

## Summer skin care tips

Sun, heat, and damp or dry weather can all affect your skin. Over years, skin damage from ultraviolet (UV) rays from the sun builds up. This is the most common cause of skin cancer. All skin types are at risk, no matter race or ethnicity. Some medicines can also make skin sensitive. Talk to your doctor about your skin damage risk.

Keep yourself safe during the summer with these easy tips:

- Wear sunscreen on your face, arms, and legs. Don't rely only on clothing to protect you. UV rays can still harm you if it is cloudy. Pick sunscreen with a sun protection factor (SPF) of 30 or more. It should block both UVA and UVB.
- Drink water throughout the day. Start before you go out in the sun.
- Stick to the shade outside. You can carry an umbrella even when it's sunny.
- Wear long-sleeved shirts and pants. These can be lightweight fabrics, so you don't get too hot. Look for clothing with UVA/UVB protection. Wear sunglasses to protect your eyes and hats for your head.
- Warm weather also means a higher risk of bugs carrying illness, like ticks and mosquitos. Bug spray can help protect you. Always follow the instructions on the label.

**Removing ticks:** 1) Grasp the tick close to the skin with tweezers—pull it straight out. Go slow. Do not squeeze or twist the tick. 2) Clean the bite with antiseptic. 3) For the next few days, check the bite area for rash. Also look for signs of infection (fever, chills, headache, muscle ache, weakness). For more, check the Centers for Disease Control and Prevention (CDC) website at [www.cdc.gov](http://www.cdc.gov) for their tick identification guide. You can also watch the video **“How to properly remove a tick”** on YouTube.

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Ask your doctor which tests are right for you and how often you should get them. The U.S Preventative Services Task Force recommends cervical cancer screening begin at age 21. How often you get screened will depend on your individual risk factors.

## For men: taking care of your prostate

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Tips to keep your prostate healthy:

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- **Exercise.** This is good for keeping your weight managed and your prostate healthy.
- **Eat a healthy diet.** Eating a diet low in fat and filled with fruits and vegetables may help with prostate health.

If you have any questions about your prostate health, reach out to your program nurse.

## Keeping up with changing conditions in ALS

Living well with amyotrophic lateral sclerosis (ALS) can be a challenge. It is a progressive disease, meaning that it will get worse over time. But there are many things you can do to maintain quality of life with ALS and plan for the future.

What are some things you should be thinking about? Below are the symptoms to look out for as you manage your ALS. As you notice issues, write them down. Tracking any and all changes in your health will help you and your doctor to better manage your care.

- **Trouble swallowing**—when eating, food may go into the windpipe and make you choke. This can cause bacteria in the lungs, leading to a lung infection. At some point your doctor will talk with you about safe feeding tube placement. This can help you get the calories and nutrition you need.
- **Shortness of breath**—at some point your doctor will order breathing tests. These tests measure how quickly you release air from your lungs. You will take this test regularly to check for changes. Your doctor will talk to you about the right time to start non-invasive positive pressure ventilation (NIV). This is a machine to help your breathing.
- **Trouble breathing at night**—this can cause fatigue and/or morning headaches. Track these symptoms if you feel them. Report any issues to your doctor.
- **Fever**—can be a sign of infection. Always report signs of fever (high temperature, chills, headache) to the doctor.

As your symptoms change over time, keep your doctor and care team informed. You may also need to add doctors to your care team. Your doctor can help you make an action plan to track health changes with your ALS. An action plan can help you to better handle any changes as they happen.

Still have questions. Reach out to your program nurse.

## Swallowing and breathing tests for ALS

Amyotrophic lateral sclerosis (ALS) weakens the muscles you use to swallow and breathe. These issues can build slowly, getting worse over time. So, it is vital to track any swallowing and breathing issues. This can be done in a journal and will help you and your doctor know the right time to make changes in care.

Screenings and tests are an important part of your ALS care. Testing your swallowing helps the doctor to see whether you are getting the nutrition you need. Your doctor may ask you to track the answers to several questions:

- How often do you choke?
- How much do you drool?
- How long does it take you to eat a meal?
- How tired are you after you eat?
- How is your gag, cough, and swallowing reflex?
- How much weight you have gained or lost since your diagnosis?
- How well are you staying hydrated (drinking water and other fluids)?

You and your doctor should discuss whether your current treatment is meeting your needs.

Treatment could mean techniques to help you eat and swallow. It could also mean a new therapy, such as using a gastric feeding tube (G-tube). This is a tube to help you get nutrients without the need to swallow. Ask your doctor what your options are.

When it comes to your breathing, a single test may not be enough. Instead, several tests will be needed, probably every 3 months. This helps catch problems early on. These tests might include:

- Forced expiratory volume (FEV)
- Forced vital capacity (FVC)
- Maximal inspiratory pressure (MIP)
- Peak cough expiratory flow (PCEF)
- Sniff nasal inspiratory pressure (SNIP)

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- **Eat a healthy diet.** Eating a diet low in fat and filled with fruits and vegetables may help with prostate health.

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## Back-to-school planning

Children with Crohn's disease often need extra support at school. To give your child the support they need, think about setting up a **504 plan or Individualized Education Program (IEP)**. These are plans you set up with your child's school to help a student with health issues or special needs. Having a 504 plan or IEP can both help your child, but one may be more appropriate than the other. This will depend upon the challenges your child faces and what their school recommends.

504 Plan	IEP
<ul style="list-style-type: none"><li>• Defines the support and services your child will get at school</li><li>• Lists each person tasked with helping your child and carrying out the plan</li><li>• Must be reviewed each year and renewed every 3 years</li></ul>	<ul style="list-style-type: none"><li>• Sets learning goals for your child</li><li>• Defines the support and services your child will get at school</li><li>• Outlines how your child will take classes and tests</li><li>• Must be reviewed each year and renewed every 3 years</li></ul>

Not sure how to get started? Your program nurse can help you learn more about 504 plans and IEPs. No matter which option you choose, make sure you have the plan in place **BEFORE** the school year starts. This way, your child can get help right away. To learn more, go to [www.understood.org](http://www.understood.org), which also has resources for helping you and your child manage a virtual school.

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## Lab results: what to look for with Crohn's disease

With Crohn's disease, screenings and lab tests are an important part of your care. The test results are not always easy to understand, however. There are often numbers and terms that you may not know how to read. You may also get these results at home, without a doctor or nurse to help explain them.

Lab results often show a set of numbers called a "reference range" or "normal values." This range or value shows what is considered a normal result.

When you look at your results, you may not have numbers inside the "normal" range. This may be called "abnormal." It does not always mean something is wrong. Healthy people can have abnormal values. If a test shows you are outside the reference range, you may simply need more tests. The same is true if you have symptoms despite a "normal" test result.

So what labs are important to you? With Crohn's, changes to your stool can tell your doctor many things. Doctors use stool samples to watch for GI problems and colon cancer, among other issues. The Fecal calprotectin (FC) test can be used to check your response to therapy. It can also be used when endoscopy is not an option.

Colonoscopies are another important screening for colon cancer. Colonoscopy can also be used to watch for other issues related to Crohn's, such as primary sclerosing cholangitis (PSC).

Do you still have any questions about your labs or screenings? Talk to your doctor or call your program nurse.

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When you look at your results, you may not have numbers inside the “normal” range. This may be called “abnormal.” It does not always mean something is wrong. Healthy people can have abnormal values. If a test shows you are outside the reference range, you may simply need more tests. The same is true if you have symptoms despite a “normal” test result.

So what labs are important for you? For those with CF, it is important to screen regularly for cystic fibrosis-related diabetes (CFRD). You (or your child) should be screened once a year, starting at age 10.

Your doctors will use other routine tests to judge your CF progress. Pulmonary function tests (PFTs) measure how well your lungs are working. PFTs test both the size of lungs and how well the air flows in and out. Doctors will also test your sputum (the mucus you cough up) for infection. Sputum color, or the presence of blood, can tell a doctor of another problem.

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Ask your doctor which tests are right for you and how often you should get them. The U.S Preventative Services Task Force recommends cervical cancer screening begin at age 21. How often you get screened will depend on your individual risk factors.

## For men: taking care of your prostate

Taking care of your prostate is an important part of staying healthy. The prostate is a small organ located below the bladder in men. It plays a key role in your ability to have children.

As men age, the prostate can become larger. This can cause pain and serious health issues. Stay on top of your prostate health by watching for any signs of prostate issues. Below are common signs and risk factors relating to prostate health:

- A frequent urge to pee or trouble peeing: you may feel like you need to go but then cant/don't. You may also pee a lot, especially at night. Or you may have a weak stream of pee or feel incomplete dribbling.
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- African American men are at higher risk for prostate issues. This includes prostate cancer.

If you notice any of these symptoms, it is important to talk to your doctor. A prostate cancer screening may be right for you. Early testing and treatment can make a big difference. It is also good to do monthly self-exams of your testes. These are the organs that produce semen. You can ask your doctor how to do this check.

Tips to keep your prostate healthy:

- **Get regular checkups.** If you notice any new symptoms, tell your doctor. Your doctor can perform a prostate-specific antigen (PSA) test or digital rectal exam (DRE). These tests check for signs of prostate cancer and other prostate problems.
- **Exercise.** This is good for keeping your weight managed and your prostate healthy.
- **Eat a healthy diet.** Eating a diet low in fat and filled with fruits and vegetables may help with prostate health.

If you have any questions about your prostate health, reach out to your program nurse.

