Care Connections[®]

ALS
OCTOBER 2023

Get the best care for ALS

When you have a long-term illness like amyotrophic lateral sclerosis (ALS), one doctor isn't enough. It can be hard to manage many doctors. An ALS clinic can make your care easier. Clinics have teams of doctors who are experts in treating ALS.

You can see many specialists at each ALS clinic visit and coordinate your care. This may include neurologists, respiratory therapists, speech-language pathologists, dietitians, physical therapists, and social workers. Clinics can help your regular doctors make a better care plan for you.

If you cannot go to an ALS clinic, that is okay. Your local doctor may still be able to work with a clinic for you. The important part is making sure your doctors talk to each other. Ask your neurologist or primary doctor to help you build a group of care providers. Your care team may also include dentists, eye doctors, your program nurse, and other providers.

To help your doctors, give them the contact info for your other care providers. Other providers should report to your primary doctor. There are many times you, your doctors, and your program nurse should talk:

- If you need to be treated for an illness or injury.
- If you are about to start a new therapy or switch medicines.
- If you schedule any sort of surgery.







You should also carry a medical I.D. It should give health care providers info about your treatment plan in an emergency. It should also have your doctors' contact info. This I.D. can be a bracelet, letter, wallet card, or USB drive. You should also carry a list of your medicines. You can ask your doctor or pharmacist for a full list. Your program nurse can also help you make a medical I.D. card.

Find an ALS clinic near you

Need help finding a clinic? The ALS Association keeps listings of clinics. Check out **www.als.org** to find one near you. Also ask your health plan provider which options are covered.

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CIDP

OCTOBER 2023

Coordinate your care for CIDP

When you have a long-term illness like chronic inflammatory demyelinating polyneuropathy (CIDP), one doctor isn't enough. Your care team may include your primary doctor, neurologists, physical therapists, and others. You will also need one or more specialists, and your program nurse.



It can be hard to manage many doctors. Making sure your doctors talk to each other is important. You can help your doctors by giving them the contact info for your other care providers. There are many times you, your doctors, and your program nurse should talk:

- If you need to be treated for an illness or injury.
- If you are about to start a new therapy or switch medicines.
- If you schedule any sort of surgery.

You should also carry a medical I.D. It should give health care providers info about your treatment plan in an emergency. It should also have your doctors' contact info. This I.D. can be a bracelet, letter, wallet card, or USB drive. You should also carry a list of your medicines. You can ask your doctor or pharmacist for a full list.







Find a Center of Excellence near you

Do you get the best care? The GBS|CIDP Foundation has a Medical Advisory Board that selects certain medical centers as "Centers of Excellence." They consider these to be the best places for the treatment of CIDP and related conditions. These centers are located around the world, with 38 sites in the United States. Go to **gbs-cidp.org** and search for "Centers of Excellence" to find one near you. Check with your health plan to find out what options are covered.

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Cystic Fibrosis

OCTOBER 2023

Coordinate your care for cystic fibrosis

When you have a long-term illness like cystic fibrosis (CF), one doctor isn't enough. Your care team may include your primary doctor, pulmonologist, dentists, eye doctors, Ob/Gyn, and others. You may also need one or more specialists, and your program nurse. Being seen at a CF center of excellence (COE) will bring together all the specialists you need. If you are not able to be seen at a CF COE, that is ok. Your local doctor could work with one for you.

It can be hard to manage many doctors. Making sure your doctors talk to each other is important. You can help your doctors by giving them the contact info for your other care providers. There are many times you, your doctors, and your program nurse may talk:

- If you feel any new symptoms or lung infection.
- If you need to be treated for an illness or injury.
- If you are about to start a new therapy or switch medicines.
- If you schedule any sort of surgery.
- If you notice a large amount of weight gain.
- If you are starting a new exercise program.
- If you are considering starting a family.

You should also carry a medical I.D. It should give health care providers info about your treatment plan in an emergency. It should also have your doctors' contact info. This I.D. can be a bracelet, letter, wallet card, or USB drive. You should also carry a list of your medicines. You can ask your doctor or pharmacist for a full list.







Find a Center of Excellence near you

Do you get the best care? CF care centers have teams of doctors who are experts in treating CF. These centers can help your regular doctors make a better care plan for you. Need help finding a center? Check out **apps.cff.org** to find one near you. Also ask your health plan provider which options are covered.

