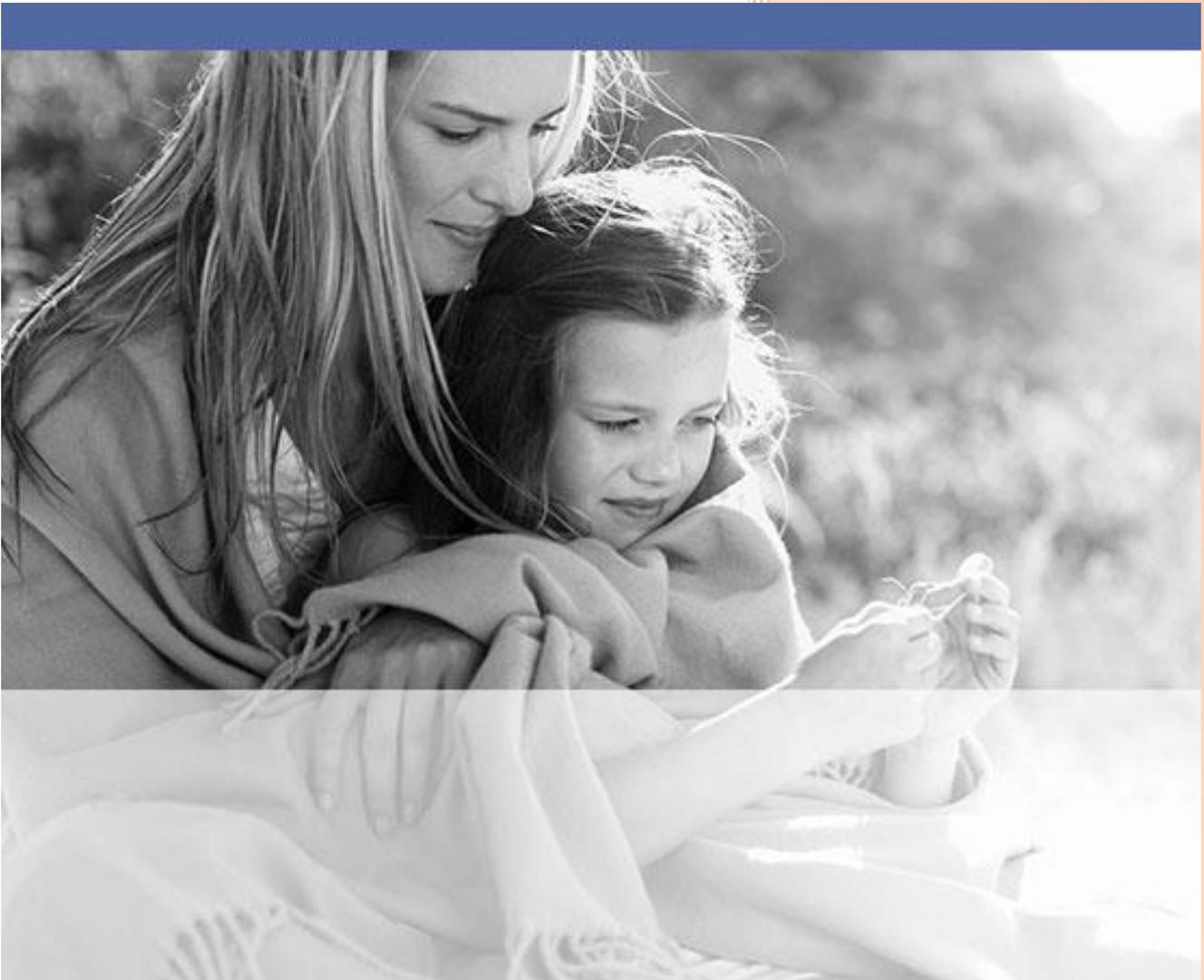


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## DIPG End of Life Education for Family Members



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### 1. INTRODUCTION TO DIPG AT PROGRESSION

Although 80% of patients show some improvement in symptoms and possible decrease in tumor after radiation therapy, DIPGs almost always begin to grow. Terms that may be used include refractory, recurrence, relapse, or progression. At this time, your provider may offer a clinical trial, additional radiation therapy, chemotherapy not associated with a clinical trial and/or comfort care only. Regardless of which treatment you and your provider choose, maximizing quality of life by supporting symptom management will be a priority. Quality of life is how a person feels from day-to-day including functional/physical, emotional, social, and spiritual wellness. Despite the best medical therapy, sometimes a medical cure is not possible and the tumor may continue to grow despite these interventions and take your child's life. Decision making becomes more difficult and you may feel powerless, scared, or alone. This booklet will answer some of the questions you may have, yet are not ready to actually ask. This booklet will also provide information on what to expect during each period of transition and serve as a guide with recommendations to your provider. Your primary medical team hopes to bring comfort, love and support to your child and family during this difficult time.

