

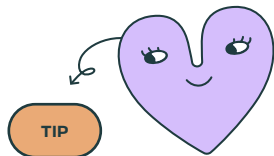
A guide for families
living with **pLGG**

You
Me &
pLGG

How this guide can help

Finding out that pLGG—a type of brain tumor that affects children—is now part of your life can be really hard. It's completely normal to feel scared, confused, angry, or sad. However you're feeling right now, please know you're not alone and we're here to help.

This guide is mainly for parents and carers. It's designed to help you make sense of the journey ahead. Inside, you'll find clear explanations of pLGG, possible treatment options for your child, medical terms you may hear from their medical team, and ways to get extra help and support. Along the way, you'll see helpful prompts and reminders designed to spark conversation and offer reassurance for both you and your child.



Take things one day at a time.
It's normal for feelings to change from day to day.





UP

THE RIGHT PLACE

Making the most of this guide

This is your go-to reference for your pLGG journey,— here to support you, not replace advice from your healthcare team. Use it to review information, jot down questions, and help make sense of what’s been discussed during appointments.

If you’re a parent or caregiver, use this guide as a tool to help explain things in a way that fits your child’s needs and come back to it whenever you need a little extra support.

Supporting your child— and yourself

Every child's experience with pLGG is different. It's normal for everyone—children, parents, and siblings—to feel a mix of emotions after a diagnosis. Understanding what your family might be processing can help you guide them through changes.

Children may worry about their bodies, missing school or friends, feeling different, time away from family, treatment, pain, or even wonder if they did something wrong. Some ask lots of questions, while others stay quiet, even if they're anxious. Remember, silence doesn't mean they're not concerned, so it's important to reassure them.

There's no single "right" way to talk with your child. Honest answers are best, even if it's "I don't know, but we can ask together." Your healthcare team can guide you on what to say and how much to share.

Looking after yourself matters too. Try to eat and sleep well, stay active if you can, and take regular breaks—self-care isn't selfish, and it helps you be there for your child and family. Stay connected with others and reach out when you need it. You may have a wider circle of support than you realize, and just letting someone know you need a hand or a listening ear can make things feel more manageable.

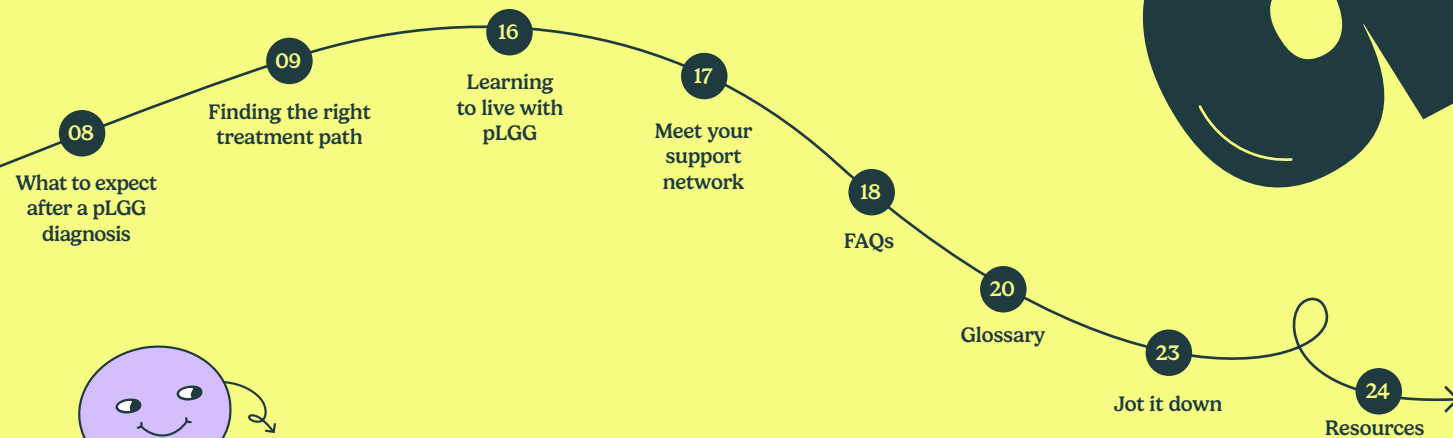
Childhood Cancer International (CCI) Europe provides information and support for parents. Visit them at <https://ccieurope.eu/>

You can also find emotional support in your country by connecting with your local patient organization: [markets to insert contact details of local patient organization(s)].

Starting your pLGG journey...



pLGG



REMEMBER

Every child reacts to a diagnosis differently. Let your child know it's okay to feel however they feel.

