



**Practical handbook**

**You  
Me &  
pLGG**



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# hello



## & intro

### What is this handbook for?

If you're reading this, you or someone you love has been diagnosed with pLGG. You've probably already received a lot of information. Maybe it's not clear, or feels like too much at once. It's a lot to take in, and that's okay.

This handbook is designed to support you and your family through life with pLGG. It will help you stay organized, express how you're feeling, and feel confident and involved throughout your journey. It doesn't explain the medical details—that's covered in your pLGG guide. Instead, this handbook focuses on you: your routines, your emotions, and the practical day-to-day moments that matter.

### Inside, you can:

- Keep key contacts and support information in one place
- Make sense of new terms and get practical answers
- Prepare for and track appointments
- Record routines, notes, questions and reminders
- Set goals and manage your wellbeing
- Express your experiences, concerns, worries and wins

# How to use this handbook:

- You can write, doodle, or stick photos in it—make it your own!
- There's space for your thoughts, questions, and plans. Like this!



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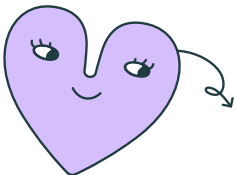
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- Use the pages you need, when you need them.
- Skip what doesn't feel useful right now.
- Bring it to appointments. Ask your care team to help you fill things in.

This is a tough journey, but you're surrounded by people who care: your family, your medical team, and others who understand what you're going through.



**you are not alone**

There is no right or wrong way to feel.  
There is no such thing as a silly question.

# So... What is pLGG anyway?

You'll find all the important medical facts in your pLGG guide. This section is for your story and what you've learned so far.

## "Here's what my diagnosis means to me:"

(Add anything you want to remember, or questions you still have)



.....

.....

.....

.....

## Worries and misunderstandings

→ "One thing that worries me about pLGG is..."

.....

.....

→ "One thing I wish people understood about what I'm going through..."

.....

.....

## Common

# myths

You might have heard a lot of things about brain tumors.  
Not all of them are true! For example...

MYTH

*“pLGG is the same as adult brain cancer.”*

FACT

pLGG is a different type of tumor than those seen in most adults. It usually grows slowly.

MYTH

*“You can always see if someone is sick with pLGG.”*

FACT

Many symptoms of pLGG (like tiredness, headaches, or worries) are invisible. Just because someone looks okay doesn't mean they feel okay.

MYTH

*“Having a brain tumor means you can't do the things you love anymore.”*

FACT

Many children and teens with pLGG keep doing activities, sports, and hobbies they enjoy—sometimes with a few adjustments.

MYTH

*“People with pLGG have to follow a special diet.”*

FACT

Most people with pLGG won't need to change their diet, but it's always best to check with your doctor just in case.



**“Here's one thing I've heard about pLGG that I'm not sure is true:”**

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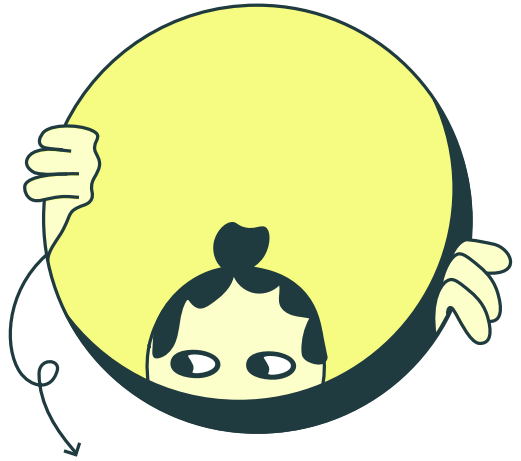
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**Got questions: See page 13 for quick answers.**

# Who's on your team?

When you have pLGG, you get a whole team of people who want to help you feel your best. Sometimes, it can be hard to remember everyone's names or who to go to for help, so this page is here to help you keep track.



## Who's who?

Here are some people who might be on your team. You can write their names in the spaces below:

→ Oncologist: Doctor who diagnoses and treats cancer and tumors

.....

→ Other specialists: Radiologist, neurologist, physical therapist, etc.

.....

.....

→ Nurse: Helps with medicines, check-ups, and answers lots of questions

.....



## remember

It's okay to forget names or to feel nervous about meeting new people. Everyone on your team wants to help.