### 2. Palliative therapy options and Advance Care Planning

The terms "palliative" and "hospice" can make people feel "hopeless". However, the kind of palliative care/comfort care your medical team wants to provide is to help with pain and symptoms associated with the disease, and additional support for your entire family. Families may choose further treatment along with palliative care which includes chemotherapy/ radiation therapy and medicines for comfort while other families may focus on comfort care only. No decision is the wrong decision. If available in your area, a palliative care team can assist with focusing on quality of life for the entire family and ensuring decisions are in alignment with this approach.

Palliative care will focus on your family's physical, social, emotional, and spiritual care. Older patients may request to be part of decision making and identifying their individual goals of medical care and interventions.

Your medical team may discuss terms of interventions if your child stops breathing or heart stops beating. This will not be further discussed in this pamphlet as these are individual discussions to have among you and your medical team.

#### **Hospice Care**

At some point, you may consider hospice services. Hospice care focuses on improving quality of life for the whole family in the home, which is sometimes where your child would prefer to be. Being home can provide more comfort and ease. It also allows the whole family to be together, which can be helpful for siblings. Hospice services include: nursing (available 24/7 for emergencies and assessments), social work, chaplain services, bereavement support, and, in some cases, child life, massage and music therapy.

Hospice resources differ in each state and region. Talk to your medical team about hospice services available for you.

#### **Maintaining Hope**

Maintaining hope throughout this journey is extremely important. Hope provides strength to both the parents and the sick child as they move forward. It is important to recognize that hope can take different forms, and may change over time. For instance, you may

## DIPG End of Life Education for Family Members

first hope for a cure for DIPG. Then you may hope your child will be able to participate in activities they enjoy. At the end you may hope your child will not feel pain and will experience a peaceful death. Encourage your child to maintain hope, even wishful thinking. Commonly, children will express desires for the future, such as: “I can’t wait until I can drive,” “I want to go to college,” or “I hope I get married someday.” These statements do not mean your child is in denial about their condition; these are simply expressions of hope.

In an attempt to encourage their child, some parents may say: “Don’t give up,” or “You can beat this cancer.” While well-intentioned, statements like this can cause confusion. At this time, better statements may include, “I am so proud of you,” “You are very brave,” “We want to make sure you are not in pain,” “We are here for you and you are not alone.”

### 3. Psychosocial For Parents

Talking with your child about their DIPG prognosis can be frightening and overwhelming. While parents often want to protect their child from this information, research has shown establishing an open, honest dialogue with your child is important. Open communication will enable your child to feel more comfortable coming to you with questions, and help reduce their fears and feelings of isolation. Most children are aware they are dying, but are often afraid to express it. They keep silent because they want to protect their loved ones. Without open communication, a child may arrive at their own conclusions about what is happening to them, which can be inaccurate and frightening. Research clearly shows that when children know what to expect, they cope better.

#### Caring For Your Child

When talking with your child and other family members, keep the following in mind:

- **Be honest.** Do not withhold information, or attempt to sugar coat difficult subject matters. Provide simple explanations, taking their lead on how much information they feel comfortable hearing. (For example, you might say, “Your tumor is growing. The chemotherapy cannot make your tumor go away. The doctor will focus on helping you be comfortable.”)
- **Include your child in difficult conversations.** Allow them to decide how much information they would like to know, and encourage them to take part in the conversation.
- **When possible, give your child choices.** There are many choices taken away from your child and allowing them to have any choice may be beneficial. Possible choices you may give them: what to wear, a favorite activity to do, what to eat, and even medical decisions (For example, it may be reasonable to ask your child if they would like to return to the hospital as they are declining, or stay home)
- **Allow your child to express grief.** Grief can manifest in many ways. Remember that their grief may feel, and therefore appear, different from yours. (Typical

## DIPG End of Life Education for Family Members

behaviors include: withdrawal, changes in eating habits, sleep disturbances, anger, anxiety, and fear.)

There are many ways to provide comfort to your child, including:

- **Be present.** Being with your child provides them with a sense of security.
- **Be their advocate.** Help be their voice both at the medical institute and in the community (school, public, friends/family).
- **Focus on their physical comfort and quality of life.**
- **Take care of their spiritual needs.** Ask your child if they would like to speak with their own pastor/priest or hospital chaplain. Play music from your religious background.

### Caring for Siblings

Siblings can deal with their brother or sister's diagnosis in different ways. They may not feel comfortable asking questions or sharing how they are feeling. Commonly, siblings fear separation from their parents, or worry they too may become sick and die. They may feel guilt, believing they may have done something to cause the DIPG tumor. A sibling might think: "Last week when I was mad, I wished they would die." Reassuring siblings they did nothing to cause the DIPG can provide relief.

Crying in front of your child is healthy. Be sure to explain to them that you will cry, and that it's okay. This will give them permission to express their own sadness. While it is beneficial for children to see their parents cry, sobbing uncontrollably in front of them can be upsetting.