## Aging: how your health changes as you age

More and more we are living longer lives. In the US, adults 65 or older represent one in every seven people. This number will only continue to increase.

It is also no surprise that your body changes as you age. Your hair may start to grey. Your bones and joints may start to ache more. Your chronic inflammatory demyelinating polyneuropathy (CIDP) may also change as you age. How does getting older affect CIDP?

The course of CIDP varies widely. A few people with CIDP may see a slow increase in numbness or weakness as they age. Others may find that they have fewer symptoms than before. With treatment, many people with CIDP do get better over time. Early treatment can help stop nerve damage and disability.

Here are some things to look out for as you get older with CIDP:

- Falls – muscle weakness, fatigue, or numbness can raise your risk of falls.
- Osteoporosis – if you take corticosteroids, this can raise your risk of broken bones from falls. Regular exercise can help with balance and bone strength. Ask your doctor about taking calcium. Also ask when you should get a bone density scan.
- High blood pressure / high cholesterol – these raise your risk of heart disease or stroke. Have your blood pressure and cholesterol checked often.
- Infections – your immune response may decrease as you age. This makes you more prone to infections. That's why it's important to stay current with vaccines.
- Cancer – schedule regular screenings such as mammograms, colonoscopy, prostate and pelvic exams.
- Diabetes – taking corticosteroids can raise this risk. A regular exercise plan can help you maintain a healthy weight and prevent diabetes.

You may also need to add doctors to your care team. Your doctor can help you make an Action Plan to track health changes that may be related to getting older.

## Lab and test results: what to look for

When living with chronic inflammatory demyelinating polyneuropathy (CIDP), screenings and lab tests become a key part of your care. Don't know where to start? First, talk with your doctors about your health risks. These will vary based on your age, sex, medical history, and family history. Your doctors may order certain screenings and lab tests. Speak with your doctor about routine vaccines (shots, like what you get for flu), screenings, and lab tests that are good to get for your overall health care (aside from CIDP).

Use this chart to track common health tests and write in others that your doctor suggests.

What I need:	Why I need it:	Appointment date(s):	Notes:
Dental Exam (every 6 months)	People who brush and floss each day still need their teeth and gums checked.		
Eye Exam (every year)	To test your eyesight and check for eye disease.		
Diabetes Test (every year)	This is extra important if you take steroid medicines.		
Physical Exam	Your doctor will check your blood lipids (cholesterol), blood pressure, and blood sugar. Find out what vaccines (like the flu shot) you might need.		
Routine Cancer Screenings	This depends on age, sex, and medical and/or family history. Talk to your doctor about your risk.		
Other Recommendations	Other tests your doctor(s) feel you need.		

Do you still have any questions about your labs or screenings? Talk to your doctor or call your program nurse.

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## Summer skin care tips

Sun, heat, and damp or dry weather can all affect your skin. Over years, skin damage from ultraviolet (UV) rays from the sun builds up. This is the most common cause of skin cancer. All skin types are at risk, no matter race or ethnicity. Some medicines can also make skin sensitive. Talk to your doctor about your skin damage risk.

Keep yourself safe during the summer with these easy tips:

- Wear sunscreen on your face, arms, and legs. Don't rely only on clothing to protect you. UV rays can still harm you if it is cloudy. Pick sunscreen with a sun protection factor (SPF) of 30 or more. It should block both UVA and UVB.
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- Stick to the shade outside. You can carry an umbrella even when it's sunny.
- Wear long-sleeved shirts and pants. These can be lightweight fabrics, so you don't get too hot. Look for clothing with UVA/UVB protection. Wear sunglasses to protect your eyes and hats for your head.
- Warm weather also means a higher risk of bugs carrying illness, like ticks and mosquitos. Bug spray can help protect you. Always follow the instructions on the label.

**Removing ticks:** 1) Grasp the tick close to the skin with tweezers—pull it straight out. Go slow. Do not squeeze or twist the tick. 2) Clean the bite with antiseptic. 3) For the next few days, check the bite area for rash. Also look for signs of infection (fever, chills, headache, muscle ache, weakness). For more, check the Centers for Disease Control and Prevention (CDC) website at [www.cdc.gov](http://www.cdc.gov) for their tick identification guide. You can also watch the video **“How to properly remove a tick”** on YouTube.

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It is also no surprise that your body changes as you age. Your hair may start to grey. Your bones and joints may start to ache more. Your Gaucher disease may also change over time. What are some things you should be thinking about as you get older? How does getting older impact your Gaucher?

Aging is a part of life. But if you plan, you can better navigate these changes. You can start to do this by tracking any changes in your Gaucher as you get older. This can help you and your doctor figure out how to best deal with any age-related changes.

Here are some things to look out for as you get older with your Gaucher disease:

- Osteoporosis—can lead to a loss of mineral content in bones. This weakens your bones and makes them more likely to break. Exercise can help to keep your bones stronger.
- Cancer—people with Gaucher may be at an increased risk to develop myeloma and liver cancer. Ask your doctor about recommended cancer screenings.
- Medicine related issues—your doctor may check your spleen and liver volume, bone density and blood counts routinely. This is to ensure that your medicine dose is appropriate. They can also catch problems early on. This will also help you feel your best.
- Infections—staying current with vaccines can help you avoid infections.

You may also need to add doctors to your care team. Be sure to discuss any new changes with your doctor. Your doctor can help you make an Action Plan to track age-related changes.

## Lab and test results: what to look for

When living with Gaucher disease, screenings and lab tests become an important part of your care. The test results are not always easy to figure out. There are often many numbers and terms that you may not know how to read. You may also receive these results at home, without a doctor or nurse there to help explain them.

Lab results often show a set of numbers called a “reference range” or “normal values.” This range or value shows what is considered by most healthcare providers to be a normal result.

When you look at your results, you may not have numbers inside the “normal” range. This may be called “abnormal,” but it does not always mean something is wrong. Healthy people can have abnormal values. If a test shows you are outside the reference range, you may simply need more testing. The same is true if you have symptoms despite a “normal” test result.

So what labs are important for you? With Gaucher, your doctors will use a range of tests. CT scans and MRIs are types of imaging tests done to look at your bones and monitor your Gaucher. These can help detect problems as they arise. The complete blood count (CBC) test can help your doctor look for anemia (low iron in your blood), infections, and other problems. They will also use skeletal tests and growth charts. The results of these tests will help to let your doctor know if your Gaucher is stable or getting worse.

Do you still have any questions about your labs or screenings? Talk to your doctor or call your program nurse.

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It is no surprise that your body changes as you age. Your hair may start to turn gray. Your bones and joints may start to ache more. Aging is a part of life. But if you plan, you can better deal with these changes.

Your hereditary angioedema (HAE) may also change over time. What are some things you should be thinking about as you get older? How does getting older impact your HAE? Here are some things to look out for over time with HAE:

- Cardiovascular disease (CVD): as you age you may face high blood pressure. Some high blood pressure medicines can be harmful for people with HAE.
- Dental care and surgery: regular dental care is an important part of your health as you age. People with HAE should check with their care team before any dental procedures or surgery. These procedures can trigger HAE attacks.
- Mental Health: people with HAE may face mental health problems such as depression and anxiety. You may feel a loss of interest in activities or sadness. Talk to your doctor about any changes in your feelings. Reach out to your care team to talk. Help is always an option.

Notice any new changes or problems? Start tracking any changes in your health. This will help your doctor figure out what changes are age-related, and which are not.

You may need to add doctors to your care team over time. Your doctors can help you make an Action Plan to track age-related changes.

## Asking your doctor about HAE treatment options

How is your treatment going? Sticking to a treatment plan for hereditary angioedema (HAE) can be hard. When you feel like your care is going well, that can make things easier. When your treatment is working, you feel motivated to stick to the plan.

Treatment for HAE includes both “on-demand” treatment and prophylaxis. On-demand treatment is given at the first sign of symptoms to stop an attack. Prophylaxis is given as a regular treatment to prevent attacks or reduce severity. There are two types:

- Short-term prophylaxis is used before a planned procedure. This could be medical, surgical, or dental.
- Long-term prophylaxis is used when on-demand treatment is not controlling attacks. Dosing varies and depends on the medicine.

Most people use regular prophylaxis. Some use only on-demand treatment. Others need both to control their HAE.

What should you do if you feel your treatment is not working well? It is important to tell your doctor when you have problems. Don't assume that problems are part of going through treatment. Your doctor depends on you to say when something is not right.

The best thing to do is to keep a record so you can show your doctor. Write down any issues or problems you might have. You can do this in a journal or on a calendar. You can also keep notes on an app on your phone. Then bring that record to your next doctor's visit.

Interested in learning more about new therapies and trials? HAE International keeps track of currently running trials for testing new HAE treatments. You can learn more at the HAE International website ([www.haei.org](http://www.haei.org)). Before signing up for any sort of test or trial, be sure to talk to your doctor about what is right for you.

If you have any questions about your treatment, talk to your doctor or program nurse.

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What are some things you should be thinking about as you get older? Here are some issues to watch for as you age with human immunodeficiency virus (HIV):

- Cardiovascular disease (CVD): adults with HIV have a higher risk for CVD. This can lower blood flow to the heart. Watch for chest pain, irregular heartbeat, or shortness of breath.
- Kidney disease: some HIV medicines can raise the risk of kidney disease in people with HIV along with other risk factors. Watch for these signs: changes in urination, tiredness, and nausea.
- Diabetes: some HIV medicines may raise your risk of diabetes. Feeling thirsty, tired, and urinating often are early signs.
- Dementia: this can build over time if the HIV virus spreads to the brain. You may have memory loss, problems with thinking, focus, or speaking clearly.
- Mental health: people with HIV may face mental health problems such as depression and anxiety. You may feel a loss of interest in activities or sadness. Talk to your doctor about any changes in your feelings. Reach out to your care team to talk. Help is always an option.

