

WHEN YOUR CHILD BECOMES AN ADULT

A child becoming an adult is a transition that every parent has to negotiate. It is often a time of mixed emotions. Feelings of pride and accomplishment are mixed with other feelings of fear and sadness. It can be challenging. The situation at home, the number of children you have, what your child is going to do, and how resilient or vulnerable you think she is can influence your reactions. It may be harder for you if you are a single parent, if you are not working, if you do not have other consuming interests, or if you do not have fulfilling relationships with other people. It could be more stressful if your child has decided to work in a dangerous place in the world or if you see your child as especially vulnerable. Because your child has experienced a serious childhood illness or condition, you could easily feel she is vulnerable. Moreover, depending on her condition, a good portion of your time may have been devoted to taking care of her, so you may have had less time to work or to develop other interests. A parent's natural fears about a child's ability to negotiate life in the real world may be increased by your worries about your child's health and thoughts about what she needs to do to maintain and protect it. You may also find you have more time on your hands to worry. Do not be surprised if you find yourself quite anxious when your child is moving out or moving on.

This chapter talks about how you might work with your adolescent and his doctor to see he gets the follow-up medical care he needs as an adult. Adult survivors may no longer be eligible for or comfortable with followup care in a pediatric clinic, and a pediatric specialist may not be comfortable having overall responsibility for the care of an adult patient, so the survivor will need to seek adult medical care. Unfortunately, many adult survivors of serious childhood conditions currently do not get appropriate medical followup care. This is true of a majority of childhood cancer survivors. I describe some of the reasons your young adult may be reluctant to take over his own followup medical care, and I offer some ideas for you to consider.

There are three separate but related practical challenges about medical care you will likely encounter when your child gets ready to leave home and is becoming more independent— all of which will affect the quality of medical care your child gets and will influence how you can best help your child take over her own care. The first is determining the most appropriate long- term followup care that will meet your child's needs and preferences throughout adulthood. Your child's pediatric specialist will be the caregiver who can give you the relevant advice about your child's follow-up guidelines. The second challenge is managing the difficulties you and your adult child will encounter as your child transitions to the adult medical world. The third challenge is getting your child to take responsibility for his or her medical care. You have an important role to play in negotiating all three challenges.

MAKING A SUCCESSFUL TRANSITION TO ADULT CARE

You can influence your child's successful transition to adult medical care and how he views his responsibility for his own medical care in various ways. Ideally, your efforts begin well before your child becomes a young adult and can take many forms:

- Giving your child a sense from early on in his medical journey that he is a partner in a joint enterprise.
- Understanding from your child's pediatric doctors what long-term followup care your child will need and why.

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- Gradually handing over to your child in early adolescence some responsibilities for his medical care and encouraging his doctor to do the same.
- Deliberately playing a less active role in meetings with the doctor and seeing they meet alone for some of the time.
- Seeing that his doctor gives him the information he needs about his diagnosis, treatment, possible late effects, and followup needs.
- Talking over with your child and his doctor what to expect in the adult medical care world
- Getting specific recommendations for adult medical care referrals from your child's doctor.
- Making the transition of care as gradual as possible and actively supporting your child during the transition, including advocating for and taking advantage of any transitional services available like a patient navigator or transition program.
- Helping your child, at least initially, navigate the adult medical world so that his medical needs are met and his caregivers develop the practice of communicating appropriately with one another.
- Communicating to your child that you do, despite some natural anxiety, have confidence that he will be able to take care of himself.
- Understanding and managing your anxiety so it does not communicate itself to your child.
- Matching your guidance to your child's style.
- Understanding that your child may go through a period of avoiding his responsibilities while recognizing this may be a temporary phase. It is likely extremely anxiety- provoking for you, but may well pass.
- Accepting that the most you can do during this phase may be to offer reminders, incentives, bargains, and prayers while containing your anxiety and your temper.

A FINAL WORD ON THE TRANSITION TO ADULT MEDICAL CARE

The transition to the world of adult medical care can be difficult to navigate for you and your child. Advance preparation, patience and careful listening can make the switch easier. Efforts that seem to help the transition go smoothly include:

- communicating the idea to your child that this transition is a positive and normal development
- checking your child has realistic expectations (neither too rosy nor too gloomy!) about adult medical care
- seeing your child knows the details about his diagnosis, treatment, and future health risks, and feels competent to manage his illness
- ensuring the timing and the details of the transfer have been carefully planned with input from you, your child, and his doctor, who has hopefully recommended where and with whom the adult followup care should happen

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- making use of any resources available to support the transition process (joint visits, using a liaison coordinator)

Making these efforts over time and tolerating your child's ambivalence during and after the transition of care has occurred while remaining in the background ready to help when your child is faced with particular medical roadblocks mean you are doing all you can to ensure your child gets the adult medical care she needs and in the long run sees herself as responsible for her own long-term health.