

The ABCs of Educational Advocacy:

Supporting your child living with low-grade glioma at school

Helpful tips for advocating for your child's needs in a school setting



Easton, lives with pediatric low-grade glioma (pLGG). Lives for painting.

An educational brochure developed as a partnership between Day One Biopharmaceuticals, Momcology, and the pLGG caregiver community.



From the Hospital to the Classroom

Supporting your child living with pediatric low-grade glioma in school



Attending school helps your child build the foundation for their future through listening, critical thinking, socializing, and problem-solving.

Living with pLGG can disrupt that process and prevent your child from achieving their goals.

You can help address the effects that pLGG may have on your child's educational experience. This brochure will provide you with guidance on how to support his or her educational needs.

The brochure is organized in the following way to help you on your journey

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"It is so important for us as parents to always be our child's biggest advocate, and in the school setting this is no different. School is such an important part of our child's life, and as the experts on our children, we need to be their voice to the classroom when they cannot speak up for themselves."

- A parent of a child living with pLGG



Maintain open, regular, and effective communication between your child's care team, teachers, and school officials to help advocate for your child at school.

Advocating in the Best Ways Possible

Keys to being an effective advocate

Advocating for their needs and communicating with teachers and school officials can help ensure your child is supported in the classroom and at school.

Here are some ways to best advocate for your child's educational needs.

Provide a summary of your child's medical history



Give information about side effects of your child's disease or treatment to their teachers and school officials.

This will help them know to watch for certain signs to make sure your child is comfortable.

Providing the medical history can help the school better understand how it may impact your child's learning.



Alert teachers and school officials to changes in your child's treatment schedule or side effects

Explain that appearances are deceiving

Children with brain tumors may seem healthy on the outside, but the tumor may still have an impact on their daily living.

For example, a child may attend a school-sponsored event one Friday night; however, they may not be ready to attend school full-time.

Brain processes are invisible to most people, yet they can impact daily living.

For example, pediatric low-grade glioma (pLGG) may affect your child's ability to see the front of the classroom clearly, but this would not be obvious unless you or your child speaks up.



Advocating in the Best Ways Possible

Plan ahead to help minimize school disruptions



Treatment for pLGG may often take your child away from school. Discuss with your child's care team the possibility of scheduling appointments and/or procedures after school or during school vacation.



Alert your child's teachers of any doctor's appointments or planned absences when possible

Form a team

Many schools have resources to help you and your child, such as:

- 1 Guidance Counselors
- 2 Social Workers
- 3 School Nurses
- 4 Teachers
- 5 School Administrators

Form a team to help support your child's academic needs throughout the year.

Be flexible and reasonable



- ✓ Determine what's working well and what could use improvement
- ✓ If there is a problem, work with the school team to determine its cause and find a solution
- ✓ Remember that educators have other students and responsibilities.
Allow them time to respond to your requests



Reach out to your child's school to find out who to speak to about any concerns regarding their education.

Bringing School to Your Child

Helping your child continue to learn while away from school

Your child may not be able to attend classes regularly. **However, it is important to continue their learning.**

Talk to your child's teachers and administrators about ways your child can continue their education while away from the classroom.

Below, you'll find ways to keep your child engaged in learning while away from school.

Create a positive learning environment for your child at home



- ✓ Work with the school to find activities or assignments that can fit into your child's schedule and abilities
- ✓ Review past assignments with your child so he or she doesn't forget what they were learning in school before treatment
- ✓ Set aside time each day for educational activities, but leave room for flexibility based on how your child is feeling

Keep educational activities light and fun when possible



Your child may be going through difficult times both physically and emotionally, therefore they may not be ready for rigorous assignments.

Encourage participation in educational activities they enjoy independently such as reading or practicing a skill.

Help From Hospital Homebound

Hospital Homebound instruction is an alternative method of teaching designed for students who are expected to be out of school for an extended period of time due to a **physical or mental condition**. The purpose is to keep students connected to a school-based curriculum until they return to the classroom setting.