# Say what?

## The pLGG word guide

Ever hear a word at the hospital and think, “Wait, what does that mean?” You’re not alone. Medical words can sound complicated, but you can totally learn to “speak the lingo.”

This section is your guide to some of the words and phrases you might hear along your pLGG journey. Remember, it’s okay if you don’t know what something means right away. Learning new words takes time!

### Biopsy

A small piece of tumor that doctors take to look at under a microscope so they can learn more.



### Brain tumor

A lump made of cells that are growing in a way they shouldn’t inside the brain.

### Cell

A tiny building block inside the body. Tumors are created when some cells start growing in an unusual way.

### Glioma

A type of brain tumor that starts in the cells that support and protect the brain.

### Grade

A way doctors describe how a tumor behaves. When doctors say “low-grade,” they mean Grade 1 or Grade 2:

- **Grade 1:** Grows very slowly
- **Grade 2:** Still growing slowly, but may need closer watching over time

### Morbidity

Health problems or complications caused by an illness or its treatment. This could be anything from feeling tired to something more serious.

### MRI

A special type of scan that helps doctors see inside your body, especially your brain.

### Oncologist

A doctor who specializes in treating cancer and brain tumors.

### Refractory

When a tumor doesn't get smaller or keeps coming back even after trying different treatments.

### Targeted therapy

A type of treatment that is designed to attack certain tumor cells while affecting fewer healthy cells.



If you come across a word you don't understand, write it down so you can ask your care team to explain.

→ “Words I want to ask about:”

.....

.....

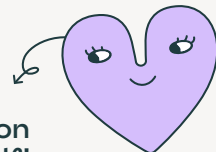
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No question is too small!



# Need to know: quick answers

You probably have A LOT of questions. Guess what? That's totally normal. This section is all about answering the things that patients and families most often wonder about. Plus, there's space to write your own questions on page 16.



## Can I still go to school?

Most kids with pLGG keep going to school. You might need some changes, or extra help. Your care team can help you and your teachers work out what's best.

## Will my friends treat me differently?

Sometimes, people might not know what to say or do. Most of the time, your friends just want to be there for you. If you want, you can help them understand what's happening.

## What if I feel too tired to do what I used to?

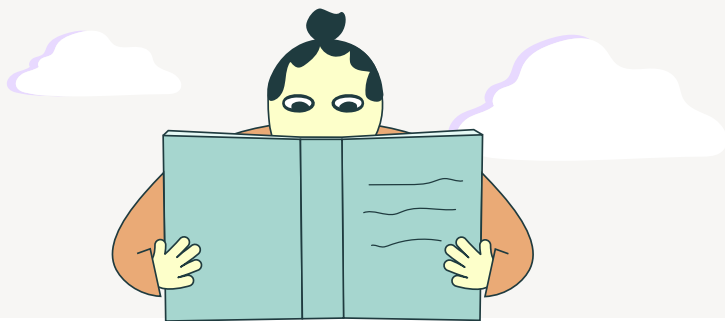
Feeling more tired is common. It's okay to rest or take things slower. Tell your family, friends, and teachers how you're feeling because they want to help.

## What should I do if I feel really worried or sad?

Everyone feels this way sometimes. Talk to someone you trust like your family, a friend, or your care team. You're never alone.

## Can I still play sports?

Most of the time, you can still enjoy playing sports. Sometimes you might need to take breaks, try gentler activities, or avoid certain contact sports. Always check with your care team about what's safe for you. The most important thing is to listen to your body and go at your own pace.



# you



PARENT

## How do I talk to my child's school about pLGG?

Start by meeting with a key staff member (teacher, school nurse, or head of year). Share information about pLGG (using your pLGG guide or a letter from your care team) and discuss what your child might need, like extra time for assignments, rest breaks, or time off for appointments.

## What support can my child get at school?

Many schools can make accommodations, such as flexible schedules, reduced homework, quiet spaces for breaks, or access to counseling. Ask your school what's possible, and involve your care team if you need extra support.

## How do I talk to my employer about needing time off or flexible hours?

Let your employer or HR department know about your child's diagnosis as soon as you feel comfortable. Explain any appointments or hospital stays you may need to attend, and ask about leave options or flexible working. Bringing a letter from the hospital can help.

## What if my workplace doesn't understand my situation?

Many employers want to help, but don't always know how. Be honest about what your family needs. If you need extra support, ask your care team about available advocacy resources.

