

LTFU

Long-Term Follow-Up Study

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We talk a lot about how important it is for survivors of serious childhood illnesses like cancer to know their treatment history and receive recommended health screenings based on their treatment risks. Some treatment side effects can be severe and staying up-to-date with recommended screenings can help preserve your health, or even save your life, by catching problems at an early stage when they can most easily be treated.

Please share this information with your doctor:

COG – The Children’s Oncology Group – provides risk-based screening recommendations for survivors of pediatric cancer online at:

<http://www.survivorshipguidelines.org>

Of course, not all side effects are life-threatening. Some survivors are coping with problems that have an impact on their *quality of life*. Problems with hearing and vision can affect work, hobbies, and relationships and leave survivors feeling isolated and helpless. They can also affect educational achievement and social interactions. It's important for survivors to be screened for hearing and vision problems, even though they may not be life-threatening. A thorough medical evaluation is key to accessing resources to help lessen the effects of hearing and vision problems.

The topic of this edition of the newsletter was suggested by a comment from a survivor, who asked if "there are additional things I could be doing to minimize the ringing in my ears, vertigo, and hearing loss due to the radiation?" We hope the information in this newsletter provides this survivor with resources for managing these treatment effects.

We welcome your suggestions for future newsletter topics. Please see the box on page 3 to learn how to contact us.

Thank you, study participants, for your continued involvement with the Long-Term Follow-Up Study!

Would you like to receive the LTFU Study newsletter by email?

Let us know where to send it!

1. Go to <http://ltfu.stjude.org>
2. Click on "Update Your Info" in the menu bar at the top of the screen.
3. Type in your contact information, including your email address (which will only be used by LTFU staff).
4. Check the box that says you'd like to receive the newsletters by email.

Study Updates

Some treatments have lasting effects on hearing and sight

A team of LTFU Study researchers led by Dr. Kimberly Whelan of the University of Alabama at Birmingham conducted two studies of late side effects experienced by childhood cancer survivors. The first study looked at hearing problems. The second looked at problems with the eyes. More than 14,000 survivors were included in each study.

Study of late effects on hearing

In the hearing study the researchers looked at four types of hearing problems reported by survivors:

- *Ringing in the ears* (tinnitus)
- *Problems hearing sounds*, words, or language in crowds
- *Hearing loss* that can be helped by a hearing aid
- *Deafness*, defined as severe hearing loss in one or both ears that can't be corrected by a hearing aid

They found that:

- ⇒ The most commonly reported problem was difficulty hearing sounds, words, or language in crowds. The second most commonly reported problem was ringing in the ears.
- ⇒ The number of survivors who reported a hearing problem was low, but the risk of developing a problem was significantly greater for survivors than for siblings.
- ⇒ Radiation to the head or neck was linked to all four types of problems.
- ⇒ Treatment with drugs known as platinum compounds was linked to hearing loss requiring a hearing aid, ringing in the ears, and problems hearing sounds in crowds. Cisplatin and carboplatin are the most common types of platinum compound drugs.
- ⇒ New hearing problems continued to develop more than 5 years after diagnosis of childhood cancer.

Study of late effects on eyesight

When the team looked at vision problems, they found that survivors commonly reported the following conditions:

- *Very dry eyes* requiring drops or ointment
- *Double vision*
- *Cataracts* (clouding of the lens of the eye that results in blurred vision)
- *Glaucoma* (damage to the optic nerve, usually caused by too much pressure in the eye)
- *Legal blindness* in one or both eyes

Here is what they found:

- ⇒ The most common problem was very dry eyes.
- ⇒ The number of survivors who reported any vision problem was low, but the risk of developing a problem was significantly greater for survivors than for siblings.
- ⇒ Treatments that were linked to eye problems included radiation to the eye or the brain, and steroid drugs like prednisone and dexamethasone. No treatments were linked to risk of glaucoma.
- ⇒ New problems, especially very dry eyes, continued to develop more than 5 years after diagnosis.

The researchers stressed the importance of early detection and continued follow-up for survivors at risk of hearing and vision problems.

If you have, or suspect, a hearing or vision problem, please share your treatment history with your doctor and schedule a medical evaluation soon.

References: Whelan KF, et al. Auditory complications in childhood cancer survivors: a report from the Childhood Cancer Survivor Study. *Pediatr Blood Cancer*. 2011 Jul 15;57(1):126-34.

Whelan KF, et al. Ocular late effects in childhood and adolescent cancer survivors: a report from the Childhood Cancer Survivor Study. *Pediatr Blood Cancer*. 2010 Jan;54(1):103-9.



Dr. Kimberly Whelan led the hearing and vision studies

Audiologic evaluation is key to making the most of your hearing



Dr. Johnnie Bass (left) conducts a hearing evaluation

Everyone who had cancer treatment that can affect the ears (such as cisplatin, high doses of carboplatin, or high doses of radiation to the brain) should have their hearing tested at least once following completion of treatment.

If hearing loss is found, testing should be repeated yearly, or as advised by an audiologist. Yet, says audiologist Johnnie Bass, of St. Jude Children's Research Hospital in Tennessee, "many survivors may not have been tested or seen by an audiologist at all—and that's a big deal because so many strategies and technologies are available to improve hearing and enhance communication. The first step is obviously to assess a person's communication needs and, if appropriate, do a hearing aid evaluation."

"I try to assess the person's lifestyle and listening needs, to find out what they would like to hear better," she continues. "For example, a student might want to be able to hear better in class. Or it might be important to improve hearing on the telephone or watching TV at home. In most situations, background noise is the hardest thing to deal with."