What is pLGG?

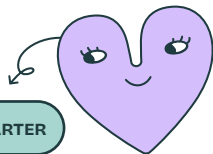
pLGG is the most common type of brain tumor in children

pLGG is a type of abnormal growth, also known as a **tumor**, in the brain or spinal cord.

Tumors in the brain are called **gliomas**. There are different types of gliomas, which are grouped by what they look like under a microscope and how fast they grow.

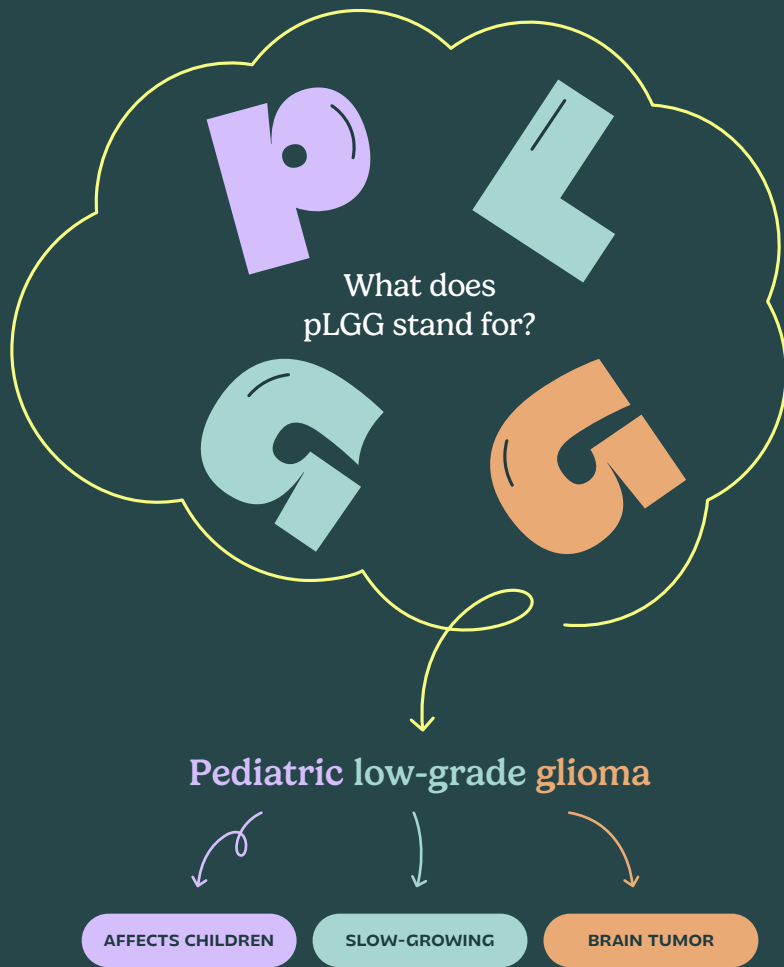
Low-grade gliomas grow **more slowly** than other types.

Thanks to advances in how we understand and treat pLGG, we're now better equipped than ever to manage it and help you and your child live life as fully as possible.