Be sure to check your state's education website to learn about the **specific rules for Hospital Homebound instruction in your area.**

Communicating With Your Child's School Team

Educating teachers and school officials

One of the keys to being an effective advocate for your child is knowing which information to share with the school.

Telling teachers and school officials about your child's needs makes it more likely that those needs will be met.

Below, you'll find a list of topics to consider discussing with your child's school



- ✓ Information about diagnosis and treatment
- ✓ Information that your child would be comfortable sharing about his/her diagnosis with his or her class, and the preferred way of sharing it
- ✓ Which symptoms to look out for on a daily basis
- ✓ Medical team's contact information and plan of action in case of an emergency
- ✓ Specific ways in which school can support your child
- ✓ Opportunities for tutoring
- ✓ How to identify learning and behavioral needs at home

Sharing your child's experience with their classmates

You may want to discuss with your child what information about their diagnosis they would feel comfortable sharing with their classmates.

Your child may choose to be open about their symptoms and treatment, or they may want to keep certain things more private.

If your child decides to disclose information about their diagnosis, you can talk to his or her teacher, school officials, or a child life specialist to determine an appropriate way of sharing their story with their classmates.

This can include addressing any questions their classmates might have or discussing ways in which they can support your child.



You may find additional tips and suggestions for talking with your child's classroom friends about cancer at [childrensoncologygroup.org](https://www.childrensoncologygroup.org).

Communicating With Your Child's School Team

Communication plan

Consider helping your child fill out the worksheet below to help organize and determine the **best way to share information about his or her diagnosis.**

What do I want to share?

How am I sharing it?

Who am I sharing it with?

Communicating With Your Child's School Team

Your child's hospital may offer assistance

Your child's hospital may also offer services or programs to help with his or her education while on treatment. A hospital-school liaison is a medical professional who can help ease the transition back to school and provide any needed support. **A hospital-school liaison can support your child by:**

- Talking to your child's class about his or her diagnosis and treatment
- Assisting you when communicating with the school about your child's diagnosis
- Helping review Individualized Education Plans (IEPs) or 504 Plans (*see page 10*)
- Consulting your family and the school on solutions to any issues that may arise



Ask your child's care team to see if a **hospital-school liaison is available** at your child's hospital.

Connecting with your child about his or her needs

Your child may have mixed feelings about attending school and may need support emotionally and academically.

It is important to discuss these feelings with your child and find ways to address his or her concerns.

You can ask questions like:



1. What are your feelings about attending school? Is there anything you are excited about?
2. Is there anything about attending school that makes you nervous?
3. What can we do to make school more enjoyable for you?
4. What can your teachers do to support you at school?



Make sure to **check in with your child regularly to see how he or she is feeling about being in the classroom.**

Communicating With Other Parents

To make sure that your child's school remains a safe environment, you may want to contact other parents to inform them that your child is immunocompromised. You can let them know that your child may not be able to fight off illness as well as other children, so it's important to keep their child home from school if they are sick.

Below, you'll find an example letter that you can edit and personalize to send to other parents.

Example Letter to Parents

Dear _____,

You may be aware that my child, _____, has been absent from school recently. The reason for this is that (he/she) has been diagnosed with pediatric low-grade glioma, which is a type of brain tumor. _____ is currently in treatment and is planning on returning to school soon.

I am writing this letter to let you know that due to the diagnosis, _____ is immunocompromised, which means that (he/she) cannot fight off illnesses as well as other kids. Because of this, I am asking that if your child is showing symptoms of being sick, please keep them home. Exposure to even mild infections could end up being serious for _____ because of (his/her) immune system.

Thank you for your understanding and support. _____ is very excited to be returning to school and, with your help, (his/her) experience will be both fun and safe.

Thanks,

_____'s parent

Discovering Protective Educational Laws

IEPs or 504 Plans can help protect the rights of children with educational needs

In addition to the help your child's teachers can provide, IEPs and 504 Plans are blueprints for how to best support your child's education.

