Infusion day planner for parents of children with Gaucher disease

For some children with types 1 and 3 Gaucher disease, enzyme replacement therapy infusions are a regular part of life. This guide can help you prepare, stay organized, and support your child through their infusions.

1 What to expect

Infusions usually happen every two weeks, last about 1-2 hours (plus prep and wait time), and are administered in a hospital or infusion clinic.

Your child's vitals will be monitored before, during, and after treatment, and the facility will give you access to a nurse or infusion specialist to answer any questions you may have.

After your child's treatment, they may experience mild side effects such as headache, fatigue, or low-grade fever.

2 Questions to ask your care team

Having a few questions ready can help you feel confident and informed.

- **Are there any pre-infusion medications we need to give at home?**
- **What should we watch for after today's infusion?**
- **Can we adjust the infusion schedule if needed for school or family travel?**
- **How should we handle any side effects?**
- **Are there local resources for Gaucher disease support or child life services?**

Continues on page 2

Continued from page 1

③ What to bring: Infusion day checklist

▶ For your child

☐ Comfort item (favorite blanket or stuffed animal)
☐ Headphones and tablet (preloaded with games, shows, or music)
☐ Favorite snacks or a treat (check to see if food is allowed)
☐ Extra clothing or cozy layers
☐ Medical ID or treatment logbook
☐ Activity books, stickers, or crayons

▶ For you

☐ Phone charger or portable power bank
☐ Water bottle and snacks
☐ Notebook or symptom tracking app
☐ Something to read or work on
☐ Headphones and relaxing music
☐ Insurance card and photo ID

④ How to pass the time

▶ For your child

☐ Audiobooks or kid-friendly podcasts
☐ Simple crafts like pipe cleaner animals or sticker mosaics
☐ Digital drawing apps or coloring games
☐ Story time or journal entries
☐ Calm breathing exercises or child-led meditation

▶ For you

☐ Use the time for personal reflection or journaling
☐ Catch up on a book or podcast
☐ Practice deep breathing or light stretching
☐ Organize your to-do list for the week
☐ Enjoy a coffee or bring a favorite snack

Creating a calm, predictable infusion day routine can help your child feel more at ease. Consider a special post-infusion reward, a consistent “infusion bag” you pack each time, or a shared ritual like reading a chapter of a book together.

These small but consistent efforts play a meaningful role in supporting your child’s emotional well-being and long-term treatment success.