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Gaucher

OCTOBER 2023

Coordinate your care for Gaucher

When you have a long-term illness like Gaucher, one doctor isn't enough. Your care team will start with your primary doctor and a Gaucher specialist. You may need other specialists such as a hematologist, liver specialist and more. You may also include dentists, eye doctors, OB-GYNs, your program nurse, and others.

Many doctors have not treated Gaucher. This is because it is so rare. Gaucher treatment centers may be a good option. These centers have teams of doctors who are experts in treating Gaucher. You can get infusions and genetic counseling. Centers can help your local doctors make a better care plan for you.

If you cannot visit a treatment center, that is okay. Your local doctor may still be able to work with a center for you. Making sure your doctors talk to each other is important. You can help your doctors by giving them the contact info for your other providers. There are many times you, your doctors, and your program nurse should talk:

- If you need to be treated for an illness or injury.
- If you are about to start a new treatment or switch medicines.
- If you schedule a surgery.
- If you have been to a Gaucher treatment center lately.







You should also carry a medical I.D. It should give health care providers info about your treatment plan in an emergency. It should also have your doctors' contact info. This I.D. can be a bracelet, letter, wallet card, or USB drive. You should also carry a list of your medicines. You can ask your doctor or pharmacist for a full list. Your program nurse can also help you make a medical I.D. card.

Find a Center of Excellence near you

Need help finding a center? Check out the National Gaucher Foundation at **www.gaucherdisease.org** to find one near you. Also ask your health plan provider which options are covered.

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Hemophilia

OCTOBER 2023

Coordinate your care for hemophilia

When you have a long-term illness like hemophilia, one doctor isn't enough. Your care team will include the Hemophilia Treatment Center (HTC). It will also include your primary doctor, dentists, eye doctors, and others. You will also need one or more specialists, and your program nurse.



It can be hard to manage many doctors. Making sure your doctors talk to each other is important. You can help your doctors by giving them the contact info for your other care providers. There are many times you, your doctors, and your program nurse should talk:

- If you need to be treated for an illness or injury.
- If you are about to start a new therapy or switch medicines.
- If you schedule any sort of surgery.
- If you notice a change in how often you infuse for bleeding.

You should also carry a medical I.D. It should give health care providers info about your treatment plan in an emergency. It should also have your doctors' contact info. This I.D. can be a bracelet, letter, wallet card, or USB drive. You should also carry a list of your medicines. You can ask your doctor or pharmacist for a full list. Your program nurse can also help you make a medical I.D. card.







Find a Hemophilia Treatment Center near you

Do you get the best care? HTCs have teams of doctors who are experts in treating hemophilia. HTCs can help your regular doctors make a better care plan for you. Need help finding an HTC? Check out the Centers for Disease Control and Prevention listings at **www.cdc.gov** to find one near you. Also ask your health plan provider which options are covered.

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Lupus

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Coordinate your care for lupus

When you have a long-term illness like lupus, seeing your rheumatologist isn't enough. Your care team may include your primary doctor, dentists, eye doctors, OB-GYNs, and others. You will also need one or more specialists and your program nurse.

It can be hard to manage many doctors. Making sure your doctors talk to each other is important. You can help your doctors by giving them the contact info for your other care providers. There are many times you, your doctors, and your program nurse should talk:

- If you need to be treated for an illness or injury.
- If you are about to start a new therapy or switch medicines.
- If you schedule any sort of surgery.
- If you are thinking about starting a family.

You should also carry a medical I.D. It should give health care providers info about your treatment plan in an emergency. It should also have your doctors' contact info. This I.D. can be a bracelet, letter, wallet card, or USB drive. You should also carry a list of your medicines. You can ask your doctor or pharmacist for a full list.







Find the right specialist

Do you get the best care? There is no single Center of Excellence for the treatment of lupus in the United States today. But rheumatologists are typically experts in treating lupus. They can work with your other doctors to make a better care plan for you. Need help finding a lupus specialist? Look for a doctor who works with a medical school. They are generally thought of as good places to go for treatment of lupus. These places may have staff involved in lupus research. The Lupus Foundation of America can help. Go to lupus.org and search for "Finding a New Doctor." Also ask your health plan provider which options are covered.

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Coordinate your care for MS

When you have a long-term illness like multiple sclerosis (MS), one doctor isn't enough. It can be hard to manage many doctors. A Center for Comprehensive MS Care can make your care easier. These Centers have teams of doctors who are experts in treating MS. They can coordinate your care.