Notice any new changes or problems? Start tracking any changes in your health. This will help your doctor figure out what changes are age-related, and which are not.

You may need to add doctors to your care team over time. Your doctors can help you make an Action Plan to track age-related changes.



## Lab results: what to look for with HIV

With human immunodeficiency virus (HIV), screenings and lab tests are an important part of your care. The test results are not always easy to understand, however. There are often numbers and terms that you may not know how to read. You may also get these results at home, without a doctor or nurse to help explain them.

Lab results often show a set of numbers called a “reference range” or “normal values.” This range or value shows what is considered a normal result.

When you look at your results, you may not have numbers inside the “normal” range. This may be called “abnormal.” It does not always mean something is wrong. Healthy people can have abnormal values. If a test shows you are outside the reference range, you may simply need more tests. The same is true if you have symptoms despite a “normal” test result.

So what labs are important to you? With HIV, tracking viral load comes first. This tests the amount of virus in your body. Those on antiretroviral therapy (ART) should be tested every 3-4 months. After 1 year of stable treatment, you can test every 6 months.

Your CD4 T Cell Count is also an important test. This test checks your response to treatment. It should be taken every 3-6 months. Once your numbers are good, your doctor may test you every 12 months.

Do you still have any questions about your labs or screenings? Talk to your doctor or call your program nurse.

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MC1400\_NALC

### Summer skin care tips

Sun, heat, and damp or dry weather can all affect your skin. Over years, skin damage from ultraviolet (UV) rays from the sun builds up. This is the most common cause of skin cancer. All skin types are at risk, no matter race or ethnicity. Some medicines can also make skin sensitive. Talk to your doctor about your skin damage risk.

Keep yourself safe during the summer with these easy tips:

- Wear sunscreen on your face, arms, and legs. Don't rely only on clothing to protect you. UV rays can still harm you if it is cloudy. Pick sunscreen with a sun protection factor (SPF) of 30 or more. It should block both UVA and UVB.
- Drink water throughout the day. Start before you go out in the sun.
- Stick to the shade outside. You can carry an umbrella even when it's sunny.
- Wear long-sleeved shirts and pants. These can be lightweight fabrics, so you don't get too hot. Look for clothing with UVA/UVB protection. Wear sunglasses to protect your eyes and hats for your head.
- Warm weather also means a higher risk of bugs carrying illness, like ticks and mosquitos. Bug spray can help protect you. Always follow the instructions on the label.

**Removing ticks:** 1) Grasp the tick close to the skin with tweezers—pull it straight out. Go slow. Do not squeeze or twist the tick. 2) Clean the bite with antiseptic. 3) For the next few days, check the bite area for rash. Also look for signs of infection (fever, chills, headache, muscle ache, weakness). For more, check the Centers for Disease Control and Prevention (CDC) website at [www.cdc.gov](http://www.cdc.gov) for their tick identification guide. You can also watch the video **“How to properly remove a tick”** on YouTube.

## For Women: Mammograms, Pap, and HPV tests

Regular screening tests are a great way to stay in control of your health. Screenings are the type of tests done to look for common issues. Should you have an abnormal test, other tests will be needed. If this occurs, your doctor will talk with you about next steps based on your risks.

The first step is to talk to your doctor about what tests are best for you based on your risk factors. Your doctor will likely talk to you about mammograms, Pap, and HPV tests.

**Mammograms:** These are X-ray pictures of the breast. A mammogram looks for breast cancer or changes in the breast that are not normal. Pictures are taken from the top and side of the breasts. A technician will help place your breasts between plates on a mammogram machine. The plates are moved slowly together to press your breast flat. This helps to get a clearer picture of your breast tissue. Some women may fear getting a mammogram because they think it will hurt. It may cause pain, but not always. You will feel some pressure or tightness, but any discomfort should not last long.

When should you get a mammogram? Opinions vary among health experts. Ask your doctor. Some women ages 40 to 49 may wish to start breast cancer screenings. Most women age 50 to 74 should have a mammogram every other year. If you have risk factors, such as family history of breast cancer, your doctor may suggest you start screenings at age 40. Screenings then repeat as often as each year.

**Pap and HPV tests:** The Pap test looks for signs of cancer on your cervix. The cervix is the narrow opening leading to your uterus. An HPV test looks for human papillomavirus (HPV) in the cervix. HPV is a type of sexually transmitted infection that can lead to cervical cancer. Pap and HPV tests can be done at the same time. For these tests, you lie on an exam table. A tool is placed in your vagina to help the doctor see better. Some cells are then scraped off the cervix. These cells will be sent to a lab for testing.

Ask your doctor which tests are right for you and how often you should get them. The U.S. Preventative Services Task Force recommends cervical cancer screening begin at age 21. How often you get screened will depend on your individual risk factors.

## For men: taking care of your prostate

Taking care of your prostate is an important part of staying healthy. The prostate is a small organ located below the bladder in men. It plays a key role in your ability to have children.

As men age, the prostate can become larger. This can cause pain and serious health issues. Stay on top of your prostate health by watching for any signs of prostate issues. Below are common signs and risk factors relating to prostate health:

- A frequent urge to pee or trouble peeing: you may feel like you need to go but then cant/don't. You may also pee a lot, especially at night. Or you may have a weak stream of pee or feel incomplete dribbling.
- Pain during ejaculation or peeing: You may have burning when peeing. You may also have pain/stiffness in your lower back or hips.
- Erectile dysfunction: it may be hard to achieve or maintain an erection.
- Blood in pee or semen: if you notice blood in your pee or semen, you should see a doctor as soon as possible.
- African American men are at higher risk for prostate issues. This includes prostate cancer.

If you notice any of these symptoms, it is important to talk to your doctor. A prostate cancer screening may be right for you. Early testing and treatment can make a big difference. It is also good to do monthly self-exams of your testes. These are the organs that produce semen. You can ask your doctor how to do this check.

Tips to keep your prostate healthy:

- **Get regular checkups.** If you notice any new symptoms, tell your doctor. Your doctor can perform a prostate-specific antigen (PSA) test or digital rectal exam (DRE). These tests check for signs of prostate cancer and other prostate problems.
- **Exercise.** This is good for keeping your weight managed and your prostate healthy.
- **Eat a healthy diet.** Eating a diet low in fat and filled with fruits and vegetables may help with prostate health.

If you have any questions about your prostate health, reach out to your program nurse.

## Back-to-school planning

Children with hemophilia often need extra support at school. To give your child the support they need, think about setting up a **504 plan or Individualized Education Program (IEP)**. These are plans you set up with your child's school to help a student with health issues or special needs. Having a 504 plan or IEP can both help your child, but one may be more appropriate than the other. This will depend upon the challenges your child faces and what their school recommends.

504 Plan	IEP
<ul style="list-style-type: none"><li>• Defines the support and services your child will get at school</li><li>• Lists each person tasked with helping your child and carrying out the plan</li><li>• Must be reviewed each year and renewed every 3 years</li></ul>	<ul style="list-style-type: none"><li>• Sets learning goals for your child</li><li>• Defines the support and services your child will get at school</li><li>• Outlines how your child will take classes and tests</li><li>• Must be reviewed each year and renewed every 3 years</li></ul>

Not sure how to get started? Your program nurse can help you learn more about 504 plans and IEPs. No matter which option you choose, make sure you have the plan in place **BEFORE** the school year starts. This way, your child can get help right away. To learn more, go to [www.understood.org](http://www.understood.org), which also has resources for helping you and your child manage a virtual school.

What else can you do to prepare your child for school? If your child ever has a problem at school, they should know who to call and how to reach them. These people are emergency contacts. Make sure the teachers and school nurse have a copy of these names and numbers. If your child is old enough, let them have a copy of an Action Plan that outlines their overall care too.

Have more questions? Call your program nurse today or reach out to them online!

## Lab results: what to look for with hemophilia

With hemophilia, screenings and lab tests are an important part of your care. The test results are not always easy to understand, however. There are often numbers and terms that you may not know how to read. You may also get these results at home, without a doctor or nurse to help explain them.

Lab results often show a set of numbers called a “reference range” or “normal values.” This range or value shows what is considered a normal result, based on the test results of healthy people.

When you look at your results, you may not have numbers inside the “normal” range. This may be called “abnormal.” It does not always mean something is wrong. Healthy people can have abnormal values. If a test shows you are outside the reference range, you may simply need more tests. The same is true if you have symptoms despite a “normal” test result.

So what labs are important to you? Those with hemophilia should test their inhibitor levels. Inhibitors in your blood stop clotting. In other words, they weaken your normal treatment with factor. High levels make bleeds much more dangerous.

Inhibitor testing should be part of your treatment plan each year. You should also get your levels tested:

- Before surgery
- If treatment with factor is not working as well as it used to
- Before and after switching factor products
- 2-3 weeks after surgery or intensive treatment (more than 5 exposure days)

Do you still have any questions about your labs or screenings? Talk to your doctor or call your program nurse.