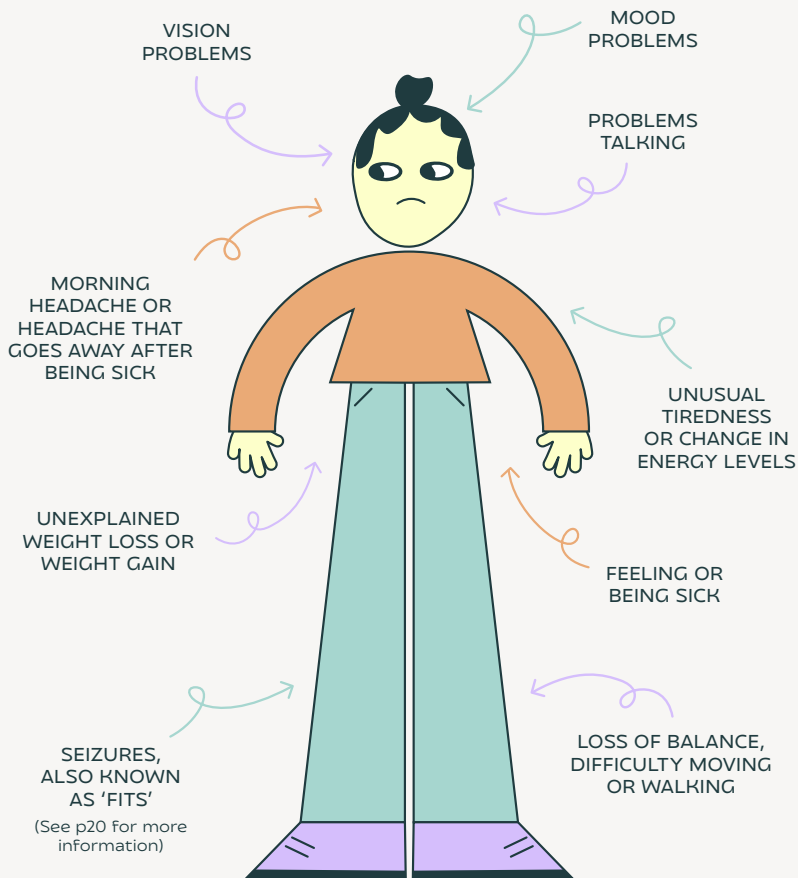


CONVERSATION STARTER

Ask your child: "Is there anything about your brain you're curious about? If we don't know the answer, let's write it down and ask the doctor together."



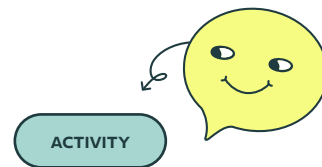
Some of the most common symptoms include:



How pLGG affects the body

Everyone experiences pLGG differently

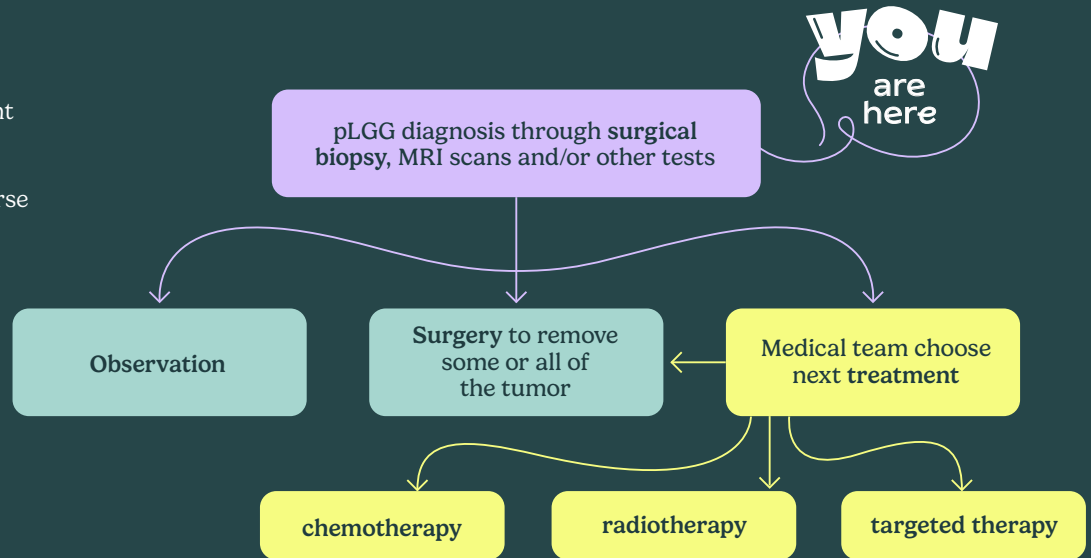
Symptoms of pLGG depend on the tumor's size and where it is in the brain. This means different people can experience different symptoms, even if they have the same diagnosis.



Keep a symptom diary together and share it with your doctor.

What to expect after a pLGG diagnosis

Your child is just starting out on their pLGG treatment journey and it may feel like there are an overwhelming number of treatment options available to them. Your healthcare team will always work with you to decide on the best course of action. Use this map as a guide to understand which direction their pLGG journey could go next.



Finding the right treatment path

Your healthcare team will work with you to choose the best approach

There are lots of different ways to manage pLGG. The same approach isn't right for everyone. The best option depends on the size and type of the tumor as well as where it is in the brain. Your healthcare team will guide you, but the most common approaches are:



SURGERY, BIOPSY & MOLECULAR TESTING

Often the first step is an operation to physically remove as much of the tumor as possible.

As part of this initial surgery, a small sample of the tumor is taken (a biopsy) and tested. This is to help your healthcare team personalize your next treatment to your specific type of pLGG.



OBSERVATION

When your doctor chooses to 'watch and wait' to see if the tumor changes in size over a few months.



RADIATION THERAPY

Kills tumor cells or slows their growth by damaging them with radiation, but can affect healthy cells nearby.



CHEMOTHERAPY

A medicine that attacks pLGG tumor cells. As this medicine isn't targeted, it can also attack some healthy cells.