If you cannot visit an MS Center, that is okay. Your local doctor may still be able to work with a Center for you. The important part is making sure your doctors talk with each other. Your care team may include neurologists, physical therapists, mental health specialists, social workers, dentists, eye doctors, OB-GYNs, and others. These specialists can help your regular doctor make a better care plan for you.

You can help your doctors by giving them the contact info for your other care providers. There are many times you, your doctors, and your program nurse should talk:

- If you need to be treated for an illness or injury.
- If you are about to start a new therapy or switch medicines.
- If you schedule any sort of surgery.

You should also carry a medical I.D. It should give health care providers info about your treatment plan in an emergency. It should also have your doctors' contact info. This I.D. can be a bracelet,







letter, wallet card, or USB drive. You should also carry a list of your medicines. You can ask your program nurse, doctor, or pharmacist for a full list.

Find the right specialist

Partners in MS Care are other doctors who have a relationship with the National MS Society. They can connect you to resources and support available. Go to **nationalmssociety.org** and search for "Find Doctors & Resources." Type in where you live and what kind of support you need. Also ask your health plan provider which options are covered.

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Coordinate your care for myasthenia gravis

When you have a long-term illness like myasthenia gravis (MG), one doctor isn't enough. Your care team may include your primary doctor, dentists, eye doctors, OB-GYNs, your program nurse, and others. You will also need one or more specialists.

The Myasthenia Gravis Foundation of America (MGFA) has a Partners in MG Care network.

These are doctors who specialize in caring for patients with MG. This network includes experts in neurology, ophthalmology, cardiothoracic surgery, general psychiatry, and hematology-oncology.

It can be hard to manage many doctors. Making sure your doctors talk to each other is important. You can help your doctors by giving them the contact info for your other care providers. There are many times you, your doctors, and your program nurse should talk:

- If you need to be treated for an illness or injury.
- If you are about to start a new therapy or switch medicines.
- If you schedule any sort of surgery.

You should also carry a medical I.D. It should give health care providers info about your treatment plan in an emergency. It should also have your doctors' contact info. This I.D. can be a bracelet, letter, wallet card, or USB drive. You should also carry a list of your medicines. You can ask your doctor or pharmacist for a full list.







Find the right specialist

Do you get the best care? Go to **myasthenia.org** and search for "Partners in MG Care." The MGFA site also offers many educational resources. Search for "MG Support Groups" to learn how to connect with others living with MG. Also ask your health care provider which options are covered.

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Myositis

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Coordinate your care for myositis

When you have a long-term illness like myositis, one doctor isn't enough. Your care team may include your primary doctor, a neurologist, your program nurse, and others. You will also need one or more other specialists, depending on your type of myositis or your other conditions.

Many people have a hard time finding doctors who know about myositis. Those with polymyositis or necrotizing myopathy are usually treated by rheumatologists. Those with dermatomyositis may work with a dermatologist. Some also consult with a pulmonologist for lung disease problems or a cardiologist for heart problems. Some can also benefit from physical therapy.

It can be hard to manage many doctors. Making sure your doctors talk to each other is important. You can help your doctors by giving them the contact info for your other care providers. There are many times you, your doctors, and your program nurse should talk:

- If you need to be treated for an illness or injury.
- If you are about to start a new therapy or switch medicines.
- If you notice a change in your symptoms.
- If you schedule any sort of surgery.

You should also carry a medical I.D. It should give health care providers info about your treatment plan in an emergency. It should also have your doctors' contact info. This I.D. can be a bracelet, letter, wallet card, or USB drive. You should also carry a list of your medicines. You can ask your doctor or pharmacist for a full list.







Find the right specialist

Do you get the best care? A major medical school or teaching hospital may be good to check out. The Myositis Association (TMA) is associated with several Myositis Research and Clinical Centers around the country. Current or former TMA staff often work at these centers. To learn more, go to: **myositis.org** and search for "Find a Doctor." Also ask your health plan provider which options are covered.

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Coordinate your care for Parkinson's disease

When you have a long-term illness like Parkinson's disease (PD), you should be seeing a neurologist who specializes in movement disorders and your primary doctor. But you may also need others on your care team. This may include your dentist, eye doctor, program nurse, physical and occupational therapists, and mental health professionals.

It can be hard to manage many doctors. Making sure your doctors talk to each other is important. You can help your doctors by giving them the contact info for your other care providers. There are many times you, your doctors, and your program nurse should talk:

- If you need to be treated for an illness or injury.
- If you are about to start a new therapy or switch medicines.
- If you schedule any sort of surgery.
- If you have symptoms that are getting worse.