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### Summer skin care tips

Sun, heat, and damp or dry weather can all affect your skin. Over years, skin damage from ultraviolet (UV) rays from the sun builds up. This is the most common cause of skin cancer. All skin types are at risk, no matter race or ethnicity. Some medicines can also make skin sensitive. Talk to your doctor about your skin damage risk.

Keep yourself safe during the summer with these easy tips:

- Wear sunscreen on your face, arms, and legs. Don't rely only on clothing to protect you. UV rays can still harm you if it is cloudy. Pick sunscreen with a sun protection factor (SPF) of 30 or more. It should block both UVA and UVB.
- Drink water throughout the day. Start before you go out in the sun.
- Stick to the shade outside. You can carry an umbrella even when it's sunny.
- Wear long-sleeved shirts and pants. These can be lightweight fabrics, so you don't get too hot. Look for clothing with UVA/UVB protection. Wear sunglasses to protect your eyes and hats for your head.
- Warm weather also means a higher risk of bugs carrying illness, like ticks and mosquitos. Bug spray can help protect you. Always follow the instructions on the label.

**Removing ticks:** 1) Grasp the tick close to the skin with tweezers—pull it straight out. Go slow. Do not squeeze or twist the tick. 2) Clean the bite with antiseptic. 3) For the next few days, check the bite area for rash. Also look for signs of infection (fever, chills, headache, muscle ache, weakness). For more, check the Centers for Disease Control and Prevention (CDC) website at [www.cdc.gov](http://www.cdc.gov) for their tick identification guide. You can also watch the video **“How to properly remove a tick”** on YouTube.

## For Women: Mammograms, Pap, and HPV tests

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The first step is to talk to your doctor about what tests are best for you based on your risk factors. Your doctor will likely talk to you about mammograms, Pap, and HPV tests.

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When should you get a mammogram? Opinions vary among health experts. Ask your doctor. Some women ages 40 to 49 may wish to start breast cancer screenings. Most women age 50 to 74 should have a mammogram every other year. If you have risk factors, such as family history of breast cancer, your doctor may suggest you start screenings at age 40. Screenings then repeat as often as each year.

**Pap and HPV tests:** The Pap test looks for signs of cancer on your cervix. The cervix is the narrow opening leading to your uterus. An HPV test looks for human papillomavirus (HPV) in the cervix. HPV is a type of sexually transmitted infection that can lead to cervical cancer. Pap and HPV tests can be done at the same time. For these tests, you lie on an exam table. A tool is placed in your vagina to help the doctor see better. Some cells are then scraped off the cervix. These cells will be sent to a lab for testing.

Ask your doctor which tests are right for you and how often you should get them. The U.S. Preventative Services Task Force recommends cervical cancer screening begin at age 21. How often you get screened will depend on your individual risk factors.

## For men: taking care of your prostate

Taking care of your prostate is an important part of staying healthy. The prostate is a small organ located below the bladder in men. It plays a key role in your ability to have children.

As men age, the prostate can become larger. This can cause pain and serious health issues. Stay on top of your prostate health by watching for any signs of prostate issues. Below are common signs and risk factors relating to prostate health:

- A frequent urge to pee or trouble peeing: you may feel like you need to go but then cant/don't. You may also pee a lot, especially at night. Or you may have a weak stream of pee or feel incomplete dribbling.
- Pain during ejaculation or peeing: You may have burning when peeing. You may also have pain/stiffness in your lower back or hips.
- Erectile dysfunction: it may be hard to achieve or maintain an erection.
- Blood in pee or semen: if you notice blood in your pee or semen, you should see a doctor as soon as possible.
- African American men are at higher risk for prostate issues. This includes prostate cancer.

If you notice any of these symptoms, it is important to talk to your doctor. A prostate cancer screening may be right for you. Early testing and treatment can make a big difference. It is also good to do monthly self-exams of your testes. These are the organs that produce semen. You can ask your doctor how to do this check.

Tips to keep your prostate healthy:

- **Get regular checkups.** If you notice any new symptoms, tell your doctor. Your doctor can perform a prostate-specific antigen (PSA) test or digital rectal exam (DRE). These tests check for signs of prostate cancer and other prostate problems.
- **Exercise.** This is good for keeping your weight managed and your prostate healthy.
- **Eat a healthy diet.** Eating a diet low in fat and filled with fruits and vegetables may help with prostate health.

If you have any questions about your prostate health, reach out to your program nurse.

## Aging: how your health changes as you age

More and more we are living longer lives. It is also no surprise that your body changes as you age. Your hair may start to grey. Your bones and joints may start to ache more. Your myasthenia gravis (MG) may also change as you age. How does getting older impact your MG?

Aging is a part of life. But if you plan, you can better handle these changes. You can start to do this by tracking any changes in your MG as you get older. This will allow you and your doctor to figure out how to best deal with any age-related changes.

Here are some things to look out for as you get older with MG:

- Falls – muscle weakness, numbness, dizziness, poor balance, and vision changes can all raise your risk for falls. Devices such as a cane, walker, or wheelchair may become needed as you age. Ask your doctor about these and if you might need physical therapy. A therapist can show you exercises to help balance and flexibility.
- High blood pressure / high cholesterol – these raise your risk for heart disease and stroke. Ask your doctor how often these should be checked.
- Osteoporosis – corticosteroids used to treat MG can raise your risk for bone loss. Ask your doctor how often you need a bone density scan.
- Cancer – talk to your doctor about routine screenings such as mammogram, colonoscopy, or pelvic exam. Your doctor will tell you when and if these are needed.
- Diabetes – long-term corticosteroid use can raise this risk. Talk to your doctor about getting tested to make sure your blood sugar stays under control.
- Cataracts – an eye doctor can check for cataracts or vision changes at routine visits.
- Loss of muscle mass – regular exercise can help build muscles at any age. Talk to your doctor to come up with a safe exercise plan for you.
- Infections – it's important to stay current with vaccines as you age. Be sure to ask your doctor about which vaccines would be most helpful for you.

You may also need to add doctors to your care team. Your doctor can help you make an Action Plan to track health changes that may be related to getting older.

## Lab and test results: what to look for

When living with a chronic illness like myasthenia gravis (MG), screenings and lab tests become a key part of your care. The test results can be hard to figure out. You might not know how to read all the numbers and terms. You may also receive these results at home, without a doctor or nurse there to help explain them.

Lab results often show a set of numbers called a “reference range” or “normal values.” These are what considered by most healthcare providers to be normal results.

Your results might not have numbers inside the “normal” range. This may be called “abnormal.” However, it does not always mean something is wrong. Healthy people can have abnormal values. If a test shows you are outside the reference range, you may simply need more testing. The same is true if you have symptoms despite a “normal” test result.

Other tests might not show a range. Let’s look at some other terms you might see on a lab report:

- Negative: the test did not find the disease or substance
- Positive: the test found the disease or substance
- Inconclusive or uncertain: the test result was not clear enough for either a positive or negative result. This may mean you need more testing.

So what labs are important to you? There are no specific tests that are used to follow MG. However, ask your doctor about getting recommended health screenings (cancer, diabetes, heart health). If you are taking a medicine that suppresses the immune system, your doctor may also order a complete blood count (CBC) test. If you take steroids, you are at greater risk for bone loss. Your doctor might recommend bone density testing to check for osteoporosis.

Do you still have any questions about your labs or screenings? Talk to your doctor or call your program nurse.

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As men age, the prostate can become larger. This can cause pain and serious health issues. Stay on top of your prostate health by watching for any signs of prostate issues. Below are common signs and risk factors relating to prostate health:

- A frequent urge to pee or trouble peeing: you may feel like you need to go but then can't/don't. You may also pee a lot, especially at night. Or you may have a weak stream of pee or feel incomplete dribbling.
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- Erectile dysfunction: it may be hard to achieve or maintain an erection.
- Blood in pee or semen: if you notice blood in your pee or semen, you should see a doctor as soon as possible.
- African American men are at higher risk for prostate issues. This includes prostate cancer.

If you notice any of these symptoms, it is important to talk to your doctor. A prostate cancer screening may be right for you. Early testing and treatment can make a big difference. It is also good to do monthly self-exams of your testes. These are the organs that produce semen. You can ask your doctor how to do this check.

Tips to keep your prostate healthy:

- **Get regular checkups.** If you notice any new symptoms, tell your doctor. Your doctor can perform a prostate-specific antigen (PSA) test or digital rectal exam (DRE). These tests check for signs of prostate cancer and other prostate problems.
- **Exercise.** This is good for keeping your weight managed and your prostate healthy.
- **Eat a healthy diet.** Eating a diet low in fat and filled with fruits and vegetables may help with prostate health.

If you have any questions about your prostate health, reach out to your program nurse.

## Aging: how your health changes as you age

More and more we are living longer lives. In the US, adults 65 or older, represent one in every seven people. This number will only increase.

It is also no surprise that your body changes as you age. Your hair may start to grey. Your bones and joints may start to ache more. Your multiple sclerosis (MS) may also change as you age. How does getting older impact your MS?

Aging is a part of life. But if you plan, you can better handle these changes. You can start to do this by tracking any changes in your MS as you get older. As years go by, MS symptoms often change. Most people start out with the relapsing form of MS. But as they age, this may become secondary progressive MS—a more serious stage.

The good news is that people with MS are living longer. Disease-modifying treatments (DMTs) have greatly increased life span for many with MS. But as you age, these treatments may not work as well as they first did.