TARGETED THERAPY

Targets proteins within cells that cause cancer growth, but only available for specific types of pLGG.

Whichever option you and your healthcare team decide on, it's okay to have questions and concerns. It's important to know each treatment will have an impact on daily life—whether it's learning to deal with the side effects, needing to take medication regularly, or having to go to hospital appointments. Find out more about the different treatment processes on the following pages.

CONVERSATION STARTER



Ask your child: "Are there things you want to ask about what the treatment could be like?"

Surgery & biopsy



WHAT IS SURGERY & BIOPSY?

The initial surgery will also include a biopsy. This is an operation to remove a piece of skull (called a craniotomy), gather cells from the tumor for testing, and confirm a pLGG diagnosis. In some cases, the tumor can be removed at the same time, which is called resection.



WHAT WILL HAPPEN DURING TREATMENT?

Your child will come into hospital for the procedure, and may stay in for a few days to be monitored afterwards. They may have the procedure when they are awake, with local anaesthetic, or fully asleep under general anaesthetic.



BENEFITS

Surgery can potentially remove all, or almost all of the tumor, and may be the only treatment needed.



RISKS AND SIDE EFFECTS

These will depend on which area of the brain is operated on, but your child may experience physical weakness in arms or legs, problems with balance, or with speaking. Sometimes they can affect how well a child learns too.



WHEN DOCTORS MIGHT RECOMMEND THIS

Surgery and biopsy usually happen right at the start of the journey, to check what kind of tumor your child may have. Your healthcare team will run tests on the part of the tumor they remove. Surgeons may be able to remove all of the tumor at the same time, which is called resection. Sometimes a tumor cannot be removed by surgery because it is growing deep in the brain or near delicate parts of the brain. This sometimes happens with optic pathway gliomas (a type of tumor that grows along the nerves which carry information from your eyes to your brain). In this case, other treatments may then also be used to shrink the tumor.

FACT

Let your child know it's okay to talk about side effects, even small ones, so the care team can help.

Molecular testing



WHAT IS MOLECULAR TESTING?

This isn't a treatment, but it's a very important part of your child's treatment journey. Your healthcare team will look inside the tumor cells and see if there are any small changes in DNA that show how a tumor will behave and grow. There are lots of different genetic variations in pLGG but the most common are called BRAF alterations.



WHAT WILL HAPPEN DURING TREATMENT?

Each type of genetic change makes cancer react differently to treatment. Based on what genetic changes the tumor has, your healthcare team may be able to personalize treatment to your child's specific type of pLGG.



BENEFITS

Getting tested could mean that more treatments become available to your child to help shrink their tumor, or avoid treatments that may be less effective.



RISKS AND SIDE EFFECTS

There aren't any side effects to the test, but the test results may reveal information about diseases that run in your child's family. Your healthcare team will help you think through what the results of molecular testing might mean for your child and your family and may recommend genetic counselling from a professional trained in inherited diseases.



WHEN DOCTORS MIGHT RECOMMEND THIS

Testing could happen at many different stages of the treatment journey. Doctors often recommend testing straight away as part of the initial biopsy, or after your child has tried a few different treatments for pLGG that haven't worked very well. In some cases, if your child's tumor was fully removed but grew back, the tumor could have changed and doctors may want to test it to see if they need to treat it differently.

Observation



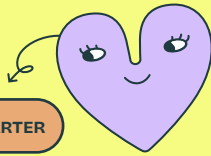
WHAT IS OBSERVATION?

For the medical team, this means watching the tumor and pLGG symptoms, but not giving treatment unless symptoms change or new ones appear. Your medical team may also call this process ‘watch and wait’.



WHAT WILL HAPPEN DURING OBSERVATION?

Your child will have regular MRI scans or other tests in the hospital, which your healthcare team will update you on.



CONVERSATION STARTER

Ask your child: “What kinds of activities might you like to do when you’re not in hospital?”



BENEFITS

Not having any treatment means your child won’t experience any treatment side effects, and they may be able to spend less time in hospital.



RISKS AND SIDE EFFECTS

Some families may feel nervous and anxious ahead of appointments to find out whether the tumor has grown or not.



WHEN DOCTORS MIGHT RECOMMEND THIS

If the tumor has been removed, or is not growing, your healthcare team may schedule regular tests and not prescribe any additional treatment.

Radiation therapy



WHAT IS RADIATION THERAPY?

Radiation therapy uses high energy radiation to shrink tumors and kill cancer cells.



WHAT WILL HAPPEN DURING TREATMENT?

Radiation therapy is given by a machine from outside the body, a bit like an X-ray. Some children may need sedation to help them stay still during treatment.



