CHAPTER 22B

Children and Brain Tumors – Longer Term Psychological and Social Issues

For most children with a brain tumor, “normal” is relative. Often there is a new normal that is not the same as the one before the illness. Perhaps this is the most difficult challenge for child and parent alike.

Paul Zeltzer 2003

Life is sometimes good. It is not always fair.

Anonymous
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Key search words
• brain injury
• pediatric
• neuropsychology
• IEP
• hospice
• child
• late effect
• school
• 504
• QOL
• development
• side effect
• Individual Education Plan
• camp
You might hear from friends and the school that cancer survivors in general have few psychological problems.\textsuperscript{1,2} This is not so for many children with brain tumors. Changes in the child’s physical appearance from dexamethasone, or hormonal imbalance such as early puberty affect the child’s body image; this can cause depression or social anxiety.\textsuperscript{3,4,5} Long-term problems also have been called the “silent illness” by Sheryl Shetsky, an adult brain tumor survivor.\textsuperscript{6} She observes that many children (and adults) \textit{appear} alright, but it is the speed of information processing by their brain which suffers. The deficits are not appreciated until a conversation or competition in the school uncovers the problem.

To further complicate matters, a recent study showed that brain tumor survivors know little about their illness, including their diagnosis.\textsuperscript{7} Such deficits could impair survivors’ future ability to seek and receive appropriate long-term follow-up care. Hence your attention to record keeping and organization will pay dividends for your child (see Chapter 3).

**PSYCHOLOGICAL AND SOCIAL LATE EFFECTS**

Children with brain tumors and their parents suffer a “double whammy” that survivors of other cancers do not share. They experience the trauma of the disease (intravenous injections, feeling unwell, facing mortality, nausea, vomiting, school and home absences, and changed body image). In addition, they live with long-term effects produced by the tumor, surgery, radiation, and chemotherapy on the brain; these can be pronounced and permanent. Many clinical trials for brain tumor treatment now have “Quality of Life” (QOL) outcome measures that let the investigators and parents know the psychological and functional capacities of these children after completion of therapy. The actual long-term effects are now better appreciated than in previous decades (see Table 22B-1).\textsuperscript{8} In terms of prevalence, clinically significant psychological distress was found in 11 percent of adult survivors of childhood brain tumors.\textsuperscript{9}
Table 22B-1 Long-term Psychological & Physical Problems in Survivors of Chilhood Brain Tumors

<table>
<thead>
<tr>
<th>Problem (Reference #)</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Post-traumatic stress disorder (PTSD) 10</td>
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<tr>
<td>• Thyroid, growth &amp; sexual maturation</td>
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<tr>
<td>• Inhibition and withdrawal 13</td>
</tr>
<tr>
<td>• Unfounded body complaints18,19</td>
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<tr>
<td>• Discouragement related to school difficulties18, 23</td>
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<tr>
<td>• Complaints of intense stress19</td>
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<tr>
<td>• Peer relationship difficulties 39</td>
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<tr>
<td>• Anxiety and panic,</td>
</tr>
<tr>
<td>• Loss of independence in adolescence 11</td>
</tr>
<tr>
<td>• Behavior problems 12</td>
</tr>
<tr>
<td>• Job seeking/ retention 13</td>
</tr>
<tr>
<td>• Infertility 14,15</td>
</tr>
<tr>
<td>• Concern about attracting the opposite sex and about career/ relationships</td>
</tr>
<tr>
<td>• Cerebellar mutism/ posterior fossa syndrome16</td>
</tr>
</tbody>
</table>

**Late Effects Guidelines for Specific Treatments**

How do parents know if their child has a “late effect?” First, ask your health care professionals at the center you receive treatment. Second, use all the references in the last table in this and the previous chapter. You also can contact the Children’s Oncology Group for many useful resources including this guide, *Children’s Oncology Group Childhood Cancer Survivor Long-Term Follow-Up Guidelines*.17

*Children’s Oncology Group Childhood Cancer Survivor Long-Term Follow-Up Guidelines* ... provides recommendations for screening and management of late effects that may potentially arise as a result of therapeutic exposures used during treatment for childhood cancer. These guidelines represent a statement of consensus from a panel of experts in late effects of treatment for pediatric malignancies. The recommendations are based on a thorough review of the literature as well as the collective clinical experience of the task force members, panel of experts, and multidisciplinary review panel (including nurses, physicians, behavioral specialists and patient/parent advocates).

Implementation of these guidelines is intended to increase awareness of potential late effects and to standardize and enhance follow-up care provided to childhood cancer survivors throughout the lifespan.

(See [http://www.childrensoncologygroup.org/disc/LE/default.htm](http://www.childrensoncologygroup.org/disc/LE/default.htm))
The facts that you need to know can be found by asking the right questions (see Chapter 5: The Team). The e-mail below is from the mother of Jordan who has cerebellar mutism. She stopped talking, had difficulty in swallowing and maintaining balance shortly after surgery (see Chapter 20: Side Effects and Later Effects).

*I guess what this all boils down to is this...don’t give up. Give yourself credit for getting through the last 10 months. Everyone has times that they feel worn out. Encouragement and love go a long way in helping a child. I tell Jordan she can do anything. She’s only limited by what she thinks she can’t do. ...We try everything and do things we never would have done before. We try to live each day enjoying our time together.*

*My advice: watch what the therapists do during their sessions and look for things you can incorporate into your home routine. Read to him and have him try all kinds of food. Try a small cocktail straw if he has trouble swallowing. Take him places he used to like to go to. Hang things on the ceiling to look at; suspend balloons from the ceiling to encourage him to move his arm up to them to push them around. Educate yourself. Most of all just be his cheerleader. Ruth, mom to Jordan, medulloblastoma.*

**Parental Role in the Child’s Adjustment**

It now becomes part of the parents’ responsibility and burden to ensure that their child receives appropriate assessment and rehabilitation for the child’s deficits. This is not an easy task in an era of shrinking health benefits, school budgets, and with little available guidance.

Some factors that help in positive adjustment are not under the child’s or parent’s control. These include absence of learning difficulties, functional and physical limitations.\(^1,18,19\) On a positive note, there are factors that are more under your control and that predict better psychological adjustment:

- The less the children believe their physical appearance is affected by cancer.\(^20\)
- High levels of support from the family, classmates, the school and the hospital.\(^5\)
- Social skills training targeted to the child’s problems (understanding slang, body language, etc.).\(^21\)