Here are some things to look out for as you get older with MS:

- Trouble walking—aids such as canes, walkers and scooters may become more needed.
- Greater risk of falls—muscle weakness, balance problems and vision changes can get worse. This makes falls more likely.
- More fatigue—try to plan activities around times of the day you feel best.
- Memory problems / depression—if these seem to get worse over time, be sure to talk to your doctor. Help is always an option.
- Infections—age-related changes can affect the immune system. It's more important than ever to stay current on vaccines as you get older.
- Heart disease—being less active is a known risk factor for heart disease.

You may also need to add doctors to your care team. Your doctor can help you make an Action Plan to track age-related changes.

## Lab and test results: what to look for

When living with multiple sclerosis (MS), screenings and lab tests become an important part of your care. The test results are not always easy to figure out. There are often many numbers and terms that you may not know how to read. You may also receive these results at home, without a doctor or nurse there to help explain them.

Lab results often show a set of numbers called a “reference range” or “normal values.” This range or value shows what is considered by most healthcare providers to be a normal result.

When you look at your results, you may not have numbers inside the “normal” range. This may be called “abnormal.” But it does not always mean something is wrong. Healthy people can have abnormal values. If a test shows you are outside the reference range, you may simply need more testing. The same is true if you have symptoms despite a “normal” test result.

So what labs are important to you? For those with MS, there are some tests your doctor will use to monitor your level of MS activity, such as:

- A magnetic resonance imaging (MRI) scan to check for new or growing lesions in your brain or spinal cord
- Blood tests to rule out other diseases that may be affecting you

These tests can also help your doctor decide whether to switch you to a new disease- modifying therapy (DMT) or other medicine.

Do you still have any questions about your labs or screenings? Talk to your doctor or call your program nurse.

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MC1400\_NALC

### Summer skin care tips

Sun, heat, and damp or dry weather can all affect your skin. Over years, skin damage from ultraviolet (UV) rays from the sun builds up. This is the most common cause of skin cancer. All skin types are at risk, no matter race or ethnicity. Some medicines can also make skin sensitive. Talk to your doctor about your skin damage risk.

Keep yourself safe during the summer with these easy tips:

- Wear sunscreen on your face, arms, and legs. Don't rely only on clothing to protect you. UV rays can still harm you if it is cloudy. Pick sunscreen with a sun protection factor (SPF) of 30 or more. It should block both UVA and UVB.
- Drink water throughout the day. Start before you go out in the sun.
- Stick to the shade outside. You can carry an umbrella even when it's sunny.
- Wear long-sleeved shirts and pants. These can be lightweight fabrics, so you don't get too hot. Look for clothing with UVA/UVB protection. Wear sunglasses to protect your eyes and hats for your head.
- Warm weather also means a higher risk of bugs carrying illness, like ticks and mosquitos. Bug spray can help protect you. Always follow the instructions on the label.

**Removing ticks:** 1) Grasp the tick close to the skin with tweezers—pull it straight out. Go slow. Do not squeeze or twist the tick. 2) Clean the bite with antiseptic. 3) For the next few days, check the bite area for rash. Also look for signs of infection (fever, chills, headache, muscle ache, weakness). For more, check the Centers for Disease Control and Prevention (CDC) website at [www.cdc.gov](http://www.cdc.gov) for their tick identification guide. You can also watch the video **“How to properly remove a tick”** on YouTube.

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**Pap and HPV tests:** The Pap test looks for signs of cancer on your cervix. The cervix is the narrow opening leading to your uterus. An HPV test looks for human papillomavirus (HPV) in the cervix. HPV is a type of sexually transmitted infection that can lead to cervical cancer. Pap and HPV tests can be done at the same time. For these tests, you lie on an exam table. A tool is placed in your vagina to help the doctor see better. Some cells are then scraped off the cervix. These cells will be sent to a lab for testing.

Ask your doctor which tests are right for you and how often you should get them. The U.S. Preventative Services Task Force recommends cervical cancer screening begin at age 21. How often you get screened will depend on your individual risk factors.

## For men: taking care of your prostate

Taking care of your prostate is an important part of staying healthy. The prostate is a small organ located below the bladder in men. It plays a key role in your ability to have children.

As men age, the prostate can become larger. This can cause pain and serious health issues. Stay on top of your prostate health by watching for any signs of prostate issues. Below are common signs and risk factors relating to prostate health:

- A frequent urge to pee or trouble peeing: you may feel like you need to go but then cant/don't. You may also pee a lot, especially at night. Or you may have a weak stream of pee or feel incomplete dribbling.
- Pain during ejaculation or peeing: You may have burning when peeing. You may also have pain/stiffness in your lower back or hips.
- Erectile dysfunction: it may be hard to achieve or maintain an erection.
- Blood in pee or semen: if you notice blood in your pee or semen, you should see a doctor as soon as possible.
- African American men are at higher risk for prostate issues. This includes prostate cancer.

If you notice any of these symptoms, it is important to talk to your doctor. A prostate cancer screening may be right for you. Early testing and treatment can make a big difference. It is also good to do monthly self-exams of your testes. These are the organs that produce semen. You can ask your doctor how to do this check.

Tips to keep your prostate healthy:

- **Get regular checkups.** If you notice any new symptoms, tell your doctor. Your doctor can perform a prostate-specific antigen (PSA) test or digital rectal exam (DRE). These tests check for signs of prostate cancer and other prostate problems.
- **Exercise.** This is good for keeping your weight managed and your prostate healthy.
- **Eat a healthy diet.** Eating a diet low in fat and filled with fruits and vegetables may help with prostate health.

If you have any questions about your prostate health, reach out to your program nurse.

## Aging: how your health changes as you age

More and more we are living longer lives. In the US, adults 65 or older represent one in every seven people. This number will only continue to increase.

It is also no surprise that your body changes as you age. Your hair may start to grey. Your bones and joints may start to ache more. Your myositis may also change as you age. How does getting older impact your myositis?

Aging is a part of life. But if you plan, you can better handle these changes. You can start to do this by tracking any changes in your myositis as you get older. This can help you and your doctor figure out how to best deal with age-related changes.

Myositis can vary from person to person. Symptoms may build slowly over months or years. Here are some things to watch for as you age with myositis:

- Osteoporosis – taking corticosteroids for your myositis can weaken your bones over time. Talk to your doctor about taking calcium or other medicines. Also ask how often you should get a bone density scan.
- Falls – myositis can cause weakness, numbness, dizziness, and poor balance. All this can raise your fall risk. A cane, walker, or wheelchair can help to stop falls. Exercise can help with balance and make muscles and bones strong.
- High blood pressure or high cholesterol – can raise your risk for heart disease and stroke. Have your blood pressure and cholesterol checked often.
- Cancer – schedule screenings such as mammograms, colonoscopy, prostate exams and pelvic exams.
- Diabetes – long-term corticosteroid use can raise your risk for diabetes. Exercise can help you maintain healthy weight and lower this risk.
- Infections – it's important to stay current with vaccines as you age.

You may also need to add doctors to your care team. Your doctor can help you make an Action Plan to track age-related changes.



## Lab and test results: what to look for

When living with a chronic illness like myositis, screenings and lab tests become a key part of your care. The test results are not always easy to figure out. You might not know how to read all the numbers and terms. You may also receive these results at home, without a doctor or nurse there to help explain them.

Lab results often show a set of numbers called a “reference range” or “normal values.” These are what’s considered by most healthcare providers to be normal results.

Your results might not have numbers inside the “normal” range. This may be called “abnormal.” However, it does not always mean something is wrong. Healthy people can have abnormal values. If a test shows you are outside the reference range, you may simply need more testing. The same is true if you have symptoms despite a “normal” test result.

Speak with your doctor about which screenings and labs are important for you. Your doctor might recommend these:

- Screenings
  - Cancer: Mammography, colonoscopy, prostate-specific antigen (PSA) test, and others based on your age and sex
  - Osteoporosis: dual-energy x-ray absorptiometry (DXA), especially if you are taking a corticosteroid
- Lab tests
  - Complete blood count (CBC): can test your general health
  - Muscle enzymes: creatinine phosphokinase (CPK), adolase; can test muscle damage
  - Inflammation: erythrocyte sedimentation rate (ESR), C-reactive protein (CRP); can indicate level of inflammation

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As men age, the prostate can become larger. This can cause pain and serious health issues. Stay on top of your prostate health by watching for any signs of prostate issues. Below are common signs and risk factors relating to prostate health:

- A frequent urge to pee or trouble peeing: you may feel like you need to go but then cant/don't. You may also pee a lot, especially at night. Or you may have a weak stream of pee or feel incomplete dribbling.
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- Blood in pee or semen: if you notice blood in your pee or semen, you should see a doctor as soon as possible.
- African American men are at higher risk for prostate issues. This includes prostate cancer.

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Tips to keep your prostate healthy:

- **Get regular checkups.** If you notice any new symptoms, tell your doctor. Your doctor can perform a prostate-specific antigen (PSA) test or digital rectal exam (DRE). These tests check for signs of prostate cancer and other prostate problems.
- **Exercise.** This is good for keeping your weight managed and your prostate healthy.
- **Eat a healthy diet.** Eating a diet low in fat and filled with fruits and vegetables may help with prostate health.

If you have any questions about your prostate health, reach out to your program nurse.

# Maintaining quality of life with Parkinson's disease

Living well with Parkinson's disease (PD) can be a challenge. PD affects everyone differently. It is a progressive disease, meaning that it will get worse over time. But there are things you can do to maintain quality of life and plan for the future.