## How can I help siblings understand and feel included?

Give siblings simple, honest information, and encourage them to ask questions. Let them know it's okay to have mixed feelings. Involve them in routines or special family time when you can.

# Wondering about?

## Don't forget to ask...

Here are some things you might want to ask at appointments. Use them to guide conversations with your healthcare team (check them off if you already know the answer!):

→ What is my treatment plan for the next few weeks?

→ Are there any side effects I should watch out for?

→ Who should I call if I have a question at home?

→ Can I still do my favorite activities?

→ When is my next scan or check-up?

→ Who do I contact for emergencies, appointments, or issues at school?

→ If I have worries, who can I talk to?

→ How will we know that the treatment is working?

Find your own space at the back of this handbook—write, draw, or list what matters most to you.

## Write your own questions

“Questions I want to ask my care team at my next appointment:”



01. ....
02. ....
03. ....
04. ....
05. ....
06. ....
07. ....
08. ....
09. ....
10. ....
11. ....
12. ....
13. ....
14. ....
15. ....

(Use this space for anything—big or small!)

# Your pLGG organizer

## Why planning helps

When you're dealing with pLGG, there's a lot to keep track of—appointments, medicines, routines, and new faces on your care team. Planning ahead (even a little) can make things feel less overwhelming and give your family more time for the things you enjoy.

### Your appointments tracker

Use this table to write down your upcoming appointments, so you never miss a date, and can get ready for each visit.



Date	Time	Who with	Where	Notes

## Treatment schedule

Knowing what's coming up can help everyone feel more prepared.

Write out your treatment schedule, or ask your care team to help fill this in:



Day/Date	Treatment/ Medicine	Where/How	Who gives it	How did it go?

# Clinic day ready

## Checklist for managing routines

When there's a lot going on, it's easy to forget little things, especially before a clinic visit. Ticking things off as you go can make life feel a bit more manageable and means you're less likely to leave something important behind.

→ Feel free to add your own items to make it work for you!

- Packed bag for hospital/clinic
- Brought handbook and notes
- Questions ready for care team
- Medicine packed
- Snacks and comfort items packed
- Contact numbers saved

... Add your own:

- 
- 
- 
- 
- 
-

## → Key contacts

Keep this info handy:

Name	Role	Phone/Email	Why call
	Main doctor		
	Nurse		
	Hospital		
	School		
	Other		

### Practical tips

- Keep your handbook in your bag or by your bed so it's always ready.
- Use colored pens, stickers, or drawings to make it fun and easy to spot important things.
- Ask someone you trust to help you fill in tricky bits—it's a team effort!
- If you miss any treatments or appointments, always talk to your healthcare team as soon as possible.

# Mission possible!

## Why set goals?

When so much feels out of your control, setting your own goals (no matter how small) and taking action towards them can be really helpful. Your goals might be about health, school, hobbies, friendships, or anything else that matters to you.

A goal is just something you'd like to work towards—one step at a time.

### How to use this section

- Use this section to set goals for yourself (or as a family).
- Your goals can change! It's okay to start small, and to celebrate every little win.
- Ask your family or care team to help you if you get stuck or need ideas.

### Goal examples

- “I went back to my dance class for a lesson.”
- “I ate breakfast every day this week.”
- “I asked a question at my hospital appointment.”
- “I messaged my friend to say hi.”
- “I told my teacher how I was feeling.”
- “I tried a new hobby and had fun.”

## → Goal-setting template

What's my goal?

*"What would you like to achieve or get better at?"*

.....

What's the challenge?

*"What could get in the way or make this tricky?"*

.....

What's one small step I can take?

*"What's the first thing you can do to get started?"*

.....

Who can help me?

*"Who could give you support, advice, or encouragement?"*

.....

How will I know I'm making progress?

*"How will you be able to tell if you're getting closer to your goal?"*

.....

How will I celebrate if I reach my goal?

*"What's something fun or special I can do to reward myself?"*

.....

## → Balancing life and medical needs

Sometimes it's hard to balance "normal life" with appointments, rest, and medicine. Here are a few ideas:

- Make a weekly planner for fun activities between hospital days.
- Ask your healthcare team how to adjust your plans if you're not feeling great.
- Remember: it's okay if plans change.
- Every step counts, even if it's tiny. Celebrate your progress.