Being present at the hospital with your child can cause separation with other children in the home. While your time with them may be limited, it's important to remember they still need you. In the time you do spend with them, emphasize quality over quantity. Try to establish and maintain a regular routine for siblings, which will provide them with a greater sense of security.

In addition, be aware people in the community (peers, friends, teachers, etc.) may ask siblings difficult questions. To prepare them for these encounters, use role playing to demonstrate how to answer these questions. Talk to siblings to learn how much information they feel comfortable sharing with others, and create responses together. (For example, a teacher might ask, "I heard your brother is in the hospital, how are they doing?" and the response could be, "Thank you for asking about my brother. I have a hard time talking about him while I'm at school.")

### Legacy Building

Legacy building can be a healing and therapeutic process for your child and the family to experience together. It also provides a way to create valuable memories and can help family members after the death. Give your child permission and encouragement to participate in legacy building, but do not force them to until they are ready. Different ideas for legacy building include:

- Interview your child (great resource: Story Corp on NPR <http://storycorps.org/great-questions>)
- Be an advocate for the DIPG cure and do public speaking
- Create awareness in your community

## DIPG End of Life Education for Family Members

- Go on a family vacation together
- Have your child write letters to family and friends
- Create a scrapbook together
- Plant a tree
- Have them help with funeral planning

### 4. Immediate Dying Process

The dying process is a unique experience for each child with DIPG. This portion of the pamphlet will attempt to provide general guidance on what to expect as the person enters the final days of life. It is important to emphasize that the signs and symptoms discussed do not occur with each child and may not occur in the sequence presented. Each child follows his/her own timeline and we will attempt to provide you with the information needed to help your child and your family during this difficult time. For some children the timeline may be in months while for other patients it may be in days. Our goal is to make your child and family as comfortable as possible no matter the timeline. The involvement of a palliative care team and/or hospice program, if available, is ideal to provide needed support to everyone involved.

#### **Sleeping:**

As your child enters the last stages of dying he/she will often begin sleeping more as his/her body begins to shut down. At times sleepiness may be due to medications that are prescribed for symptoms such as pain or anxiety. We encourage families to continue to spend time with their loved ones during this time and know that your child may be able to hear you speak which may provide comfort.

#### **Disorientation:**

It is common that your child may become confused about time, place and the identity of the people around them. This may worsen as he/she enters the final days and hours of life. It is important that families and medical staff speak softly and clearly to lessen any negative reaction from your child. Medications can be used to assist the patient if the symptoms are consistent with delirium and it is believed that treatment may improve their quality of life.

#### **Decrease in food and fluid intake:**

Both food and fluids become unnecessary in the time prior to death. As a person begins the dying process, it is natural that they have decreased appetite and thirst as their body's need for sustenance declines. Do not force your child to eat or drink. Offer food and drink in small amounts and for comfort. Swallowing and the ability to protect the airway is often a significant issue for patients with DIPG at the end of life. Involvement of a speech therapist to assist the patient may be needed. Some families choose to let their child eat or drink for comfort at the end of life even in the case where there is a chance for aspiration or choking. You should discuss these options with your primary medical team.

#### **Breathing changes:**

A change in the breathing pattern is common in children with DIPG. Oxygen provided by nasal cannula may be beneficial to provide comfort but may also be uncomfortable for some children. Focusing on what makes the individual child comfortable is most important. At the final stages of life the patient will have irregular breathing and will have

## DIPG End of Life Education for Family Members

long pauses in breathing prior to death. Medications that are provided for comfort can ease the breathing pattern and decrease the feeling of breathlessness experienced by your child. The increased work of breathing and abnormal breathing pattern can be distressing to patients and families and the inclusion of comfort measures/medications may be essential.

### **Congestion:**

Your child may have increased secretions and congestion during the last stages of the dying process. This may include gurgling and other sounds that may be difficult for the family to hear. Use of medications to decrease secretions as well as limiting fluid intake (both by mouth and intravenous) is often necessary. It is important to note that increased secretions are often distressing to the family but typically does not cause discomfort for the child.

### **5. Tumor Donation**

If you wish, you have the option to donate your child's brain and tumor to research through a limited autopsy. Tumor tissue will be used for studies to help researchers learn more about what causes pediatric brain tumors and about how to make treatment better for those with this disease. To learn more about having a tumor donation performed please contact your primary physician.

### **6. Logistics after death**

In the final stages, your child will stop breathing and the heart will stop beating. If your child is in the hospital, the medical team will confirm the death, remove equipment and take away medications. Some families wish to help the medical team bathe the child. The medical team will help contact the funeral home at the request of the family. If your child at home enrolled on hospice, a hospice nurse will come to the home for confirm death. The staff will help the family bathe your child and contact the funeral home. The funeral home will come to the house and transport your child to the funeral home. The staff will provide support to the family.

### **References**

*Hinds PS et al. "Trying to be a good parent" as defined by interviews with parents who made phase I, terminal care, and resuscitation decisions for their children; J Clin Oncol 2009.*

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