BENEFITS

Radiation is really good at killing cancer cells, and can be used on very large areas such as the whole brain or spine, or on very small areas of the brain.



RISKS AND SIDE EFFECTS

Radiation therapy is very good at killing cancer cells, but it can also damage normal healthy brain tissue nearby. It can also make your child feel sick, weak or dizzy after treatment and they may lose some hair. Radiation in the brain may change how well your child learns, and these effects can be long lasting.



WHEN DOCTORS MIGHT RECOMMEND THIS

Radiation therapy is normally used after surgery to destroy remaining tumor cells. Because radiation therapy can cause long-term damage, healthcare teams are very careful when recommending it, especially to growing children.

Chemotherapy



WHAT IS CHEMOTHERAPY?

Chemotherapy is a treatment that uses medicines to kill cancer cells. There are many different types of chemotherapy and all depend on the type and stage of the tumor.



WHAT WILL HAPPEN DURING TREATMENT?

This treatment may be given by injection through a drip, or in a tablet. It is usually given in hospital over a few hours. Some extra time may need to be spent in hospital afterwards in order to be monitored.



TIP

Let your child know it's okay to talk about side effects, even small ones, so the care team can help.



BENEFITS

Chemotherapy is good at killing cancer cells, and there are lots of different types. It can also be used in combination with other treatments that can give a better chance of shrinking the tumor.



RISKS AND SIDE EFFECTS

Short-term side effects from chemotherapy can include nausea, vomiting, hair loss, and feeling tired. It can also increase the chance of getting an infection. Long-term changes from chemotherapy may affect your child when they're older, like changes to hormones or their ability to learn.



WHEN DOCTORS MIGHT RECOMMEND THIS

Chemotherapy may be given alongside surgery or radiotherapy to shrink the tumor. Because it travels in the bloodstream, chemotherapy can be used if the brain tumor is hard to reach with surgery.

Targeted therapy



WHAT IS A TARGETED THERAPY?

This medicine targets the messengers that tell cancer cells to grow or divide, helping them stop the growth and spread of cancer cells.



WHAT WILL HAPPEN DURING TREATMENT?

This treatment may be given by injection through a drip, or in a tablet. Your child might come into hospital for a few hours to receive the medicine, or they might be able to take it at home.



BENEFITS

Because targeted therapies are designed to act on cancer cells while limiting damage to healthy cells, they often cause fewer side effects, and those side effects are usually less severe, than with treatments such as chemotherapy or radiotherapy.



RISKS AND SIDE EFFECTS

Not everyone can receive targeted therapies. Your child will need to have a test to see if they could work for them. Targeted therapy may cause changes in hair color. They may also make skin itchy or sensitive to light, and could cause your child to feel tired, nauseous, feverish, or have diarrhea.



WHEN DOCTORS MIGHT RECOMMEND THIS

Most people try targeted therapy after other types of medicine or surgery haven't managed to shrink the tumor. They are often combined with other types of cancer treatment such as surgery, chemotherapy, or radiation therapy.

Learning to live with pLGG

Help is out there

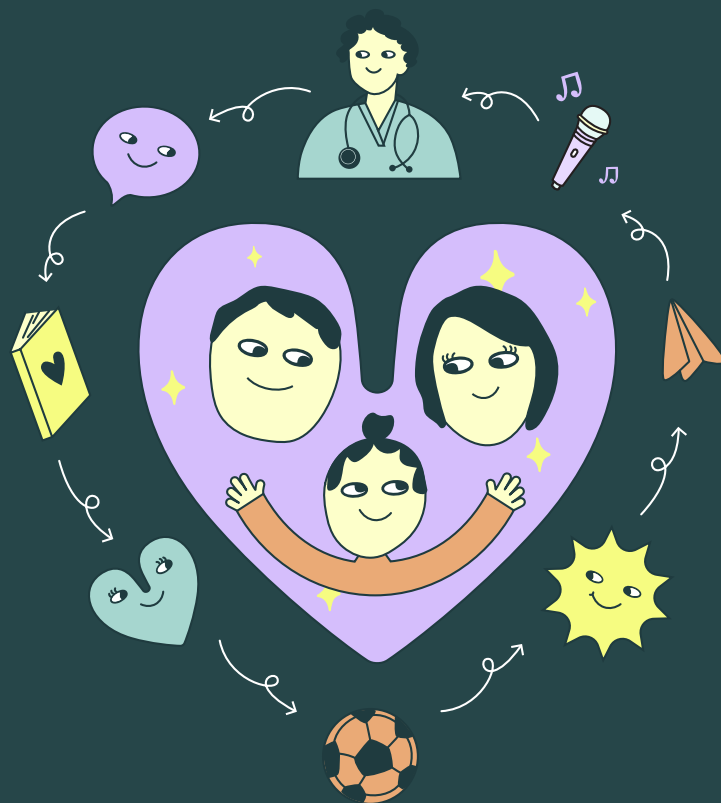
Children with pLGG and their caregivers can sometimes feel isolated, particularly if the disease has relapsed, or the tumor has grown.