## Find out as much as you can about PD

First, have an honest talk with your doctor about what to expect. Ask questions. Talk to your friends and family too. They'll want to be involved in helping you. Your doctor can help you make an Action Plan to track changes in your PD symptoms over time.

## Focus on quality of life

Try to work habits into your daily routine to help you deal with your symptoms. Steps you can take to live life more fully may include:

- Exercise (as much as you can). Ask your doctor before starting something new.
- Do things you enjoy.
- Ask your doctor to explain instructions or terms you don't know. They are there to address your concerns.
- Manage stress. Plan your day with down time for both you and your family.
- If you feel depressed, talk to your doctor. There are medicines that can help lift your mood.
- Try a support group or a new hobby.

## Be prepared

Plan for your future care needs with your family and caregivers. Try to talk about these needs early when the urgency of making changes is less. Talk about hiring home care services or a caregiver if needed. At some point, it will become harder to speak and eat. Plan ahead for this. Talk with your family about your end of life wishes. Prepare for the possible need for hospice or comfort care.

## Look into assist technology and devices

There are many types of devices that can make your life easier. These can be as simple as a cane, walker, or wheelchair. Many companies sell adaptive equipment for your home. For details, visit

<https://Parkinson.org/>.

## Lab and test results: what to look for

When living with a chronic illness like Parkinson's disease (PD), screenings and lab tests become an important part of your care. The test results are not always easy to figure out. You might not know how to read all the numbers and terms. You may also receive these results at home, without a doctor or nurse there to help explain them.

Lab results often show a set of numbers called a “reference range” or “normal values.” This range or value shows what is considered by most healthcare providers to be a normal result.

When you look at your results, you may not have numbers inside the “normal” range. This may be called “abnormal.” However, it does not always mean something is wrong. Healthy people can have abnormal values. If a test shows you are outside the reference range, you may simply need more testing. The same is true if you have symptoms despite a “normal” test result.

Other tests might not necessarily show a range. Let's look at some other terms you might see on a lab report:

- Negative: the test did not find the disease or substance
- Positive: the test found the disease or substance
- Inconclusive or uncertain: the test result was not clear enough for either a positive or negative result. This may mean you need more testing.

So what's important for you? There is no specific testing tied to your PD care. However, you should still receive the normal range of wellness screenings. This includes checks for cancer and heart health. Also, your doctor might want to follow you for diabetes (blood glucose and/or hemoglobin A1c levels). They might also test you for kidney disease with a test called estimated glomerular filtration rate, or eGFR. A test called thyroid stimulating hormone, or TSH, might also be done to check for thyroid disease. The screenings you need will depend on your age, sex, and other common factors.

Do you still have any questions about your labs or screenings? Talk to your doctor or call your program nurse.

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More and more we are living longer lives. In the US, adults 65 or older represent 1 in every 7 people. This number will only increase.

It is also no surprise that your body changes as you age. Your hair may start to grey. Your bones and joints may start to ache more. Your rheumatoid arthritis (RA) may also change over time. What are some things you should be thinking about as you get older? How does getting older impact your RA?

Aging is a part of life. But if you plan, you can better navigate these changes. You can start by tracking any changes in your RA as you get older. This can help you and your doctor figure out how to best handle any age-related changes.

Here are some symptoms to look out for as you age with RA:

- Cardiovascular disease—this can lead to reduced blood flow to the heart.
- Infection—there may be a higher risk of infections which has been linked to steroid use.
- Diabetes—people with RA may have a higher risk of diabetes. Long-term corticosteroid use can raise your risk for diabetes. Regular exercise can help you maintain healthy weight and reduce this risk.
- Lung disease—you may also experience RA-related lung disease. This may cause shortness of breath or a persistent dry cough.
- Carpal tunnel syndrome—this can cause pressure on the nerves of the hand. Tell your doctor if you feel any numbness and tingling.
- Depression—people with RA do experience higher rates of depression over time. This might mean feeling less productive. Relationships with family and friends might break down. Tell your doctor about any struggles you feel. Help is always an option.

You may also need to add doctors to your care team. Your doctor can help you make an Action Plan to track age-related changes.

## Lab and test results: what to look for

When living with rheumatoid arthritis (RA), screenings and lab tests become an important part of your care. The test results are not always easy to figure out. There are often many numbers and terms that you may not know how to read. You may also receive these results at home, without a doctor or nurse there to help explain them.

Lab results often show a set of numbers called a “reference range” or “normal values.” This range or value shows what is considered by most healthcare providers to be a normal result.

When you look at your results, you may not have numbers inside the “normal” range. This may be called “abnormal,” but it does not always mean something is wrong. Healthy people can have abnormal values. If a test shows you are outside the reference range, you may simply need more testing. The same is true if you have symptoms despite a “normal” test result.

So what labs are important to you? For those with RA, there are a few common tests your doctor will use to judge your level of RA activity. Erythrocyte sedimentation rate (ESR) and C-reactive protein (CRP) are blood tests that measure your inflammation levels. These can help your doctors judge whether you are in remission. Complete blood count (CBC) is helpful for finding issues like anemia, infections, or blood clots. Vectra DA® is another blood test that helps measure the amount of active inflammation from RA.

Doctors will also use scans such as MRIs and X-rays to take images of your joints. These scans can show damage, swelling, cartilage loss, fluid, and other issues. Tracking your symptoms and being open with your doctor will help your care team figure out which, if any, of these tests you may need.

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The first step is to talk to your doctor about what tests are best for you based on your risk factors. Your doctor will likely talk to you about mammograms, Pap, and HPV tests.

**Mammograms:** These are X-ray pictures of the breast. A mammogram looks for breast cancer or changes in the breast that are not normal. Pictures are taken from the top and side of the breasts. A technician will help place your breasts between plates on a mammogram machine. The plates are moved slowly together to press your breast flat. This helps to get a clearer picture of your breast tissue. Some women may fear getting a mammogram because they think it will hurt. It may cause pain, but not always. You will feel some pressure or tightness, but any discomfort should not last long.

When should you get a mammogram? Opinions vary among health experts. Ask your doctor. Some women ages 40 to 49 may wish to start breast cancer screenings. Most women age 50 to 74 should have a mammogram every other year. If you have risk factors, such as family history of breast cancer, your doctor may suggest you start screenings at age 40. Screenings then repeat as often as each year.

**Pap and HPV tests:** The Pap test looks for signs of cancer on your cervix. The cervix is the narrow opening leading to your uterus. An HPV test looks for human papillomavirus (HPV) in the cervix. HPV is a type of sexually transmitted infection that can lead to cervical cancer. Pap and HPV tests can be done at the same time. For these tests, you lie on an exam table. A tool is placed in your vagina to help the doctor see better. Some cells are then scraped off the cervix. These cells will be sent to a lab for testing.

Ask your doctor which tests are right for you and how often you should get them. The U.S. Preventative Services Task Force recommends cervical cancer screening begin at age 21. How often you get screened will depend on your individual risk factors.



## For men: taking care of your prostate

Taking care of your prostate is an important part of staying healthy. The prostate is a small organ located below the bladder in men. It plays a key role in your ability to have children.

As men age, the prostate can become larger. This can cause pain and serious health issues. Stay on top of your prostate health by watching for any signs of prostate issues. Below are common signs and risk factors relating to prostate health:

- A frequent urge to pee or trouble peeing: you may feel like you need to go but then can't/don't. You may also pee a lot, especially at night. Or you may have a weak stream of pee or feel incomplete dribbling.
- Pain during ejaculation or peeing: You may have burning when peeing. You may also have pain/stiffness in your lower back or hips.
- Erectile dysfunction: it may be hard to achieve or maintain an erection.
- Blood in pee or semen: if you notice blood in your pee or semen, you should see a doctor as soon as possible.
- African American men are at higher risk for prostate issues. This includes prostate cancer.

If you notice any of these symptoms, it is important to talk to your doctor. A prostate cancer screening may be right for you. Early testing and treatment can make a big difference. It is also good to do monthly self-exams of your testes. These are the organs that produce semen. You can ask your doctor how to do this check.

Tips to keep your prostate healthy:

- **Get regular checkups.** If you notice any new symptoms, tell your doctor. Your doctor can perform a prostate-specific antigen (PSA) test or digital rectal exam (DRE). These tests check for signs of prostate cancer and other prostate problems.
- **Exercise.** This is good for keeping your weight managed and your prostate healthy.
- **Eat a healthy diet.** Eating a diet low in fat and filled with fruits and vegetables may help with prostate health.

If you have any questions about your prostate health, reach out to your program nurse.

## Back-to-school planning

Children with sickle cell disease often need extra support at school. To give your child the support they need, think about setting up a **504 plan or Individualized Education Program (IEP)**. These are plans you set up with your child's school to help a student with health issues or special needs. Having a 504 plan or IEP can both help your child, but one may be more appropriate than the other. This will depend upon the challenges your child faces and what their school recommends.

504 Plan	IEP
<ul style="list-style-type: none"><li>• Defines the support and services your child will get at school</li><li>• Lists each person tasked with helping your child and carrying out the plan</li><li>• Must be reviewed each year and renewed every 3 years</li></ul>	<ul style="list-style-type: none"><li>• Sets learning goals for your child</li><li>• Defines the support and services your child will get at school</li><li>• Outlines how your child will take classes and tests</li><li>• Must be reviewed each year and renewed every 3 years</li></ul>

Not sure how to get started? Your program nurse can help you learn more about 504 plans and IEPs. No matter which option you choose, make sure you have the plan in place **BEFORE** the school year starts. This way, your child can get help right away. To learn more, go to [www.understood.org](http://www.understood.org), which also has resources for helping you and your child manage a virtual school.

