercise for ulcerative colitis

Staying active is a must for good health. Regular exercise can make your muscles, joints, and bones stronger. It can boost your mood, give you more energy, and help you sleep better at night. It can even lower your risk for illnesses like diabetes and heart disease.

When you have ulcerative colitis (UC), how you exercise will depend on many factors. Your age, experience, and interests all play a part. First, be sure to talk with your doctor about what kinds of exercise are best for you.

So, what should those with UC know when planning to exercise? There is a lot you can do, but keep these things in mind:

- Stay hydrated: Drink water before, during, and after exercise.
- Let your body rest. Hold off on exercising if you are not feeling well or having a flare-up with your UC. Flares may limit your exercise routines. Speak with your doctor about what to do when this happens.
- Plan exercises around bathroom breaks. You may need to take short breaks during exercise.

Staying active is more than an exercise routine. Try to make active choices each day to keep yourself fit and healthy. Here are a few ideas:

- Take the stairs instead of the elevator.
- Go for daily walks (ask a friend to join you!).
- Don't sit for too long—stand up and move around every half hour.

You can find more examples of exercises to try through the Crohn's and Colitis Foundation at **www.crohnscolitisfoundation.org**.

Still have questions about exercise and staying active? Give your program nurse a call!

Nutrition—eating healthy for ulcerative colitis

Eating well is a key part of your total health. What and how you eat affects many things, like healing, energy, immune health, and sleep.

No food or diet can cure illness. Eating well may improve your overall health, however. Sometimes, it can also help to lessen some symptoms of illness.

The first step is talking with your doctor about a plan for your diet. Here are some tips to help you make the right choices when eating:

- Be smart about drinks—some are better for you than others (water beats soda).
- Watch out for these foods and ingredients:
 - Salt (too much can be bad for your heart health)
 - Animal fats like butter and tropical oils like coconut and palm (limit to less than 10% of your calories per day; choose olive and canola oil instead)
 - Sugars (limit to less than 10% of your calories per day)

Here are some important diet and nutrition points you should think about with ulcerative colitis (UC):

- Eat a balanced diet. You should eat a diet filled with foods such as fruits, vegetables, whole grains, lean proteins, and healthy fats. During a flare you may have trouble digesting high-fiber foods such as fruits, vegetables, and whole grains.
- You should drink plenty of fluids, including water. Avoid alcohol and sugary drinks.
- Avoid trigger foods. There may be some foods that worsen your UC symptoms. These may include spicy foods, caffeine, and alcohol. You can use a food diary to track any foods that may make your symptoms worse.
- Work with a dietitian. A dietitian can make a meal plan based on your needs and goals. You may also need to take calcium supplements. You can discuss this more with your doctor or dietitian.

Still have questions about healthy eating? Ask your program nurse online or give them a call today!

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