Because the condition affects only them, they may feel it's their problem to deal with alone. But the truth is, there are lots of people who are there to help.

Reaching out to friends, family, or your healthcare team and sharing feelings can make a real difference. Even though you might feel like avoiding social activities when you're unhappy or tired, keeping up with your usual interests (if you have the energy) can help. Taking a break and doing something you enjoy is good for both you and those around you.

Remember, some friends may not know what to say or may avoid the subject, so you might need to bring it up yourself when you're ready. Others may surprise you with their support and understanding.

Some people find it helpful to talk with a counselor or join a support group, as it can help them feel more in control. Ask your healthcare team about what support services are available in your area. You'll also find some helpful links at the end of this guide.



TIP

Encourage your child to talk about their feelings by sharing your own first. For example, you might say, "I feel a bit worried sometimes, but talking about it helps me."

Meet your support network

Providing the care and support needed every step of the way

Name

PSYCHOLOGIST

A healthcare professional who can support with mental health and emotional wellbeing

Name

PHYSIOTHERAPIST

A healthcare professional who helps to improve or maintain movement

Name

OCCUPATIONAL THERAPIST

A healthcare professional who helps people overcome challenges in performing daily tasks due to a medical condition

Name

OPHTHALMOLOGIST

A doctor specialized in eye and vision problems

Name

PEDIATRIC NEUROLOGIST

A doctor specialized in problems of the brain, spinal cord, and nervous system in children

Name

PEDIATRIC ONCOLOGIST

A doctor specialized in cancers in children including tumors and gliomas

Name

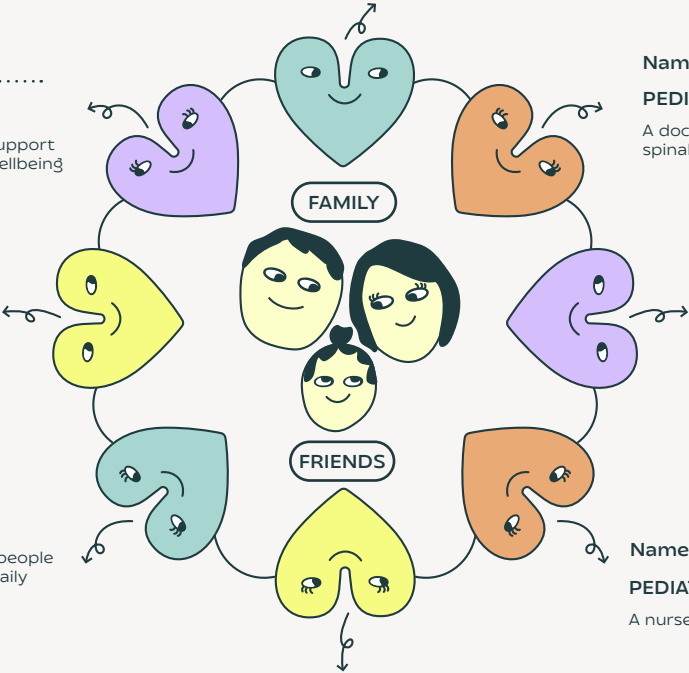
PEDIATRIC NURSE

A nurse specialized in the care of children

Name

NEUROSURGEON

A doctor specialized in brain surgery



CONVERSATION STARTER

Ask your child: "Which of your friends do you feel most comfortable talking to when you have big feelings or worries?"

Questions to



your healthcare team

The answers you need start with a conversation

In addition to the information in this guide, it's a good idea to speak to your healthcare team about anything you are unsure of or don't understand. Here are a few questions to get you started



REMEMBER

Ask who to contact if you have questions between appointments, or if something changes.

BEFORE TREATMENT

- Q Can my child have molecular testing?
- Q How will the results of molecular testing affect which medicine we get?
- Q What is our current treatment plan?
- Q What are the goals of treatment and how will they be measured?

AFTER TREATMENT

- Q What are the next steps now my child has finished treatment?
- Q How often will my child need follow-up appointments or scans?

