

LIFELine

St. Jude for Life



Winter 2017

Dear St. Jude Alumni,



Each time you come to the After Completion of Therapy clinic or return to St. Jude for a LIFE Study evaluation, we give you a packet of information that includes a very important document—your Survivorship Care Plan, sometimes referred to as the SCP.

The SCP contains a concise, but complete, record of your treatment and the health screenings recommended for you in one short document. We update the SCP each time you come, with information you give us and results from your evaluation, so it also contains a good overview of your current health.

You can share this document with your primary care doctor and all the providers who care for you. Don't forget your dentist, your eye doctor, your counsellor, or your chiropractor if you have one. If you attend college or university share it with the providers at your school's health service.

When you share the plan with your providers you don't need to worry about signing a release form. And your doctors won't have to request, and wait for, copies of your complete medical records, most of which they may not need.

Since most providers care for very few adult survivors of childhood cancer, they may not be familiar with your unique medical needs. The SCP is key to communicating with your doctor and ensuring you get the best possible risk-based survivorship care.

Make the most of your Survivorship Care Plan (SCP)

The care plan lists the most important health screenings and the recommended screening schedule, based on your treatment exposures. This information helps your doctor understand why you may need to be screened for some common conditions earlier than most of his or her patients who weren't treated for childhood cancer. For example, if you're a woman who received radiation to the chest your doctor should order yearly mammograms and breast MRI starting as early as your twenties.

Some survivors may be unsure of how to use the SCP or they may not realize how useful it can be. We hope the information in this issue will help you to be comfortable using this important tool together with all your health care providers.

If you don't have a copy of your Survivorship Care Plan please call us at 1-866-899-6677 to request one. Read on for a tour of the SCP and tips on how to make the most of it.

To your health!

Melissa M. Hudson, MD

Principal Investigator, St. Jude Lifetime Cohort Study

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DR. FOLSE: Educate your doctor, advocate for yourself

Most likely you'll meet Dr. Tim Folse when you come to the After Completion of Therapy clinic for an appointment or when you return to St. Jude for a LIFE Study evaluation. Dr. Folse is the Clinical Director of the St. Jude LIFE Study. Before he came to St. Jude he spent more than 20 years practicing family medicine in Memphis, caring for infants, children, and adults of all ages. So he has been on both sides of the survivorship health care experience. Dr. Folse says that most community providers are not aware of how to care for

adult survivors of childhood cancer. "Most community physicians will only ever see one or two childhood cancer survivors during their entire years of practicing. I never saw even one survivor that I can recall before I began working at St. Jude. And I didn't appreciate the health risks associated with being treated for childhood cancer," he says.

Because of this experience Dr. Folse works hard to make sure his patients understand the role of the Survivorship Care Plan in communicating with all their health care providers.

"As a physician, I feel that teaching patients about their unique health risks is one of my most important roles," he says.

Survivors can also be teachers

Dr. Folse says, "Most providers are not trained in survivorship—you may be the first childhood cancer survivor they encounter. So you can use your care plan both to educate your providers and to advocate for your own health.

"Here's an example," he continues. "I recently saw a patient here at St. Jude who had been treated with high-dose radiation as a young child. Not surprisingly, thirty years later he sees a pulmonologist.

"He told me his pulmonologist relies on the care plan. It shows my pulmonologist that my lung problems are

from radiation damage and it helps him understand what my risks are and the health screenings I need. I'd have a hard time explaining all this without the plan!" my patient told me. In fact, without his care plan he might not receive the risk-based screenings that he needs to maintain his health."

How can you get the most out of your care plan?

"Not all patients understand why it's important the first time they see it and neither do many providers," says Dr. Folse. "Handing the plan to the doctor once may not be effective because often they just stick it in the chart—it's just another piece of paper. They need to get used to seeing it regularly."

Good advice from Dr. Folse:

"Study your care plan, make notes on it, and take your most recent copy with you every time you see your doctor!"

"The Survivorship Care Plan is a living document. We update it every time you come for a clinic appointment or a LIFE Study evaluation, based on what you tell us and new information we have learned. It is the crucial link between your oncology team at St. Jude and the providers in your community who are responsible for your ongoing survivorship care. We depend on you to share this great tool and make that connection."

IMPORTANT NOTE

All St. Jude long-term survivors are eligible to receive a care plan even if they did not attend A.C.T. Clinic or do not participate in the the LIFE Study. You can request one by calling the A.C.T. clinic:

1-866-899-6677

Share this with your doctors, too!

The Information available on the Children's Oncology Group's website is a great supplement to your care plan—it's available here:

www.survivorshipguidelines.org

This site has additional details, targeted to health care professionals, on screening recommendations for survivors. It also has a set of patient education materials called "Health Links" that both you and your providers can use.