You should also carry a medical ID It should give health care providers info about your treatment plan in an emergency. It should also have your doctors' contact info. This ID can be a bracelet, letter, wallet card, or USB drive. Also carry a list of your medicines you take and those you should avoid. You can ask your program nurse, doctor, or pharmacist for a full list.







Find a Center of Excellence near you

The Parkinson's Foundation lists 54 medical centers around the world as Centers of Excellence. There are 40 of these in the U.S. Each has teams of doctors who are up to date on the latest PD medications, therapies, and research to provide the best care. These Centers can help your regular doctors make a better care plan for you. Need help finding a Center? Go to: **parkinson.org** and search for "Finding Care" to locate one near you. A movement center at a medical school is another great option. Also ask your health plan provider which options are covered.

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Coordinate your care for rheumatoid arthritis

When you have a long-term illness like rheumatoid arthritis (RA), seeing your rheumatologist isn't enough. Your care team may include your primary doctor, dentists, eye doctors, Ob/Gyn, and others. You may also need other specialists based on your other conditions. You also have access to your program nurse.

It can be hard to manage many doctors. Making sure your doctors talk to each other is important. You can help your doctors by giving them the contact info for your other care providers. There are many times you, your doctors, and your program nurse should talk:

- If you need to be treated for an illness or injury.
- If you are about to start a new therapy or switch medicines.
- If you schedule any sort of surgery.
- If you experience any changes in symptoms or flares.
- If you start a new exercise routine or new diet.
- If you feel any new stress, anxiety or depression.

You should also carry a medical I.D. It should give health care providers info about your treatment plan in an emergency. It should also have your doctors' contact info. This I.D. can be a bracelet, letter, wallet card, or USB drive. You should also carry a list of your medicines. You can ask your doctor or pharmacist for a full list.







Find the right specialist

Do you get the best care? Rheumatologists are experts in treating RA. They can work with your other doctors to make a care plan for you. Need help finding a rheumatologist? Check out **arthritis.org** for rheumatologists in your area. Also ask your health plan provider which options are covered.

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Scleroderma

OCTOBER 2023

Coordinate your care for scleroderma

When you have a long-term illness like scleroderma, one doctor isn't enough. Your care team may include your primary doctor, dentists, eye doctors, OB-GYNs, and others. You will also need one or more specialists, and your program nurse.

It can be hard to manage many doctors. Making sure your doctors talk to each other is important. You can help your doctors by giving them the contact information for your other care providers. There are many times you, your doctors, and your program nurse should talk:

- If you need to be treated for an illness or injury.
- If you are about to start a new therapy or switch medicines.
- If you schedule any sort of surgery.
- If your symptoms suddenly get worse, such as:
 - Your blood pressure gets too high (over 140/90 mm Hg).
 - You have problems eating or unplanned weight loss.
 - You have chest pain, problems breathing, or persistent cough.

You should also carry a medical I.D. It should give health care providers info about your treatment plan in an emergency. It should also have your doctors' contact info. This I.D. can be a bracelet, letter, wallet card, or USB drive. You should also carry a list of your medicines. You can ask your doctor or pharmacist for a full list.







Find the right specialist

Do you get the best care? The National Scleroderma Foundation recommends certain medical centers as Scleroderma Research & Treatment Centers. To locate one near you, go to **scleroderma.org**. To learn about research studies, contact each Center directly. What if you don't live near a Center? Contact the Foundation at: info@scleroderma.org or (800) 722-4673. Ask them about rheumatologists nearby who work with a medical school. These doctors typically have experience treating people with scleroderma. Also ask your health care provider which options are covered.

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Coordinate your care for sickle cell

When you have a long-term illness like sickle cell disease, one doctor isn't enough. Your care team may include your primary doctor, dentists, eye doctors, OB-GYNs, and others. You will also need one or more specialists, and your program nurse.

Being seen at a sickle cell Center of Excellence (COE) can bring together all the specialists you need. If you cannot visit a COE, that is okay. Your local doctor may still be able to work with a center for you. The important part is making sure your doctors talk to each other. You can help your doctors by giving them the contact info for your other care providers. There are many times you, your doctors, and your program nurse should talk:

- If you feel any new symptoms.
- If you need to be treated for an illness or injury.
- If you are about to start a new therapy or switch medicines.
- If you are thinking of starting a family.
- If you have issues getting your medicines.
- If you have issues sticking to your treatment plan.
- If you schedule any sort of surgery.
- If you have been to a sickle cell treatment center lately.

