Desmoplastic Infantile Ganglioglioma - Childhood - Treatment Options [1]

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ON THIS PAGE: You will learn about the different ways doctors use to treat children with DIG. To see other pages, use the menu on the side of your screen.

In general, tumors in children are uncommon, so it can be hard for doctors to plan treatments unless they know what has been most effective in other children. That?s why more than 60% of children with cancer are treated as part of a clinical trial. Clinical trials [3] are research studies that compare standard treatments (the best known treatments available) to newer approaches to treatments that may be more effective. Clinical trials may test such approaches as a new drug, a new combination of standard treatments, or new doses of current therapies. Studying new treatments involves careful monitoring using scientific methods, and all participants are followed closely to track their health and progress.

To take advantage of these newer treatments, children with a brain tumor should be treated at a specialized cancer center. Doctors at these centers have extensive experience in treating children and have access to the latest research. A doctor who specializes in treating children with cancer is called a pediatric oncologist. If a pediatric cancer center is not nearby, general cancer centers sometimes have pediatric specialists who are able to be part of your child?s care.

In many cases, a team of doctors works with a child and the family to provide care; this is called a multidisciplinary team [4]. Pediatric cancer centers often have extra support services for children and their families, such as child life specialists, dietitians, physical and occupational therapists, social workers, and counselors. Special activities and programs to help your child and family cope may also be available.

Descriptions of the most common treatment options for DIG are listed below. Treatment options and recommendations depend on several factors, including the type and grade of the tumor, possible side effects, the family?s preferences, and your child?s overall health. Your child?s care plan may also include treatment for symptoms and side effects, an important part of care for DIG. Take time to learn about all of your child?s treatment options and be sure to ask questions about things that are unclear. Also, talk about the goals of each treatment with your child?s doctor and what your child can expect while receiving the treatment. Learn more about making treatment decisions [5].

Surgery

Surgery is the most common treatment for a child with DIG, and often it is the only treatment necessary. Surgery is the removal of the tumor and some surrounding healthy tissue during an operation. A neurosurgeon is a doctor who specializes in removing a tumor in the brain or spine with surgery.

Surgery to the brain requires the removal of part of the skull, a procedure called a craniotomy. After the surgeon removes the tumor, the patient?s own bone will be used to cover the opening in the skull. There have been rapid advances in surgery for brain tumors, including the use of cortical mapping, which allows doctors to identify certain areas of the brain that control the senses, language, and motor skills, and better imaging tests to give surgeons more tools to plan and perform the surgery.

After surgery, the doctor will decide if additional treatment is necessary based on the following criteria:

- The amount of tumor removed
- Your child?s age
- Whether the disease has spread

Sometimes, surgery cannot be performed because the tumor cannot be reached or is near a vital structure. Tumors that cannot be removed with surgery are called inoperable. In these situations, the doctor will recommend treating the tumor in another way, such as chemotherapy (see below).

Side effects from surgery for DIG can vary. Talk with your child?s doctor about possible short-term and long-term side effects of treatment.

Learn more about the basics of surgery [6].

Chemotherapy

Chemotherapy is the use of drugs to destroy tumor cells, usually by stopping the cells? ability to grow and divide. Chemotherapy is given by a pediatric oncologist or a medical oncologist, a doctor who specializes in treating a tumor with medication.

Systemic chemotherapy gets into the bloodstream to reach tumor cells throughout the body. Common ways to give chemotherapy include an intravenous (IV) tube placed into a vein using a needle or in a pill or capsule that is swallowed (orally).

A chemotherapy regimen (schedule) usually consists of a specific number of cycles given over a set period of time. A patient may receive one drug at a time or combinations of different drugs at the same time.

Chemotherapy may sometimes be used to slow or stop the growth of DIG when surgery is not an option. It also may be given before surgery to shrink the tumor or to destroy any tumor remaining after surgery. The side effects of chemotherapy depend on the individual and the dose used, but they can include fatigue, risk of infection, nausea and vomiting, hair loss, loss of appetite, and diarrhea. These side effects usually go away once treatment is finished.

Learn more about the basics of chemotherapy [7] and preparing for treatment [8]. The medications used to treat a tumor are continually being evaluated. Talking with your child?s doctor is often the best way to learn about the medications prescribed for your child, their purpose, and their potential side effects or interactions with other medications. Learn more about your child?s prescriptions by using searchable drug databases [9].