# Thriving with pLGG

pLGG might change some things, but there are still lots of ways to enjoy life and look after yourself. Taking care of your body and mind can help you feel stronger, happier, and more in control, even on tough days.

## body & mind

### Tips for staying healthy

#### Sleep



- Try to go to bed and wake up around the same time each day.
- Create a bedtime routine (reading, listening to music, or a warm bath).
- If you have trouble sleeping, talk to your care team for ideas.

#### Nutrition



- Eat a variety of foods: fruit, veggies, protein, and snacks you enjoy.
- If some foods taste strange or you're not hungry, that's okay. Tell your nurse or doctor—they may be able to help.
- Drink plenty of water!

#### Activity & movement



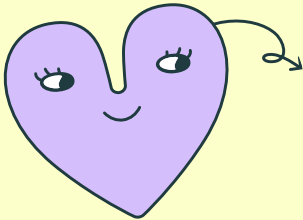
- Stay as active as you feel able—gentle walks, stretching, or dancing at home all count!
- If you need to take it slow, that's okay. Rest is important too.

## Fun, hobbies & social life



- Make time for things that make you smile: games, art, music, reading, video calls, or time with friends.
- If you can't see friends in person, try sending a message, drawing a picture, or playing an online game together.

# emotional wellbeing



It's normal to have good days, bad days, and in-between days. Here are some ways to look after your feelings:

- Talk to someone you trust about how you're feeling—family, friend, or someone on your care team.
- Try writing or drawing in your journal.
- Practice simple breathing exercises when you feel worried. Breathe in for four counts, out for four counts. Try this a few times!
- Make a “feel-good” list: songs, activities, people, or places that help you feel calm or happy.

# Checking in: thoughts, feelings & concerns



These pages are a safe space to write down what's on your mind—anything at all! Remember: every feeling and concern is important and worth talking about with someone you trust.

## prompts & ideas

### Prompt examples



- Something that made me happy today:
- Something that made me sad/worried/frustrated:
- A question I have:
- Something I'd like help with:

### Ideas for using these pages



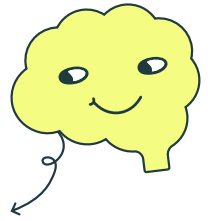
- Fill them in every day, once a week, or whenever you want.
- Use emojis, words, or drawings—whatever feels easiest.
- If you run out of space, scan the QR code to print off a new page.



All your feelings are valid. You don't have to figure things out alone. Sharing what's on your mind is a brave and important step.

# My check-in chart

Thoughts, feelings & concerns

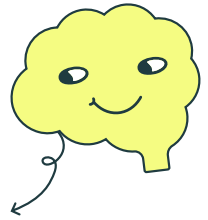


Date	What's on my mind? (Describe the worry or win you are focused on)	How I'm feeling	Who can help? (Consider who to talk to in your circle)	What I want to ask (Write what you'd like to share at your next visit)

# checking in

(continued)

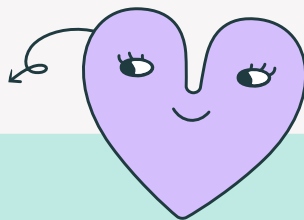
Date	What's on my mind? (Describe the worry or win you are focused on)	How I'm feeling	Who can help? (Consider who to talk to in your circle)	What I want to ask (Write what you'd like to share at your next visit)
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<b>Date</b>	<b>What's on my mind? (Describe the worry or win you are focused on)</b>	<b>How I'm feeling</b>	<b>Who can help? (Consider who to talk to in your circle)</b>	<b>What I want to ask (Write what you'd like to share at your next visit)</b>
-------------	--	----------------------------	---	---


# Make it yours

This is your journey. This space is for you.  
There's no right or wrong way to use it!



- Doodle, draw, or paint.
- Add photos.
- Write your story, poems, or lists.
- Jot down dreams, plans, or feelings.
- Make a memory page for something special.

→ Whatever you put here is important, just because it matters to you.

Today I'm proud of: .....

One thing that helped me today: .....

→ Whatever you put here is important, just because it matters to you.

Someone I'm grateful for is: .....

Something that made me laugh: .....

→ Whatever you put here is important, just because it matters to you.

→ Whatever you put here is important, just because it matters to you.