You should also carry a medical I.D. It should give health care providers info about your treatment plan in an emergency. It should also have your doctors' contact info. This I.D. can be a bracelet,







letter, wallet card, or USB drive. You should also carry a list of your medicines. You can ask your doctor or pharmacist for a full list. Your program nurse can also help you make a medical I.D. card.

Find a Center of Excellence near you

Do you get the best care? Sickle cell centers are important to manage your care well. They have teams of doctors who are experts in treating sickle cell. These centers can help your regular doctors make a better care plan for you. Need help finding a center? Check out the National Alliance for Sickle Cell Centers at www.sicklecellcenters.org to find one near you. Also ask your health plan provider which options are covered.

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Epilepsy

OCTOBER 2023

Get the best care for epilepsy

If you have intractable (hard-to-control) epilepsy, you may need an expert. Neurologists who specialize in epilepsy are called "epileptologists." You may find an epileptologist in private practice or at an epilepsy center. Epilepsy centers also have neurosurgeons, neuropsychologists, and staff trained to help people with epilepsy. They also have specialists like psychiatrists for mental health issues.

Those with hard-to-control epilepsy should be assessed at an epilepsy center. Epilepsy centers have access to clinical trials and expertise with new antiseizure medicines. The epilepsy center can work with your regular doctor to give you state-of-the-art care. You may only have to visit to an epilepsy center once. If you live nearby and your seizures continue, you may return more often. The center can share what they learn with your health care team.

Ask your neurologist or primary doctor to help you build a group of care providers. Your care team may include dentists, eye doctors, Ob/Gyns, your program nurse, and others. To help your doctors, give them the contact info for your other providers. There are many times you, your doctors, and your program nurse should talk:

- If you need to be treated for an illness or injury.
- If you are about to start a new treatment or switch medicines.
- If you have issues getting your medicines.
- If you have issues sticking to your treatment plan.
- If you schedule any sort of surgery.
- If you visit an epilepsy center. Ask to have findings sent to your regular doctors.







You should also carry a medical I.D. It should give health care providers info about your treatment plan in an emergency. It should also have your doctors' contact info. This I.D. can be a bracelet, letter, wallet card, or USB drive. You should also carry a list of your medicines. You can ask your doctor or pharmacist for a full list. Your program nurse can also help you make a medical I.D. card.

Find an epilepsy Center of Excellence near you

Need help finding an epilepsy center? The Epilepsy Foundation keeps listings of centers. Check out **www.epilepsy.org** to find one near you. Also ask your health plan provider which options are covered.

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Care Connections[®]

Crohn's Disease

OCTOBER 2023

Get the best care for Crohn's disease

When you have a long-term illness like Crohn's disease, one doctor isn't enough. It can be hard to manage many doctors. A gastrointestinal (GI) specialty center can make your care easier. GI centers have teams of doctors who are experts in treating Crohn's.

The goal of Crohn's treatment is to reduce flares and reach remission. This is the focus of GI centers. You can see many specialists at each center visit and coordinate your care. They are a good source for second opinions. These centers also have more access to clinical trials and new medicines. They can help your regular doctors make a better care plan for you.

If you cannot visit a GI center, that is okay. They may be far away and costly to visit. Your local doctor may still be able to work with a center for you. The important part is making sure your doctors talk to each other. Ask your primary doctor to help you build a group of care providers. This may include a specialist in Crohn's disease. Your care team should also include dentists, eye doctors, Ob/Gyns, your program nurse, and others.

To help your doctors, give them the contact info for your other care providers. There are many times you, your doctors, and your program nurse should talk:

- If you need to be treated for an illness or injury.
- If you are about to start a new therapy or switch medicines.
- If you schedule any sort of surgery.







You should also carry a medical I.D. It should give health care providers info about your treatment plan in an emergency. It should also have your doctors' contact info. This I.D. can be a bracelet, letter, wallet card, or USB drive. You should also carry a list of your medicines. You can ask your doctor or pharmacist for a full list. Your program nurse can also help you make a medical I.D. card.

Find a GI specialty center near you

Need help finding a GI center? The Crohn's and Colitis Foundation keeps listings of practices. Check out **www.crohnscolitisfoundation.org** to find one near you. Also ask your health plan provider which options are covered.