Here are some important details about IEPs and 504 Plans:

	IEP	504 Plan
What is the purpose of the plan?	Guarantee a free and appropriate education for each child with a disability	Protect the rights of individuals with disabilities in programs that receive federal assistance from the Department of Education
Who oversees the plan?	A team including regular and/or special education teachers, transition services agency representative(s), and parents	A Section 504 coordinator
Who qualifies for the plan?	Only 13 disabilities qualify for an IEP Plan, including other health impairments, which may include a pLGG diagnosis or traumatic brain injury (TBI) in some states	All disabilities are eligible, including pLGG. The disability must make 1 or more major life activities more difficult for your child either physically, mentally, or both—for example, participating in physical activities in gym class or concentrating on lessons in the classroom
What is my involvement?	Parent participation, consent, and notification are required	Parental consent is required
Is an evaluation needed?	Yes	Yes

You can find many additional resources about IEPs and 504 Plans online, such as:

understood.org

parallellearning.com

Educating on Available Accommodations at School

Asking for accommodations can help your child with schoolwork

Some students need accommodations or modifications to their educational program so they can participate and be successful in school.



An accommodation allows a student to complete the same assignment or test as other students, but with a change in the timing, formatting, setting, scheduling, response, and/or presentation. This accommodation does not alter in any significant way what the test or assignment measures.

If your child qualifies for an IEP or 504 Plan, special accommodations are made available to help with their experience at school. These plans include a list of all accommodations your child will be provided, including in-classroom assistance, extra time for assignments, and more.

Below, you'll find a list of potential accommodations that may help your child. This is not a comprehensive list, and you may want to ask about additional accommodations, especially if your child qualifies for an IEP or 504 Plan.

In-Classroom



- Being provided with notes
- Shortened or fewer assignments to target the learning objectives
- Taking breaks as needed in a quiet place
- Preferential seating
- Extra time on tests
- Cueing to stay on task
- Word banks or formula sheets to assist with memory deficits
- Regular locker checks to look for lost/missing work
- Grades based on work completed rather than work assigned
- Knowing which assignments take priority when your child comes back after a long absence
- Permission to wear a hat inside the classroom if your child chooses to cover scars or a bald head

Out-of-School



- Shortened school days/flexible scheduling
- Optional homework
- In-home tutoring to help your child catch up after a prolonged hospital stay
- Second set of textbooks to be kept at home
- Borrowing a large-screen desktop computer for home use

Educating on Available Accommodations at School

Physical Education (PE)



- Can meet PE requirements in an alternative manner
- When the class is outside, allow your child to stay inside or ensure that a nurse can help apply a sunscreen

Accessibility



- Allowed to come to class 5 minutes late and leave 5 minutes early
- Locker located near majority of classrooms
- Buddy system for any necessary visit to the nurse's office
- Elevator pass provided
- Access to the disabled bathroom
- Access to the bathroom anytime
- Allowed to use speak-to-text software
- A quiet space outside the nurse's office available for rest breaks
- A nurse available, or someone trained and delegated by the nurse, to watch for symptoms that need immediate attention
- Timely phone contact with parent when contagious illness is present in the classroom
- Emergency evacuation plan for any student with limited mobility



You may want to discuss this list with your child and together decide which accommodations may be helpful. **It can also be useful to take notes to be prepared for conversations with the school.**

Helping You Help Your Child

Asking for accommodations can help your child with schoolwork

Use this worksheet to assist
in your conversations with
teachers and school officials.

Student's name _____

Student's grade _____

Diagnosis _____

Side effects/symptoms student is experiencing

Treatment plan

Planned absences

Date/time

Reason

Accommodation(s)

How they will help

--	--

School staff members to contact:

Name _____

Position _____

Telephone # _____

Name _____

Position _____

Telephone # _____

Additional information to share with the school



Day One Biopharmaceuticals would like to thank all those who contributed in the creation of this resource and for their dedication to helping children living with pLGG thrive in school.

This guide was created in partnership with
Momcology and the pLGG community.



"I want to give my child the best chance to succeed in whatever she chooses to pursue in life. I also want to make sure she has a positive experience at school where she can just be a kid and have fun with her friends."

- A parent of a child living with pLGG

Download other helpful and informative resources at:

rethinkPLGG.com