SURVIVORSHIP CARE PLAN: As easy as 1 - 2 - 3!

There is a wealth of information in your survivorship care plan. Start the conversation with your providers by sharing these key sections:

- 1 Go to the **THERAPY** section on the first page and show your provider the details of your treatment. This section is really like a mini-medical record that has everything your doctor needs to know about how you were treated.

Therapy						
Surgeries						
Date	Procedure					
6/3/2011	Placement, Venous Port, Percutaneous, Subclavian, Left					
6/23/2011	Laparotomy; Nephroureterectomy, Radical, Right; Adrenalectomy, Radical, Right					
10/13/2011	Placement, Gastrostomy Tube					
Radiation						
Start Date	Stop Date	Radiation Type	Source Type	Site	Cumulative Site Dose (cGy)	Boost Site Dose (cGy)
7/13/2011	7/22/2011	Conventional	Linear Acceleration	Abdomen, Whole	1050	
Chemotherapy						
Cumulative Dosage Summarization						
Drug Name				Drug Route	Dose /m2	
Dactinomycin				Intravenous	5	
Doxorubicin - Adriamycin				Intravenous	128	
Vincristine				Intravenous	24	

(Example only)

- 2 Next, go to the **SPECIAL CONCERNS** section, which shows how your treatment exposures might affect specific organs and tissues in your body. As a simple example, if your treatment included radiation to the brain your doctor might not know that it can cause ear wax buildup, as well as damage to nerve cells that affect both hearing and balance. If you received anthracycline chemotherapy drugs your doctor will want to screen you for heart disease much earlier than other patients who did not take these drugs.

Special Concerns

- 3 Follow up with the **SUGGESTED EVALUATIONS** section and go over the list of screenings that are recommended for you based on your specific treatment exposures.

Suggested Evaluations Related to Your Specific Treatment for Childhood Cancer

Recommendations on this Summary apply only to adult survivors of childhood cancer who are 1) two years past cancer treatment, 2) asymptomatic, that is, they have no symptoms of cancer-related medical problems. If you have known medical problems related to your cancer treatment, discuss the type and frequency of follow-up evaluations with your medical provider.

JEFF DAVIS: Four good reasons to take care of my health

Jeffrey Davis was diagnosed with Hodgkin lymphoma in 1968 when he was just eight years old. Doctors in Chattanooga, where he lived, referred his family to St. Jude for diagnosis after they saw the enlarged lymph nodes in Jeff's neck. At St. Jude, Jeff was treated with both chemotherapy and high-dose radiation to an area that included his heart and his lungs. "I was at St. Jude for most of the year I was in third grade," he recalls.

As a result of his treatment Jeff developed some chronic illnesses that have had a big impact on his health. He has reduced airflow through his lungs as well as pulmonary hypertension (high blood pressure in the lungs.) In 2000, he was diagnosed with third degree heart block, a serious problem with the heart's electrical system. He had surgery to insert a pacemaker that helps keep his heart beat regular. He also requires ongoing thyroid hormone replacement therapy because his thyroid, a gland that is important for regulation of body temperature, heart rate, blood pressure, and metabolism, was damaged by the radiation therapy he received.

When Jeff graduated from therapy at St. Jude in the early 70s not much was known about the long-term effects of treatment for children who survived to adulthood. Doctors in that early era necessarily focused on finding cures, not on future consequences. One of the important benefits of research at St. Jude, including the LIFE Study, is that the experiences of patients like Jeff have led to new treatments that have fewer side effects while still achieving cures.

Today, Jeff still lives in Chattanooga. He works as a computer programmer for an insurance company there. One treatment side effect Jeff was told he might expect was infertility—the inability to father a child. "Because of my treatment I didn't think I'd be



able to have kids," says Jeff who married his wife Kimberly in 1989. "So our first child was a surprise!" The couple's first son was born in 1993 and was followed by a sister born in 1995 and a brother born in 2000. "Each one was a wonderful surprise!" Jeff says fondly. "I'm grateful for my wife and kids and grateful to St. Jude for giving me the tools I need to take care of my health!"

"I don't believe I ever had a copy of my treatment history written down until I started participating in the LIFE Study. Now my survivorship care plan is included in the packet I receive after every clinic visit or LIFE Study appointment. I always share the updated results with my pulmonologist here in Chattanooga. I also share them with both my cardiologists, the local one and also one in Nashville. I like to be able to keep up with the Study and have them keep up with me. And it's great to be able to keep my local doctors informed."



Please stay in touch with us!

- ☞ Call us toll-free at: **1-800-775-2167**
- ☞ Send us an email: **sjlife@stjude.org**
- ☞ Visit our website: **www.stjude.org/sjlife**

Thank you!
for participating in survivor research