Getting care for symptoms and side effects

A tumor and its treatment often cause side effects. In addition to treatment to slow, stop, or eliminate the tumor, an important part of care is relieving a child?s symptoms and side effects. This approach is called palliative or supportive care, and it includes supporting the child with his or her physical, emotional, and social needs.

Palliative care is any treatment that focuses on reducing symptoms, improving quality of life, and supporting patients and their families. Any person, regardless of age or type and grade of tumor, may receive palliative care. It works best when palliative care is started as early as needed in the treatment process. Children often receive treatment for the tumor and treatment to ease side effects at the same time. In fact, people who receive both often have less severe symptoms, better quality of life, and families report they are more satisfied with treatment.

Palliative treatments vary widely and often include medication, nutritional changes, relaxation techniques, emotional support, and other therapies. Your child may also receive palliative treatments similar to those meant to eliminate the tumor, such as surgery or chemotherapy. Talk with your child?s doctor about the goals of each treatment in the treatment plan.

Before treatment begins, talk with your child?s health care team about the possible side effects of the specific treatment plan and palliative care options. And during and after treatment, be sure to tell your child?s doctor or another health care team member if your child is experiencing a problem so it can be addressed as quickly as possible. Learn more about palliative care [10].

Remission and the chance of recurrence

A remission is when the tumor cannot be detected in the body and there are no symptoms. This may also be called having ?no evidence of disease? or NED.

A remission may be temporary or permanent. This uncertainty causes many people to worry that the tumor will come back. While many remissions are permanent, it?s important to talk with the doctor about the possibility of the tumor returning. Understanding your child's risk of recurrence and the treatment options may help people feel more prepared if the tumor does return. Learn more about coping with the fear of recurrence [11].

If the tumor does return after the original treatment, it is called a recurrent tumor. DIG most often comes back in the same place as the original tumor, which is called a local recurrence.

When this occurs, a cycle of testing will begin again to learn as much as possible about the recurrence. After testing is done, you and your child?s doctor will talk about the treatment options. Often the treatment plan will include the treatments described above such as surgery and chemotherapy, but they may be used in a different

combination or given at a different pace. Your child?s doctor may also suggest clinical trials that are studying new ways to treat this type of recurrent tumor. Whichever treatment plan you choose, palliative care will be important for relieving symptoms and side effects.

If your child is diagnosed with a recurrence, you and your family may experience emotions such as disbelief or fear. You are encouraged to talk with your child?s health care team about these feelings and ask about support services to help your family cope. Learn more about dealing with a recurrence [12].

If treatment fails

Although treatment is successful for the majority of children with DIG, sometimes it is not. If a child?s tumor cannot be cured or controlled, this is called advanced or terminal disease. This diagnosis is stressful, and advanced DIG may be difficult to discuss. However, it is important to have open and honest conversations with your child?s doctor and health care team to express your family?s feelings, preferences, and concerns. The health care team is there to help, and many team members have special skills, experience, and knowledge to support patients and their families.

Parents or guardians are encouraged to think about where the child would be most comfortable: at home, in a home-like setting elsewhere, in the hospital, or in a hospice environment. Hospice care is a type of palliative care for people who are expected to live less than six months. It is designed to provide the best possible quality of life for people who are near the end of life. Nursing care and special equipment can make staying at home a workable alternative for many families. Some children may be happier if they can arrange to attend school part-time or keep up other activities and social connections. The child?s health care team can help parents or guardians decide on an appropriate level of activity. Making sure a child is physically comfortable and free from pain is extremely important as part of end-of-life care. Learn more about caring for a terminal ill child [13] and advanced care planning [14].

The death of a child is an enormous tragedy, and families may need support to help them cope with the loss. Pediatric cancer centers often have professional staff and support groups to help with the process of grieving. Learn more on grieving the loss of a child [15].

The next section in this guide is About Clinical Trials[3] and it offers more information about research studies that are focused on finding better ways to care for people with cancer. Or, use the menu on the side of your screen to choose another section to continue reading this guide.

Links:
[1] http://www.cancer.net/cancer-types/desmoplastic-infantile-ganglioglioma-childhood-tumor/treatment-options
[2] http://www.cancer.net/about-us
[3] http://www.cancer.net/node/18737
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