DURING TREATMENT

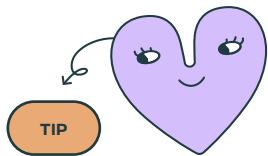
- Q What are the side effects of treatment and how can we manage them?
- Q Who should I inform about my child's condition?
- Q What organizations or support groups are there?
- Q How might pLGG affect my child's schooling, learning, or attendance?

- Q What signs or symptoms should we watch out for between appointments?
- Q Can my child be fully active again?

Answering your **child's** questions

Knowing what to say

Children may ask questions that are hard to answer on the spot, or that you may not feel prepared for. Here are some common questions children might ask, along with ways you can respond. You can always ask your healthcare team if you're unsure how to explain something.



Encourage your child to write down any questions they have for the doctor or nurse, or even draw how they're feeling.

BEFORE TREATMENT

- Q** Why do I have to go to the hospital?
- A** The hospital is a place where doctors and nurses can help you feel better and make sure you're getting the care you need.
- Q** Is it my fault that I got sick?
- A** No, nothing you did caused this. Sometimes things like this just happen, and it's not anyone's fault.

STARTING TREATMENT

- Q** Will I get better?
- A** The doctors are doing everything they can to help you get better. Some treatments can take time, but we're all here to help you every step of the way.
- Q** Why do I have to take medicine or have treatment?
- A** The medicine and treatments are there to help your body fight the tumor and help you feel better. Some might make you feel a bit tired or unwell, but the doctors will help manage that.

DURING TREATMENT

- Q** Will I have to stay in the hospital for a long time?
- A** Sometimes you might have to stay for a little while, but the doctors will let us know when you can go home. We'll be with you the whole time.
- Q** What if I'm scared or sad?
- A** It's okay to feel scared or sad—lots of people feel that way sometimes. You can always talk to me about how you're feeling.
- Q** Can I still go to school and see my friends?
- A** Many kids with pLGG do go to school and spend time with friends when they feel up to it. We'll talk with your doctor and teachers about what's best for you.

Words you might hear and what they mean

The pLGG glossary

- Biopsy** (BY-op-see) → When a doctor takes a tiny piece of tissue from your body so they can look at it under a microscope. This helps them find out what might be causing a disease.
- BRAF fusion** (BEE-raf FYOO-zhun) → When two pieces of DNA in a cell join together in an unusual way and create a “mixed” gene. This mixed gene can send the wrong signals to the cell, sometimes causing the cell to grow too fast. Doctors check for BRAF fusions to help understand certain tumors and choose the best treatment.
- BRAF altered** (BEE-raf AWL-terd) → When the *BRAF* gene (which helps control how cells grow) has changed in some way. When it is altered, it may send the wrong signals, which can make cells grow too quickly. Doctors look for BRAF alterations to help understand certain cancers and decide on the best treatment.
- BRAF inhibitors** (BEE-raf in-HIB-ih-ters) → Medicines that block the signals sent out by an altered *BRAF* gene. These altered genes can make cells grow too fast. BRAF inhibitors help slow down or stop this fast-growing cell behavior.
- Cancer** (KAN-ser) → A disease where some of the body’s cells start growing in a way they shouldn’t. These cells don’t stop growing when they’re supposed to and can form lumps or spread to other parts of the body. Doctors use tests and treatments to help control or remove these cells.
- DNA** (DEE-en-ay) → A set of instructions inside almost every cell in your body. It tells your body how to grow, look, and work. You can think of it like a recipe book that makes you “you”.

CONVERSATION STARTER

Ask your child: “Are there any words the doctor used that were confusing or that you’d like to understand better?”

- Genetic** (juh-NET-ik) → Something that comes from your genes. These are the instructions inside your body that you get from your parents. Genetics can affect how you look, how your body works, and sometimes your chances of getting certain diseases.
- Glioma** (GLEE-oh-muh) → A type of brain or spinal cord tumor that starts in the support cells of the nervous system, called glial cells.
- Grade** (GRAYD) → Describes how serious or fast-growing a tumor is. A low-grade tumor grows slowly and is less dangerous. Doctors use the grade to decide the best treatment.
- Motor function** (MOH-ter FUNGK-shun) → Your body’s ability to move your muscles. It includes things like walking, picking up objects, writing, or even smiling. Your brain and nerves control these movements.
- Molecular testing** (muh-LEK-yuh-ler TES-ting) → A type of medical test that looks at tiny parts of your cells, like DNA or proteins, to see if something is working normally or causing disease. Doctors use it to help diagnose problems and choose the best treatment.
- Mutation** (myoo-TAY-shun) → A change in a gene or DNA. Sometimes mutations are harmless, but other times they can make cells act differently, which can lead to health problems or diseases.
- Optic pathway glioma** (OP-tik PATH-way GLEE-oh-muh) → A type of brain tumor that grows along the optic nerves, which carry information from your eyes to your brain. This tumor can affect vision.
- pLGG** (pee-ell-jee-jee) → Stands for pediatric low-grade glioma. It is a slow-growing brain tumor that usually happens in children.
- Seizures** (SEE-zhur) → When the brain sends too many electrical signals at once, which can make a person shake, lose control of their body, or act strangely for a short time. Doctors help treat seizures with medicine or other therapies.
- Tumor** (TOO-mer) → A lump or growth of extra cells in the body. Some tumors are benign, which means they don’t spread or cause serious harm, and some are malignant, which means they can grow quickly and spread to other parts of the body.