**Printed Booklet**  
Section Tab Dividers

Intro

Diagnosis

Care team

Glossary

FAQs

Planning

Goals

Wellbeing

My space

# Your journal & guide



## You & Me & pLGG

References: National Cancer Institute. Children with Cancer: A Guide for Parents. 2015. Available from: <https://www.cancer.gov/publications/patient-education/children-with-cancer.pdf>. Accessed December 2025. National Cancer Institute. PDQ Cancer Information Summaries, Childhood brain and spinal cord tumors treatment overview. [Internet] 2021. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK65913/>. Accessed: December 2025. SIOP Europe. Standard Clinical Practice Recommendations for Low Grade Gliomas. Available from: <https://siop.eu/media/documents/escp-low-grade-gliomas-lgg.pdf>. Accessed: December 2025. The Children & Young People's Cancer Association. Looking after yourself. 2025. Available from: <https://www.cclg.org.uk/about-cancer/my-child-and-cancer/my-child-has-cancer/looking-after-yourself>. Accessed December 2025. Canadian Cancer Society. Targeted therapy. 2025. Available from: <https://cancer.ca/en/treatments/treatment-types/targeted-therapy>. Accessed December 2025. Pediatric Brain Tumor Foundation. Starfolio Resource Guidebook for Newly Diagnosed Families. 4th ed. 2024. Available from: <http://www.rethinkplgg.com/about-plgg>. Accessed December 2025. National Cancer Institute. Children with Cancer: A Guide for Parents. 2015. Available from: <https://www.cancer.gov/publications/patient-education/children-with-cancer.pdf>. Accessed December 2025. National Cancer Institute. PDQ Cancer Information Summaries, Childhood brain and spinal cord tumors treatment overview. [Internet] 2021. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK65913/>. Accessed: December 2025. Musial-Bright L, *et al*. Pediatric low-grade glioma survivors experience high quality of life. *Child's Nervous System*. 2011;27(11):1895-1902. Pediatric Brain Tumor Foundation. Starfolio Resource Guidebook for Newly Diagnosed Families. 4th ed. 2024. Available from: <https://curethekids.org/resource/support-for-families/educational-tools/newly-diagnosed-resource-notebook/>. Accessed December 2025. National Cancer Institute. Dictionary of Cancer Terms - Morbidity. Available from: <https://www.cancer.gov/publications/dictionaries/cancer-terms/def/morbidity>. Accessed December 2025. National Cancer Institute. Dictionary of Cancer Terms - Refractory. Available from: <https://www.cancer.gov/publications/dictionaries/cancer-terms/def/refractory>. Accessed December 2025. Macmillan Cancer Support. Cancer and your emotions. Available from: <https://www.macmillan.org.uk/cancer-information-and-support/treatment/coping-with-treatment/cancer-and-your-emotions>. Accessed: December 2025. Cancer Research UK. Recovering after children's brain surgery. Available from: <https://www.cancerresearchuk.org/about-cancer/childrens-cancer/brain-tumours/treatment/recovering-after-brain-surgery>. Accessed December 2025. National Cancer Institute. Emotions and Cancer. Available from <https://www.cancer.gov/about-cancer/coping/feelings>. Accessed December 2025. Stavleu DC, *et al*. Support Care Cancer. 2024;32(7):419. The Children & Young People's Cancer Association. Looking after yourself. 2025. Available from: <https://www.cclg.org.uk/about-cancer/my-child-and-cancer/my-child-has-cancer/looking-after-yourself>. Accessed December 2025. Macmillan Cancer Support. Returning to work. Available from: <https://www.macmillan.org.uk/cancer-information-and-support/impacts-of-cancer/work-and-cancer/returning-to-work>. Accessed: December 2025. <https://curethekids.org/resource/support-for-families/educational-tools/newly-diagnosed-resource-notebook/>. Accessed December 2025. The Royal Marsden NHS Foundation Trust. Low-grade glioma. 2023. Available from: <https://patientinformation.royalmarsden.nhs.uk/document/download/102>. Accessed December 2025. Rethink pLGG. Inside pLGG [Internet]. n.d. Available from: <https://www.rethinkplgg.com/inside-plgg>. Accessed December 2025. Rethink pLGG. Testing [Internet]. n.d. Available from: <https://www.rethinkplgg.com/testing>. Accessed December 2025. Ojemda (tovorafenib) Patient Information Leaflet (PIL) 2025 [DRAFT].

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