Most people with hearing loss will benefit from hearing aids and there are many types available. An audiologist can recommend the best type for an individual's specific needs. Unfortunately, says Dr. Bass, hearing aids are usually not covered by health insurance, and they can be expensive. There are charitable and community-based groups that can help with the cost and Medicaid covers the cost for pediatric patients.

State vocational rehabilitation programs might also be able to help. A list of vocational rehab programs by state can be found at:

<http://www.fda.gov/downloads/AboutFDA/WorkingatFDA/UCM277757.pdf>

Dr. Bass says that "the best idea might be to connect with an audiologist in your local community who can help you find the resources to pay for hearing aids. The audiology community is a small one and most audiologists know one another and know what resources are available in a given area to help their patients."

In addition to hearing aids, there are many other resources for people with hearing loss. Cochlear implants (surgically implanted electronic devices that restore a sense of sound) are an option for those who are deaf or severely hard of hearing and unable to benefit from hearing aids. "There are also many assistive listening technologies available that can work with hearing aids to enhance hearing in specific situations," says Dr. Bass. These include:

- ⇒ **FM systems:** These devices are particularly useful in schools. The teacher wears a microphone that transmits sound over FM radio waves directly to a receiver worn by the person with hearing loss.
- ⇒ **Telecoils:** These small copper coils are an option on most hearing aids and are built into cochlear implant processors. They improve hearing by using the magnetic signal from a regular telephone to represent sound.
- ⇒ **Audio streamers:** These systems wirelessly connect hearing aids to TVs, MP3 players, computers, and Bluetooth-enabled phones and devices. Some are also compatible with FM systems. The signal from the connected device is sent wirelessly and directly to the hearing aids.
- ⇒ **Tinnitus maskers:** People with severe ringing in the ears can benefit from these devices, which look like hearing aids but produce a low level of "white noise" to distract users from the ringing sounds.

Other options include speech therapy, speech reading training, and behavioral therapy like tinnitus retraining therapy. For students with hearing loss, working with a school specialist can help ensure that they are able to sit at the front of the classroom. Dr. Bass stresses the importance of wearing hearing aids throughout the teen years, even though doing so may make students feel uncomfortable and "different," because going without the aids may affect their school work.

As Dr. Bass emphasizes, the crucial first step to better hearing is be evaluated—important advice also for people with vision problems and other sensory conditions. Having a complete medical evaluation is the first step to addressing, and potentially improving, the problem.

Do you have a suggestion for a future newsletter topic?

The LTFU is the world's longest-running study of survivors of serious childhood illnesses like cancer. Study researchers have published results of more than 250 studies of survivorship. Their findings are based in large part on information our survivor and sibling participants have provided on the follow-up surveys over the past 20 years. The studies cover just about every aspect of survivorship. If you have a question about survivorship, chances are there is a study that addresses your concern.

Please let us know what topics you would like to see covered in future newsletters. You can send us your ideas by using the suggestion box on the right-hand side of the newsletters page on the study website:

<https://lftu.stjude.org/newsletters.html>

Candice Stevens: Growing up with hearing loss

Candice Stevens of Columbus, Georgia, was 15 months old when she was diagnosed with neuroblastoma, a malignant tumor that can develop in nerve tissue. She was treated and cured at St. Jude Children's Research Hospital. As part of her therapy she received cisplatin, a drug that can damage hearing. Her hearing loss was discovered when she was about six years old and she has worn hearing aids in both ears since then.

Candice sees an audiologist periodically to adjust her hearing aids, and also for speech therapy. "I do struggle with words that contain the letters 's' and 'r,'" she says, and the speech therapy helps with this.

Candice lost her hearing at a young age and takes it completely in stride. She is studying social work at Columbus State University in her home town and uses an FM system in class. "The teacher wears a microphone and the signal goes directly to my hearing aids," she explains.

She also uses several other coping strategies at school. "I always sit in the front of class, and I read lips," she says. "I also have some disability accommodations. My professors help me fill out some paperwork and I get extra time on tests. I was offered help with note-taking, but I prefer to take my own notes!" she says.

Candice is a music lover. "But I don't wear ear buds, and I keep the volume down," she says. "I want to preserve the hearing that I do have."

After graduation, Candice plans to become a counselor, possibly working in the area of family counseling. Of her hearing loss she says, "I'm thankful for the outcome—it could have been a lot worse. It's really just a normal part of my life. I'm a survivor and I feel truly blessed!"



Candice during treatment and today (photo: John Pyle)

Online Resources: Finding and Paying for Survivorship Care

The Children's Oncology Group, creators of the Survivorship Guidelines, provide the following resources for finding and paying for care:

http://survivorshipguidelines.org/pdf/healthlinks/English/finding_and_paying_for_healthcare_Eng.pdf

<http://applications.childrensoncologygroup.org/Surveys/lateEffects/lateEffects.PublicSearch.asp>

Enter your state into the search engine on this page to find a survivorship clinic near you.

Online Resources for People with Hearing Problems

http://survivorshipguidelines.org/pdf/healthlinks/English/hearing_loss_Eng.pdf

<http://ashacertified.org/find/>

Find an audiologist in your area

<http://www.hearingloss.org/content/financial-assistance-programs-foundations>

Resources for finding financial assistance for hearing aids and assistive technology, from the Hearing Loss Association of America

Online Resources for People with Vision Problems

http://survivorshipguidelines.org/pdf/healthlinks/English/eye_health_Eng.pdf

http://survivorshipguidelines.org/pdf/healthlinks/English/cataracts_Eng.pdf

<http://ssa.gov/people/blind/>

Blind/low vision individuals may be eligible for US Social Security disability assistance. Social Security Administration publications and notices are available in accessible formats, including large-print, audio, and Braille.