Cancer Survivor Follow-up, Adult
After Childhood Cancer Treatment

Cancer treatment has improved greatly in the past 10 to 20 years. More and more people now beat cancer. Today, one of every 1,000 Americans is a survivor of childhood cancer. They had cancer before age 20. Most are now 20 to 34 years old. And, they live normal lives. However, anyone who had cancer as a youth needs to be alert for what are called the *late effects* of the disease and its treatment. These are health problems that can develop months or years after cancer treatment.

Cancer begins when cells in the body divide too rapidly. They get out of control. To stop this, treatment often includes *radiation therapy* (X-rays) or *chemotherapy* (chemicals) or both to kill the cancer cells. It also may include surgery to remove the cancerous *tumor* (mass of cells). These methods work. But, they also can have effects that show up in adult life. That is why it is important to watch carefully for any signs of problems. Then, new treatment should be started as soon as possible.

CAUSES

- Many things can cause an adult to have late effects of childhood cancer. They include:
  - The type of cancer.
  - The treatments used to treat the cancer.
  - The age of the child when the cancer was treated.
  - The child's health before cancer.
  - *Genetics*. This is information inside cells that is passed from one generation to the next. Some genes that people are born with can make future health problems more likely.
- Most late effects are caused by treatment of childhood cancer.
  - Chemotherapy drugs kill cancer cells. They can also damage other cells that grow quickly. In children, many cells are growing quickly. These include cells in the bones and the brain.
  - Radiation therapy kills cancer cells. It also can hurt normal cells. It may cause some normal cells to become cancer cells years later.
  - Sometimes chemotherapy and radiation are both used. The chance of health problems later in life is bigger if both treatments were used rather than if just one was used.
  - *Bone marrow transplants* are used to treat some types of childhood cancer. Bone marrow is soft, fatty tissue inside the bones. It may have been bad. Or, it might have been harmed by chemotherapy or radiation. Then, new marrow is put in its place (a *transplant*). This sometimes leads to bone loss, blood cancer or liver damage later in life.
  - Surgery. This gets rid of the cancer. But, sometimes nerves or blood vessels can be damaged during an operation. This can cause problems later in life.
- Some childhood cancers return. One or more treatments were successful. Even so, the cancer sometimes comes back years later, when the child is an adult.

SYMPTOMS

Signs of the late effects of childhood cancer vary. The type of cancer makes a difference. So does the type of treatment that was given. Symptoms can affect almost any part of the body, such as:

- *Nervous system*. This is a network in the body that includes the brain, spinal cord, *retina* (eye), nerves and *neurons* (special cells). It regulates much of the body's activity. Late effects may include:
  - Vision problems.
  - Hearing loss.
  - Memory or learning difficulties.
  - *Numbness* (no feeling) in the hands or feet.
- *Cardiovascular system*. This includes the heart and blood vessels. Possible problems include:

- Heart weakness.
- Heart attack.
- Damaged heart valves. These open and close to let blood flow in and out of the heart.
- Damaged blood vessels. They carry blood from the heart to all parts of the body (arteries). And they bring blood back to the heart (veins).
- *Dyslipidemia* (having too much fat in the blood).

