Living Well with Gaucher

Around 125,000 people are living with Gaucher in the world. You are not alone. This guide, created by Gaucher patients and caregivers, offers advice to help you manage your journey, especially for those who are newly diagnosed.

You are not alone. We are here to help.

1. Connect and Support

Connecting with others who understand your journey can be a lifeline. A strong support network will bring security and comfort to your daily life.

JOIN ONLINE COMMUNITIES

Connect with others on Facebook to share your story and create a sense of community

BUILD YOUR PERSONAL NETWORK:
Surround yourself with a support network that includes family, friends, and trusted healthcare professionals. Talk openly with loved ones about the disease and the kind of support you need.

SHARE YOUR STORY:
Telling your own story about living with Gaucher allows others to learn from your experiences and helps them feel a sense of belonging.

FIND PATIENT ORGANISATIONS
You can find patient organisations by visiting the International Gaucher Alliance website

https://tinyurl.com/4nh28wd8

https://tinyurl.com/4mbpjx9p

General Support

https://tinyurl.com/f9c477wb

Support General Group

https://tinyurl.com/yc5jyk3d

Types 2 & 3 Specific

IGA INTERNATIONAL GAUCHER ALLIANCE
Driven by passion for patients
International advocacy for Gaucher patients since 1994

IWGGD The International Working Group on Gaucher Disease

Charity Number: 1192011

2. Understanding Your Journey

Knowledge gives you power and helps you feel more in control.

LEARN ABOUT TREATMENTS:
Stay informed about the treatments available for Gaucher disease at

gaucheralliance.org

You can also ask your healthcare team about current research in the field.
PARTNER WITH YOUR HEALTHCARE TEAM:
Build a strong relationship with your Gaucher specialist. Prepare questions for your appointments to ensure you get the information you need.

3. Making Treatment Easier

Finding a routine that works for you can make a big difference.

HOME THERAPY:
For information on home therapy, visit gaucheralliance.org

COMFORT DURING INFUSIONS:
Make your infusion time more relaxing. Bring a book, listen to music, or connect with others online to pass the time.

MANAGE FATIGUE:
Pace your activities and prioritise tasks to manage your energy levels. Communicate how you're feeling with your healthcare team and loved ones.

COPE WITH PAIN:
Discuss pain management strategies with your healthcare team. You can also explore gentle movement and relaxation techniques.

4. Nurturing Your Well-being

Self-care is an important part of living well with a chronic condition.

PRACTICE SELF-CARE: Focus on a balanced diet and engage in gentle exercise as you are able. Prioritise consistent and restful sleep.
ENJOY LIFE: Find activities that bring you joy, keeping your limitations and other health conditions in mind.
BUILD RESILIENCE: Focus on coping strategies and positive thinking. Seek emotional support from friends, family, or a therapist if needed.
STAY ON TRACK: Follow your prescribed treatment regimen and attend all scheduled check-ups and control tests.

5. A SECTION FOR CAREGIVERS

Being a caregiver is avital role. Remember to also care for yourself.

SUPPORT THE PATIENT: Learn how to provide emotional support and help the patient manage their symptoms and treatments.

MANAGE YOUR OWN STRESS: Taking care of yourself is not selfish. Find ways to de-stress and seek support from other caregivers or support groups.

COMMUNICATE EFFECTIVELY: Work with the patient and the healthcare team to ensure everyone is on the same page.

6. PRACTICAL AND FINANCIAL MANAGEMENT

Livingwith a chronicconditionofteninvolvesadministrative work.Get support from the national organisation for Gaucher disease or Rare Diseases.

ORGANISE YOUR PAPERWORK: Learn how to handle administrative documentation, insurance claims, and other paperwork. This will help you manage your financial burdens.

FIND FINANCIAL ASSISTANCE: If needed, look for financial assistance resources and advice on how to ensure you are financially covered.

