

TRANSITION TO SURVIVORSHIP

Various serious childhood health conditions have different trajectories and place different demands on you as the parent. Some serious childhood conditions do not have end points of treatment. Some do. Chronic conditions such as diabetes, sickle cell anemia, and some heart conditions require initial treatment that may stabilize the problem but require continuing, ongoing maintenance treatment for the stabilization to continue. There may be periodic exacerbations of the condition that are then hopefully controlled medically. In these situations, your child continues treatment, although the medical demands may lessen. You and your family face how to incorporate this ongoing reality into your family life. The treatment of childhood cancer, on the other hand, hopefully does have an end point and holds out the possibility of a complete cure along with the possibility of late effects requiring conscientious followup. A bad injury requires intense treatment initially and often only occasional followup later, which puts it into a similar category.

This chapter is most relevant to parents of children whose treatment has an end point or to parents of children where the medical demands have decreased significantly. Chapter 17 is about the followup care needed and possible late effects for children treated for cancer. There are important survivorship issues that are unique to this population that you need to know about if you have had a child with cancer. Chapter 18, “Emotional Effects of a Serious Childhood Illness,” chapter 19, “Healthy Living,” and chapter 20, “When Your Child Becomes an Adult” will be relevant to parents of children who have had any kind of serious medical condition, including those that require ongoing medical care.

ENDING TREATMENT

Your child has now finished his or her treatment. Perhaps your child has had the last hospitalization connected with his injury. Perhaps she has recovered from the rare viral infection that incapacitated her for some time. If your child had cancer, he may have had his last chemotherapy or his final necessary surgery. Now the visits to your child’s oncologist or the specialist will be check ups and will hopefully occur with decreasing frequency. If your child had a central line such as a portacath, it will likely be removed shortly. Your child should be able to attend school more regularly. Your family will assume a new normal where you will reestablish family life while recognizing and responding to new perspectives and attitudes in your family.

Don’t be surprised if you feel a complicated mix of emotions. You may be enormously relieved and ready to get back to family life with fewer medical demands and as little contact with the medical staff as you can responsibly manage. Or you may find it very anxiety- provoking to see less of the medical staff. If your child had cancer, the treatment may have signified to you the disease was being held at bay. Once treatment stops, you may worry that the cancer could return. Sometimes parents miss the contact with the clinic and the familiar people there who have been a source of support and reassurance. For some parents and for parents dealing with different diagnoses, the change may not feel so dramatic because you may have already reduced the frequency of your clinic visits.

All of these reactions are normal and reasonable. Remind yourself that you will still have the continuing opportunity to ask questions of your child’s doctor. Every large hospital has doctors on call in the emergency room. In most children’s cancer treatment centers, there is an oncologist on call who will be available to answer your questions if something unexpected occurs outside normal clinic hours, even if your child has finished treatment. Depending on your child’s condition, there are likely to be different resources and information available to you as you begin your child’s survivorship journey.¹ Be sure the

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specialist has sent your child's pediatrician all the relevant information on his treatment and necessary followup care as you will hopefully gradually see more of the pediatrician and less of the specialist.