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## Survivors of Childhood Brain Tumors: the Potential for Late Effects

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The survival rate of patients with childhood brain tumors continues to improve. However, survivors are at risk for a variety of physical, medical, cognitive, and/or psychosocial late effects. These late effects may be directly related to the type, location and extent of the brain tumor itself or a result of treatment, which may include surgery, chemotherapy and/or radiation therapy. Age at diagnosis may also play an important role in a child's overall outcome, with infants and young children having a higher risk of long term treatment-related side effects. Finally, a very small number of children are at a higher risk of treatment related late effects because of rare inherited conditions that predispose normal tissues to severe side effects, particularly after radiation therapy.

To assess your risk for late effects it is important that you know what therapy you received. If you are followed in a survivor program through the cancer center where you were treated for your brain tumor, you may have already received this information. However, if you don't have this information you may request it. If you are not followed regularly, you may contact the cancer center where you were treated and request a treatment summary or a release of information form to obtain the medical records about your treatment.

Some of the more common late effects that may occur following treatment for a brain tumor are summarized below. It is very important to keep in mind that you may experience none, one, or several of these problems in the months or years after your treatment ends.

**Educational:** Learning disabilities, which may range from subtle to profound, may occur after treatment with radiation to the brain or whole body. Surgery, especially for tumors located in the part of the brain known as the cerebral hemisphere, may also be associated with learning disabilities.

*Additional risk factors:* Younger age at the time of treatment or female gender.

*Recommended evaluation:* Neurocognitive testing (testing to evaluate intellectual ability, visual-motor and motor skills, language, memory and learning, academic achievement, behavior and social functioning) by a pediatric neuro-psychologist familiar with the late effects of childhood cancer therapy.

*Intervention:* If weaknesses or deficits are detected, then school programs may need to be developed or modified in order to maximize the student's learning potential.

**Neuroendocrine (Hormones):** Changes in thyroid hormone, growth hormone, reproductive hormones and other hormones, may occur after treatment with

radiation to the brain or whole body. These hormonal imbalances or deficiencies may lead to hypothyroidism (low thyroid), hyperthyroidism (high thyroid), growth delay or short stature, delayed or early puberty, osteoporosis (weak bones) or obesity.

*Additional risk factors:* Higher dose of radiation, younger age at time of treatment, and surgery to the brain, especially near the pituitary gland may increase the risk of development hormonal problems.

*Recommended evaluation:* Yearly physical exam with measurement of height, weight, assessment of pubertal status, and appropriate blood work for specific concerns.

*Intervention:* Specific to the problem, may include hormone replacement such as treatment with growth hormone for growth hormone deficiency or thyroid hormone for hypothyroidism.

**Reproductive (Fertility):** Both male and female fertility may be affected after treatment with radiation to the brain (especially higher doses to the areas of the brain such as the hypothalamus or pituitary gland) and after treatment with some chemotherapy agents such as cyclophosphamide (Cytosan), melphalan (Alkeran), lomustine (CCNU), and cisplatin (Platinol).

*Additional risk factors:* Children who are undergoing puberty during treatment may be at a higher risk of infertility.

*Recommended evaluation:* Yearly evaluation with appropriate hormone testing and monitoring of pubertal status. Semen analysis may be recommended in males.

*Intervention:* Evaluation and treatment by endocrinologist (hormone specialist) as needed.

**Hearing:** Hearing loss, speech delays and tinnitus (ringing in the ears) most commonly occur after treatment with the chemotherapy agent cisplatin (Platinol). Hearing loss may also occur after radiation to the brain (especially if the beam is directed toward the brainstem or the ear) or after neurosurgery. Hearing loss rarely occurs after treatment with the chemotherapy agent carboplatin (Paraplatin)

*Additional risk factors:* Age less than 4 years at time of treatment, cisplatin total dose of 360 mg/m<sup>2</sup> or higher, radiation doses greater than 30 Gy, exposure to antibiotics such as gentamicin or tobramycin.

*Recommended evaluation:* Audiogram (hearing test) at baseline and periodically throughout treatment for children who will receive chemotherapy with cisplatin or carboplatin. Additional follow-up based on audiology results.

*Intervention:* Amplification systems (hearing aids).

**Emotional & Behavioral:** The brain is the control center of emotions and responses. Treatment with radiation to the head and surgery to the brain thus may alter emotional responses.

*Additional risk:* Location of the tumor, higher doses of radiation, and extent of surgical involvement.

*Recommended Evaluation:* Evaluation by a mental health professional, social worker, psychologist, psychiatrist or counselor as clinically indicated.

**Vision:** Visual loss can result from tumors that affect the optic nerves (nerves to the eyes) or after radiation in the area of the optic nerve. Cataracts may occur after treatment with radiation to the brain, spine, and total body.

*Additional risk factors:* Long term use of dexamethasone or other steroids such as prednisone.

*Recommended evaluation:* Ophthalmologic (eye) evaluation.

*Intervention:* Ongoing ophthalmologic follow-up once visual loss or a cataract has been identified. Cataracts may eventually require surgical removal.

**Vascular (Blood Vessel):** Radiation to the brain can damage blood vessels and decreased blood flow or hemorrhage (bleeding). Stroke is a possible consequence of decrease blood flow to the brain.

*Additional risk factors:* Radiation to an area of the brain known as the diencephalons. Patients with hereditary conditions such as neurofibromatosis type 1 (NF-1) may be at increased risk of vascular problems following radiation.

*Intervention:* In some cases a special surgical procedure may be recommended to decrease the risk of a stroke.

**Dental:** Increased risk of cavities, shortened or thinning roots, missing or small teeth, problems with enamel, and abnormal growth of jaw may occur after treatment with radiation to the brain, head, and total body or after chemotherapy.

*Additional risk factors:* Younger age at time of treatment, particularly if younger than 5, and higher doses of radiation.

*Recommended evaluation:* Dental cleaning and evaluation every 6 months.

*Intervention:* Good oral care and as recommended by a dentist.

For additional information on survivorship issues and guidelines for the screening tests recommended after treatment with specific chemotherapy, radiation therapy and surgery please see the Children's Oncology Group (COG) public website. This web site can be a great guide for both you the survivor and also for your primary health care provider. The web address is: [www.survivorshipguidelines.org](http://www.survivorshipguidelines.org)

There is no upper age limit at which time your physician can say that late effects will no longer occur. It is important to remember that you may experience none, one or several of these problems in the months or years after your treatment ends. Therefore, lifetime follow-up (medical surveillance) with a medical care provider who is familiar with the potential toxicities is highly recommended for your continued health and well being.