What else can you do to prepare your child for school? If your child ever has a problem at school, they should know who to call and how to reach them. These people are emergency contacts. Make sure the teachers and school nurse have a copy of these names and numbers. If your child is old enough, let them have a copy of an Action Plan that outlines their overall care too.

Have more questions? Call your program nurse today or reach out to them online!

## Lab results: what to look for with sickle cell

With sickle cell disease, screenings and lab tests are an important part of your care. The test results are not always easy to understand, however. There are often numbers and terms that you may not know how to read. You may also get these results at home, without a doctor or nurse to help explain them.

Lab results often show a set of numbers called a “reference range” or “normal values.” This range or value shows what is considered a normal result, based on the test results of healthy people.

When you look at your results, you may not have numbers inside the “normal” range. This may be called “abnormal.” It does not always mean something is wrong. Healthy people can have abnormal values. If a test shows you are outside the reference range, you may simply need more tests. The same is true if you have symptoms despite a “normal” test result.

So what labs are important to you? For those with sickle cell, there are a few common tests your doctor will use. Urinalysis and estimated glomerular filtration rate (eGFR) are used to monitor kidney function. A complete blood count (CBC) with white blood cell (WBC) differential, reticulocyte count, and platelet count are used to monitor those on hydroxyurea. These tests are taken every 2-3 months.

Your doctor may also screen you for stroke and pulmonary hypertension. You may be screened as much as once per year. Screenings can depend on your age and genotype, so talk to your doctor about which tests and labs are right for you.

Do you still have any questions about your labs or screenings? Talk to your doctor or call your program nurse.

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MC1400\_NALC

### Summer skin care tips

Sun, heat, and damp or dry weather can all affect your skin. Over years, skin damage from ultraviolet (UV) rays from the sun builds up. This is the most common cause of skin cancer. All skin types are at risk, no matter race or ethnicity. Some medicines can also make skin sensitive. Talk to your doctor about your skin damage risk.

Keep yourself safe during the summer with these easy tips:

- Wear sunscreen on your face, arms, and legs. Don't rely only on clothing to protect you. UV rays can still harm you if it is cloudy. Pick sunscreen with a sun protection factor (SPF) of 30 or more. It should block both UVA and UVB.
- Drink water throughout the day. Start before you go out in the sun.
- Stick to the shade outside. You can carry an umbrella even when it's sunny.
- Wear long-sleeved shirts and pants. These can be lightweight fabrics, so you don't get too hot. Look for clothing with UVA/UVB protection. Wear sunglasses to protect your eyes and hats for your head.
- Warm weather also means a higher risk of bugs carrying illness, like ticks and mosquitos. Bug spray can help protect you. Always follow the instructions on the label.

**Removing ticks:** 1) Grasp the tick close to the skin with tweezers—pull it straight out. Go slow. Do not squeeze or twist the tick. 2) Clean the bite with antiseptic. 3) For the next few days, check the bite area for rash. Also look for signs of infection (fever, chills, headache, muscle ache, weakness). For more, check the Centers for Disease Control and Prevention (CDC) website at [www.cdc.gov](http://www.cdc.gov) for their tick identification guide. You can also watch the video **“How to properly remove a tick”** on YouTube.

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## Aging: how your health changes as you age

More and more we are living longer lives. In the US, adults 65 or older represent one in every seven people. This number will only continue to increase.

It is also no surprise that your body changes as you age. Your hair may start to grey. Your bones and joints may start to ache more. Your scleroderma may also change as you age. What are some things you should be thinking about as you get older? How does getting older impact your scleroderma?

Aging is a part of life. But if you plan, you can better handle these changes. You can start by tracking any changes in your scleroderma as you get older. This will help you and your doctor figure out what changes are age-related, and which are not. Symptoms of scleroderma often overlap with common symptoms of aging.

Here are some of the main things to look out for as you get older with scleroderma:

- High blood pressure – check your blood pressure regularly at home. Talk to your doctor if it suddenly increases (140/90 mmHg or higher).
- Heart problems – watch for shortness of breath, chest pain, swollen ankles or feet, or dizziness. Let your doctor know if you have any of these changes.
- Kidney disease – sudden high blood pressure can be a sign of kidney failure. Other signs may include headaches, fatigue, muscle cramps, changes in urine, or joint pain. Tell your doctor if you have any of these.
- Lung issues – have your lungs checked often by your doctor. Get the flu shot each year. Ask about pneumonia vaccines too.

You may also need to add doctors to your care team. Your doctor can help you make an Action Plan to track age-related changes.



## Lab and test results: what to look for

When living with scleroderma, screenings and lab tests become an important part of your care. The test results are not always easy to figure out. There are often many numbers and terms that you may not know how to read. You may also receive these results at home, without a doctor or nurse there to help explain them.

Lab results often show a set of numbers called a “reference range” or “normal values.” This range or value shows what is considered by most healthcare providers to be a normal result.

When you look at your results, you may not have numbers inside the “normal” range. This may be called “abnormal,” but it does not always mean something is wrong. Healthy people can have abnormal values. If a test shows you are outside the reference range, you may simply need more testing. The same is true if you have symptoms despite a “normal” test result.

So what labs are important to you? For those with scleroderma, screening should start early for lung problems. Baseline pulmonary function tests (PFTs) are done to check your breathing capacity. To check your heart, Doppler echocardiograms (heart scan) and electrocardiograms (EKGs) may be done. BNP or pro-NT BNP are types of blood tests that can also detect heart problems. If there are no problems, these tests should be repeated every year. They may be done more often if you have any new symptoms.

To check for kidney problems, your blood pressure should be taken often (several times per week). If you should get two readings in a row higher than 140/90 mmHg (not related to exercise), tell your doctor right away. It's best to wait at least 30 minutes after exercise to take your blood pressure.

Do you still have any questions about your labs or screenings? Talk to your doctor or call your program nurse.

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## For men: taking care of your prostate

Taking care of your prostate is an important part of staying healthy. The prostate is a small organ located below the bladder in men. It plays a key role in your ability to have children.

As men age, the prostate can become larger. This can cause pain and serious health issues. Stay on top of your prostate health by watching for any signs of prostate issues. Below are common signs and risk factors relating to prostate health:

- A frequent urge to pee or trouble peeing: you may feel like you need to go but then can't/don't. You may also pee a lot, especially at night. Or you may have a weak stream of pee or feel incomplete dribbling.
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Tips to keep your prostate healthy:

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- **Exercise.** This is good for keeping your weight managed and your prostate healthy.
- **Eat a healthy diet.** Eating a diet low in fat and filled with fruits and vegetables may help with prostate health.

If you have any questions about your prostate health, reach out to your program nurse.

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More and more we are living longer lives. In the US, adults 65 or older represent one in every seven people. This number will only increase.

It is also no surprise that your body changes as you age. Your hair may start to grey. Your bones and joints may start to ache more. Your lupus may also change as you age. How does getting older impact your lupus?

Aging is a part of life. But if you plan, you can better handle these changes. You can start to do this by tracking any changes in your lupus as you get older. This can help you and your doctor figure out how to best deal with any age-related changes.

Here are some things to look out for as you get older with lupus:

- High blood pressure (BP) – this adds to your risk for heart disease. Kidney disease, obesity, and some lupus medicines raise your risk of high BP. Ask your doctor about how often you should check your BP.
- Diabetes – long-term corticosteroid use raises this risk. Regular exercise can help you maintain a healthy weight and lower risk of diabetes. Talk to your doctor about getting screened for diabetes.
- Kidney disease – lupus can cause a kidney disease called lupus nephritis. Stay on top of labs to track your kidney function.
- Obesity – lupus raises the risk of weight gain. It can make it harder to perform certain exercises. Certain lupus medicines can also be a factor in weight gain. Strive for healthy eating habits. Exercise as much as you can to maintain a healthy weight.
- Osteoporosis – if you take corticosteroids, bone loss can occur over time. Ask your doctor about getting regular bone density scans.
- Cancer – schedule regular screenings as needed, such as mammograms, colonoscopy, prostate, and pelvic exams.
- Infection – stay current with vaccines as you age.
- Depression / mood disorders – with lupus, you are at risk to develop depression. Talk to your doctor if you have mood issues. Help is always an option.

You may also need to add doctors to your care team. Your doctor can help you make an Action Plan to track age-related changes.

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So what labs are important to you? You should receive regular screenings to test your heart, kidneys, and blood sugar. These may include your complete blood count (CBC), estimated glomerular filtration rate (eGFR), and diabetes screening tests such as oral glucose tolerance (OGTT) and hemoglobin A1c (HbA1c).

Urinalysis tests are especially important. These tests check kidney function and screen for lupus nephritis. Nephritis, or renal disease, can cause progressive loss of kidney function due to lupus. Check with your doctor about how often you should have urinalysis done.

Do you still have any questions about your labs or screenings? Talk to your doctor or call your program nurse.

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If you notice any of these symptoms, it is important to talk to your doctor. A prostate cancer screening may be right for you. Early testing and treatment can make a big difference. It is also good to do monthly self-exams of your testes. These are the organs that produce semen. You can ask your doctor how to do this check.