- *Endocrine system*. This is a group of hormones and *glands* (chemicals produced by the body, and the organs that control them). It is in charge of things in the body that happen slowly. Like growth, or moods. Late effects of childhood cancer could cause:
  - A child to not grow normally.
  - A person to not be able to have children.
  - Problems with sexual development.
  - Damage to the *thyroid gland* (a gland in the neck that controls many body functions).
- Bones. Late effects could be:
  - *Osteonecrosis*. The bone tissue dies.
  - *Osteoporosis*. Bones become brittle and can break easily.
- Digestive system. This changes food that you eat into a form that the body can use. It helps give you energy. Problems in this area can affect:
  - Teeth. Cavities (decay in teeth) can result. So can gum disease.
  - Scar tissue. This can form after surgery for cancer. It can keep digestive organs from working right. The liver, for example. It can also block digestion. This might happen in the intestines, for instance.
  - Digestion of food. The body might not be able to turn food into usable material. Or, it may not be able to do this as fully as it needs to.
  - Weight control. Several body systems can play a role in this. But, obesity (being very overweight) sometimes can be related to cancer treatment years earlier.
- *Respiratory system*. This lets you breathe. It pulls *oxygen* (a gas that you need to live) into your lungs. And it pushes extra *carbon dioxide* (a waste gas) out of the body. Scar tissue can develop long after cancer surgery. This can make breathing difficult.
- Breasts. The amount of breast tissue may decrease. Or, abnormal growths could develop.
- *Urinary tract*. This system takes care of urine (liquid waste). It makes it, stores it and gets it out of the body. This helps the body *filter* (clean) the blood of waste that could cause problems. Late effects of childhood cancer can lead to:
  - Urination that cannot be controlled.
  - Blood in the urine.
  - High blood pressure.
- The mind. Late effects of childhood cancer can include *psychological* (mental) problems such as:
  - Not being able to cope with stress.
  - Fear of dealing with other people.
  - Feeling overly sad or anxious.

FOLLOW-UP FOR ADULTS

Good follow-up care is very important for any adult who has had cancer before age 20. This means getting regular check-ups. And watching closely for any signs of problems. But it means more than that. A childhood cancer survivor should also:

- Have a long-term care plan. Just what your plan includes will depend on the type of cancer you had and the treatment you got. Work with your *oncologist* (cancer specialist) and your regular healthcare providers to come up with a plan just for you.
- Keep a detailed record of all cancer treatments. People move. Doctors change. Things happen. But no matter what, everything about your cancer treatment should be recorded. It should be easy to find if any bit of information is needed. Make sure it includes:
  - Personal information. Include date of birth, sex, current address. List who should be contacted in an

emergency. Update this at least once a year.

- Cancer diagnosis information, including:

1. The date the diagnosis was made.
2. The date of every treatment.
3. The date the last treatment was finished.
4. Names and contact information (phone number, e-mail address) for oncologists and other caregivers involved in your treatment.

- Treatment information, including:

1. Chemotherapy drugs. Include drug names, dosages, the total amount you received, and how the drug was given.
2. Radiation therapy. Include the total dose of radiation received. Also include your age when radiation was started.

- Bone marrow transplants. Include dates of all procedures. Note any reactions to the transplant.
- Surgery. List all surgeries related to the cancer. Include the area of the body where the operation was performed.
- Any other treatments that were related to childhood cancer.
- Caregiver explanations. Include all summaries, letters, notes from your oncologist and other caregivers. Make sure there is a date on each of them.
- Personal material. Some cancer patients keep diaries of their treatment. Or logs that indicate how they were feeling while being treated. Anything like this should also be kept with your records.

➢ Make lifestyle choices that might make late effects less likely to develop. These are called *modifiable risk factors*. They are things you can change about your life. They include such things as:

- Eating healthily. For example, try to eat more fruits and vegetables. Eat fewer fatty foods. Use less salt. Drink more water. For specific ideas, talk with a *nutritionist* (a food and diet expert).
- Getting regular exercise. Check with your healthcare provider before starting a new exercise routine. In general, though, exercise has been proven good for people who have battled cancer.
- Not smoking.
- Avoiding risky behaviors. This includes not using illegal drugs. Also, limiting alcohol consumption.
- Limiting your time in the sun. Use sunscreen whenever your skin is exposed to the sun's rays.
- Paying attention to mental health issues. If you have a concern, talk with someone.
- Seeing a dentist every 6 months.
- Doing monthly self-exams. For women, this is a breast exam. For men, it is a testicular exam. Ask your caregiver for help if you are not sure how to do this.
- Having a checkup with your primary caregiver at least once a year.
- Keeping your medical insurance up-to-date.

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