

young Gauchers patients



Gauchers
ASSOCIATION

Young Gaucher Patients

Transitioning to Adult care

If you are a teenager/young adult living with Gaucher disease, you face some unique challenges. Not only do you have to juggle schoolwork, activities and post-graduation planning, you also have to start learning how to manage your own health.

Taking Charge of Your Health

As you get older, it is important to start being an advocate for your own health. You will want to include your parents along the way so they can help you make informed health decisions.

Key steps to consider taking include:

Understanding your medication: Know which medications you take for various issues, as well as how much and how often to take them.

Identifying your medical issues: As a young adult, you want to be able to talk about your major medical issues with any doctor you may need to see.

Planning your appointments: Get involved in scheduling your own appointments, considering your education and activity schedules to avoid conflicts.

Visiting doctors independently: At some point, you will probably want to meet with your doctor on your own without a parent around. Depending on your age, your parents may also let you travel to and from appointments alone. What about a combination of having some time on your own and then later inviting your parents in, this could be a transition.





ERT Infusion tips for Teenagers

If you have received ERT infusions since childhood, the process may not be a big deal to you anymore. However, if you are newly diagnosed, you might be a little freaked out about getting an intravenous (IV) infusion.

Here are a few tips to help make your infusion easier:

Take deep breaths: Deep breathing can help you relax while the IV is inserted.

Distract yourself: Focusing on something else can help you relax, whether it's listening to music or texting a friend. Just make sure you are not holding your phone with the hand the nurse needs for your IV.

Pass the time: It can be boring waiting for your infusion to be prepared and sitting around during the infusion. Be sure to take something along to pass the time like homework, a book or a tablet for watching movies.

What about watching how to make up your treatment with a possible future involvement in managing your own treatment?

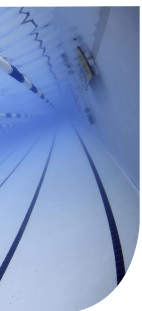


Participating in Sports and Activities

With proactive management of Gaucher disease, many teens/young adults can lead busy and active lives. That said, you may need to consider physical limitations or the need for infusions when it comes to activities. Many people with Gaucher disease still participate in activities like:

- Sports
- Extracurricular activities like theatre and dance
- Working or studying away from home

Having Gaucher disease does not have to totally interfere with your life. The important part is talking about your plans with your specialist team so you can limit any impact on your health.



Dealing with Gaucher Disease

The reality of living with Gaucher disease may weigh you down at times. For instance, having to make your infusion appointment every 2 weeks can be a pain, especially if it means missing fun activities or important events.

It is important to remember that Gaucher disease does not define you. Many teens/young adults find talking to someone can help them sort through issues like school, parents, living with Gaucher disease and feeling different from others. You may also find it useful to connect with others who are dealing with the same issues around Gaucher disease.

Transitioning to University and Adulthood

As you get ready to leave home, you will have to learn how to manage your Gaucher disease and treatment on your own.

Key issues to consider include:

Sticking with treatment: It is extremely important to remember that stopping treatment just because you feel better can lead to severe problems.

Accessing doctors: You may need to consider staying close to a Gaucher specialist as you decide where to go to college or university, or study abroad.

New treatment options: Once you are 18 years old, you may have the option of switching to substrate reduction therapy (oral medication) for Gaucher disease. You can talk to your Gaucher specialist about making the switch.