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Care Connections[®]

Ulcerative Colitis

OCTOBER 2023

Get the best care for UC

When you have a long-term illness like ulcerative colitis (UC), one doctor isn't enough. It can be hard to manage many doctors. A gastrointestinal (GI) specialty center can make your care easier. GI centers have teams of doctors who are experts in treating UC.

The goal of UC treatment is to reduce flares and reach remission. This is the focus of GI centers. You can see many specialists at each center visit and coordinate your care. They are a good source for second opinions. These centers also have more access to clinical trials and new medicines. They can help your regular doctors make a better care plan for you.

If you cannot visit a GI center, that is okay. They may be far away and costly to visit. Your local doctor may still be able to work with a center for you. The important part is making sure your doctors talk to each other. Ask your primary doctor to help you build a group of care providers. This may include a specialist in UC. Your care team should also include dentists, eye doctors, Ob/Gyns, your program nurse, and others.

To help your doctors, give them the contact info for your other care providers. There are many times you, your doctors, and your program nurse should talk:

- If you need to be treated for an illness or injury.
- If you are about to start a new therapy or switch medicines.
- If you schedule any sort of surgery.







You should also carry a medical I.D. It should give health care providers info about your treatment plan in an emergency. It should also have your doctors' contact info. This I.D. can be a bracelet, letter, wallet card, or USB drive. You should also carry a list of your medicines. You can ask your doctor or pharmacist for a full list. Your program nurse can also help you make a medical I.D. card.

Find a GI specialty center near you

Need help finding a GI center? The Crohn's and Colitis Foundation keeps listings of practices. Check out **www.crohnscolitisfoundation.org** to find one near you. Also ask your health plan provider which options are covered.

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Coordinate your care for HIV

When you have a long-term illness like HIV, your HIV health care provider may not be enough. Your care team may include your primary doctor, dentists, dietitians, and others. You may also need one or more specialists based on your other conditions. You also have access to your program nurse.

It can be hard to manage many providers. Making sure your providers talk to each other is important. You can help your provider by giving them the contact info for your other providers. There are many times you, your providers, and your program nurse should talk:

- If you need to be treated for an illness.
- If you are about to start a new therapy or switch medicines.
- If you schedule any sort of surgery.
- If you experience any new symptoms.
- If you have issues getting your medicines.
- If you have issues sticking to your treatment plan.
- If you feel any new stress.

You should also carry a medical ID. It gives providers info about your treatment plan in an emergency. It can also have your providers' contact info. This ID can be a bracelet, letter, wallet card, or USB drive. You should also carry a list of your medicines. You can ask your provider or pharmacist for a full list.







Find the right specialist

Do you get the best care? Infectious disease (ID) specialists are experts in treating HIV. They can work with your other providers to make a care plan for you. Need help finding an ID specialist? Check out **locator.hiv.gov** for an ID specialist in your area. Also ask your health plan provider which options are covered.

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Coordinate your care for HAE

When you have a long-term illness like hereditary angioedema (HAE), one doctor isn't enough. Your care team may include your primary doctor, dentists, eye doctors, Ob/Gyns, and others. You will also need one or more specialists, and your program nurse.

Being seen at an HAE Center of Excellence (COE) can bring together all the specialists you need. If you cannot visit a COE, that is okay. Your local doctor may still be able to work with a center for you. The important part is making sure your doctors talk to each other. You can help your doctors by giving them the contact info for your other care providers. There are many times you, your doctors, and your program nurse should talk:

- If you need to be treated for an illness or injury.
- If you are about to start a new therapy or switch medicines.
- If you schedule any sort of surgery or dental procedure.
- If you are treated for high blood pressure.
- You want to start birth control or hormone therapies.
- You become pregnant.
- If your primary doctor treats an attack.
- If you plan to travel or move to a new city.
- In case of an emergency. The local ER or hospital needs to know who you are in case of an attack. Before an attack happens, ask the hospital to keep your treatment plan on file. Your HAE specialist can also help you talk to the hospital/ER.







You should also carry a medical I.D. It should give health care providers info about your treatment plan in an emergency. It should also have your doctors' contact info. This I.D. can be a bracelet, letter, wallet card, or USB drive. You should also carry a list of your medicines. You can ask your doctor or pharmacist for a full list. Your program nurse can also help you make a medical I.D. card.

Find the right specialist

Do you get the best care? HAE specialists are experts in treating HAE. They can work with your other doctors to make a better care plan for you. Need help finding a specialist? Check out the U.S. Hereditary Angioedema Association listings at **www.haea.org** for specialists in your area. Also ask your health plan provider which options are covered.

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