For teachers:

what you need to know



WHY YOU'RE RECEIVING THIS

You're receiving this information because a student in your care has been diagnosed with pLGG (pediatric low-grade glioma), a type of brain tumor that affects children. You may have questions as to what to expect and how the school can support your student and their family throughout their journey. Here is some information to get you started.



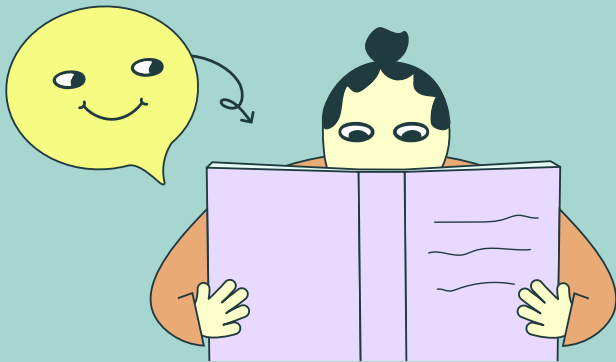
WHAT IS pLGG?

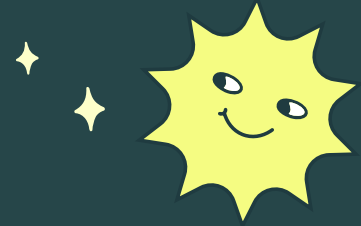
pLGG is a type of abnormal growth, also known as a **tumor**, in the brain or spinal cord, found in children. Children with pLGG may be going through treatments, tests, and regular hospital visits. Their ability to participate in school activities may vary from day to day.



WHAT TO EXPECT AT SCHOOL

- The student may not feel well enough to fully take part in daily school life.
- They may be tired, miss class, or have difficulty concentrating.
- There may be physical changes due to treatment (such as hair loss or changes in appearance).
- They may feel emotionally and physically fragile.
- Some days will feel "normal," others may be more challenging.
- They may need extra time with schoolwork or support for absences.





HOW YOU CAN HELP

- Be understanding and flexible about absences, tiredness, or changes in behavior.
- Keep communication open with the family about your student's needs.
- Encourage classmates to keep in touch and be supportive.
- Work with the family (and healthcare providers, if needed) on individual education or support plans.



WHO TO CONTACT

Please reach out to the student's parents or caregivers first with any questions. They can connect you with healthcare providers or support organizations if needed.



FOR MORE INFORMATION

For further resources and tips on support, there are several online resources you can go to:

CHILDREN'S BRAIN TUMOR INFORMATION AND SUPPORT

rethinkpLGG.com

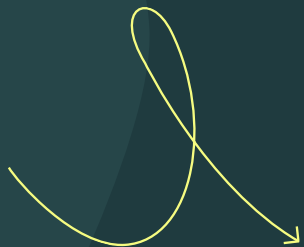
For information about pLGG including the science behind it and personal stories.

PEDIATRIC BRAIN TUMOR FOUNDATION

curethekids.org

Caring for families, helping survivors, and finding a cure.

Looking for more answers?



Here are some useful links & resources

CHILDREN'S BRAIN TUMOR INFORMATION AND SUPPORT



RethinkLGG.com

For information about pLGG including the science behind it and personal stories.

rethinkplgg.com



Pediatric Brain Tumor Foundation

Caring for families, helping survivors, and finding a cure.

curethekids.org

[Insert local children's cancer support group here]

CHILDREN'S CANCER INFORMATION AND SUPPORT



Childhood Cancer International Europe

Working with parents and clinicians to advocate for better education and care in childhood cancer.

ccieurope.eu



Youth Cancer Europe

Helping young people with lived experience of cancer to connect with each other and influence cancer care.

youthcancereurope.org

[Insert local children's cancer support group here]



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://siope.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: <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://patientinfo.library.royalmarsden.nhs.uk/document/download/1102>. 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].