Tips to keep your prostate healthy:

- **Get regular checkups.** If you notice any new symptoms, tell your doctor. Your doctor can perform a prostate-specific antigen (PSA) test or digital rectal exam (DRE). These tests check for signs of prostate cancer and other prostate problems.
- **Exercise.** This is good for keeping your weight managed and your prostate healthy.
- **Eat a healthy diet.** Eating a diet low in fat and filled with fruits and vegetables may help with prostate health.

If you have any questions about your prostate health, reach out to your program nurse.

## Back-to-school planning

Children with epilepsy often need extra support at school. To give your child the support they need, think about setting up a **504 plan or Individualized Education Program (IEP)**. These are plans you set up with your child's school to help a student with health issues or special needs. Having a 504 plan or IEP can both help your child, but one may be more appropriate than the other. This will depend upon the challenges your child faces and what their school recommends.

504 Plan	IEP
<ul style="list-style-type: none"><li>• Defines the support and services your child will get at school</li><li>• Lists each person tasked with helping your child and carrying out the plan</li><li>• Must be reviewed each year and renewed every 3 years</li></ul>	<ul style="list-style-type: none"><li>• Sets learning goals for your child</li><li>• Defines the support and services your child will get at school</li><li>• Outlines how your child will take classes and tests</li><li>• Must be reviewed each year and renewed every 3 years</li></ul>

Not sure how to get started? Your program nurse can help you learn more about 504 plans and IEPs. No matter which option you choose, make sure you have the plan in place **BEFORE** the school year starts. This way, your child can get help right away. To learn more, go to [www.understood.org](http://www.understood.org), which also has resources for helping you and your child manage a virtual school.

What else can you do to prepare your child for school? If your child ever has a problem at school, they should know who to call and how to reach them. These people are emergency contacts. Make sure the teachers and school nurse have a copy of these names and numbers. If your child is old enough, let them have a copy of an Action Plan that outlines their overall care too.

Have more questions? Call your program nurse today or reach out to them online!

## Lab results: what to look for with epilepsy

With epilepsy, clinic visits and lab tests are an important part of your care. The test results are not always easy to understand, however. There are often numbers and terms that you may not know how to read. You may also get these results at home, without a doctor or nurse to help explain them.

Lab results often show a set of numbers called a “reference range” or “normal values.” This range or value shows what is considered a normal result, based on the test results of healthy people.

When you look at your results, you may not have numbers inside the “normal” range. This may be called “abnormal.” It does not always mean something is wrong. Healthy people can have abnormal values. If a test shows you are outside the reference range, you may simply need more tests. The same is true if you have symptoms despite a “normal” test result.

So which tests are important to you? For those with epilepsy, an electroencephalograph (EEG) or video-EEG reading is crucial. This test can help diagnose and monitor seizure activity. These readings tell your doctor three things:

1. the presence of seizure activity
2. the type of epilepsy
3. the location of the seizure focus

EEGs also help your doctor figure out what type of anti-seizure medicine (ASM) is right for you. Your doctor may also want to track the level of ASM in your body. This will help them find the right “therapeutic level” or dose for you. Ask your doctor what other lab tests you might need depending on the ASM you take.

Do you still have any questions about your labs or treatment? Talk to your doctor or call your program nurse.

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♥ **CVS specialty** nurse care management

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### Summer skin care tips

Sun, heat, and damp or dry weather can all affect your skin. Over years, skin damage from ultraviolet (UV) rays from the sun builds up. This is the most common cause of skin cancer. All skin types are at risk, no matter race or ethnicity. Some medicines can also make skin sensitive. Talk to your doctor about your skin damage risk.

Keep yourself safe during the summer with these easy tips:

- Wear sunscreen on your face, arms, and legs. Don't rely only on clothing to protect you. UV rays can still harm you if it is cloudy. Pick sunscreen with a sun protection factor (SPF) of 30 or more. It should block both UVA and UVB.
- Drink water throughout the day. Start before you go out in the sun.
- Stick to the shade outside. You can carry an umbrella even when it's sunny.
- Wear long-sleeved shirts and pants. These can be lightweight fabrics, so you don't get too hot. Look for clothing with UVA/UVB protection. Wear sunglasses to protect your eyes and hats for your head.
- Warm weather also means a higher risk of bugs carrying illness, like ticks and mosquitos. Bug spray can help protect you. Always follow the instructions on the label.

**Removing ticks:** 1) Grasp the tick close to the skin with tweezers—pull it straight out. Go slow. Do not squeeze or twist the tick. 2) Clean the bite with antiseptic. 3) For the next few days, check the bite area for rash. Also look for signs of infection (fever, chills, headache, muscle ache, weakness). For more, check the Centers for Disease Control and Prevention (CDC) website at [www.cdc.gov](http://www.cdc.gov) for their tick identification guide. You can also watch the video **“How to properly remove a tick”** on YouTube.

## For Women: Mammograms, Pap, and HPV tests

Regular screening tests are a great way to stay in control of your health. Screenings are the type of tests done to look for common issues. Should you have an abnormal test, other tests will be needed. If this occurs, your doctor will talk with you about next steps based on your risks.

The first step is to talk to your doctor about what tests are best for you based on your risk factors. Your doctor will likely talk to you about mammograms, Pap, and HPV tests.

**Mammograms:** These are X-ray pictures of the breast. A mammogram looks for breast cancer or changes in the breast that are not normal. Pictures are taken from the top and side of the breasts. A technician will help place your breasts between plates on a mammogram machine. The plates are moved slowly together to press your breast flat. This helps to get a clearer picture of your breast tissue. Some women may fear getting a mammogram because they think it will hurt. It may cause pain, but not always. You will feel some pressure or tightness, but any discomfort should not last long.

When should you get a mammogram? Opinions vary among health experts. Ask your doctor. Some women ages 40 to 49 may wish to start breast cancer screenings. Most women age 50 to 74 should have a mammogram every other year. If you have risk factors, such as family history of breast cancer, your doctor may suggest you start screenings at age 40. Screenings then repeat as often as each year.

**Pap and HPV tests:** The Pap test looks for signs of cancer on your cervix. The cervix is the narrow opening leading to your uterus. An HPV test looks for human papillomavirus (HPV) in the cervix. HPV is a type of sexually transmitted infection that can lead to cervical cancer. Pap and HPV tests can be done at the same time. For these tests, you lie on an exam table. A tool is placed in your vagina to help the doctor see better. Some cells are then scraped off the cervix. These cells will be sent to a lab for testing.

Ask your doctor which tests are right for you and how often you should get them. The U.S. Preventative Services Task Force recommends cervical cancer screening begin at age 21. How often you get screened will depend on your individual risk factors.



## For men: taking care of your prostate

Taking care of your prostate is an important part of staying healthy. The prostate is a small organ located below the bladder in men. It plays a key role in your ability to have children.

As men age, the prostate can become larger. This can cause pain and serious health issues. Stay on top of your prostate health by watching for any signs of prostate issues. Below are common signs and risk factors relating to prostate health:

- A frequent urge to pee or trouble peeing: you may feel like you need to go but then can't/don't. You may also pee a lot, especially at night. Or you may have a weak stream of pee or feel incomplete dribbling.
- Pain during ejaculation or peeing: You may have burning when peeing. You may also have pain/stiffness in your lower back or hips.
- Erectile dysfunction: it may be hard to achieve or maintain an erection.
- Blood in pee or semen: if you notice blood in your pee or semen, you should see a doctor as soon as possible.
- African American men are at higher risk for prostate issues. This includes prostate cancer.

If you notice any of these symptoms, it is important to talk to your doctor. A prostate cancer screening may be right for you. Early testing and treatment can make a big difference. It is also good to do monthly self-exams of your testes. These are the organs that produce semen. You can ask your doctor how to do this check.

Tips to keep your prostate healthy:

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- **Exercise.** This is good for keeping your weight managed and your prostate healthy.
- **Eat a healthy diet.** Eating a diet low in fat and filled with fruits and vegetables may help with prostate health.

If you have any questions about your prostate health, reach out to your program nurse.

## Back-to-school planning

Children with ulcerative colitis (UC) often need extra support at school. To give your child the support they need, think about setting up a 504 plan or Individualized Education Program (IEP). These are plans you set up with your child's school to help a student with health issues or special needs. Having a 504 plan or IEP can both help your child, but one may be more appropriate than the other. This will depend upon the challenges your child faces and what their school recommends.

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Have more questions? Call your program nurse today or reach out to them online!

## Lab results: what to look for with UC

With ulcerative colitis (UC), screenings and lab tests are an important part of your care. The test results are not always easy to understand, however. There are often numbers and terms that you may not know how to read. You may also get these results at home, without a doctor or nurse to help explain them.

Lab results often show a set of numbers called a “reference range” or “normal values.” This range or value shows what is considered a normal result.

When you look at your results, you may not have numbers inside the “normal” range. This may be called “abnormal.” It does not always mean something is wrong. Healthy people can have abnormal values. If a test shows you are outside the reference range, you may simply need more tests. The same is true if you have symptoms despite a “normal” test result.

So what labs are important to you? With UC, fecal calprotectin (FC) tests can be used to check your response to therapy. It can also be used when endoscopy is not an option.

Colonoscopies are another important screening for colon cancer. Colonoscopy can also be used to watch for other issues related to UC, such as primary sclerosing cholangitis (PSC).

Do you still have any questions about your labs or screenings? Talk to your doctor or call your program nurse.

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