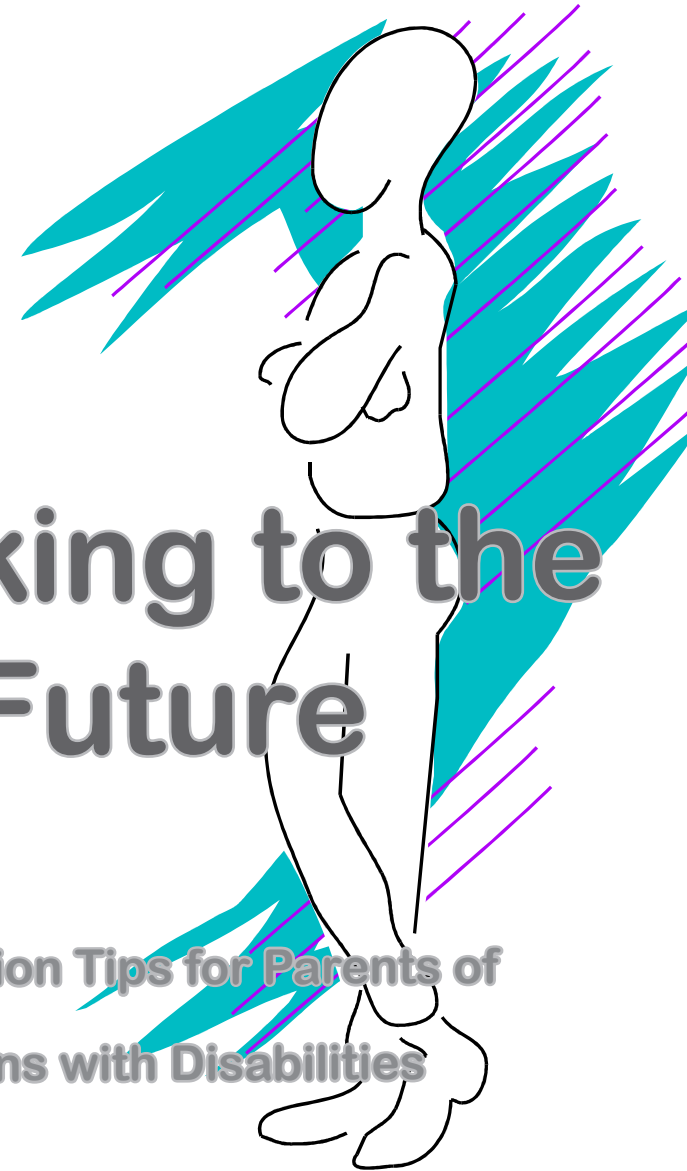




Looking to the Future

Transition Tips for Parents of
Teens with Disabilities

Shriners Hospitals for Children
Intermountain
Fairfax Road at Virginia Street
Salt Lake City, Utah 84103
801 – 536 – 3500
http://www.shrinershq.org/Hospitals/Salt_Lake_City/

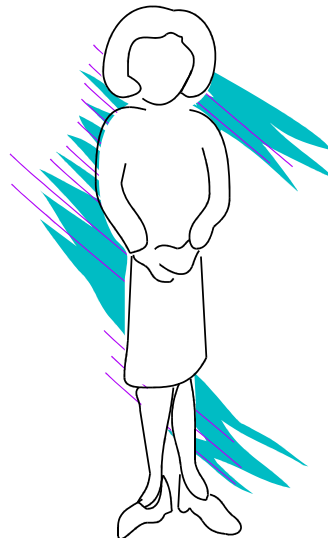


Taking care of you!

- Take good care of yourself physically, emotionally and spiritually. Your teen is learning how to take care of herself as an adult by watching you.
- Stay connected with friends, family, church and community.
- Remember that asking for help is a sign of strength. Your teen will learn from you that asking for help is ok.
- Find a mentor. Seek out someone who has “walked in your shoes” and is doing well. Join a support group for parents of youth with disabilities.
- Recognize that you may have new emotions as your teen starts maturing. Seeing your child physically become an adult may create anxiety about the future.

How can I help my teen stay physically healthy?

- Encourage your teen to be active. Participate in physical activities as a family. Involve your teen in adapted recreation programs in your community.
- Encourage healthy eating habits. Keep your kitchen stocked with healthy snack choices
- Encourage good hygiene. Teach your teen how to take care of her physical body including bathing and showering, toileting, shaving, etc. Give your teen the supplies he needs such as deodorant, shampoo and shaving cream.
- Encourage your teen to be safe by using seat belts and/or wheelchair restraints.
- Talk with your teen about smoking, drinking, drugs and sex. Share your expectations.

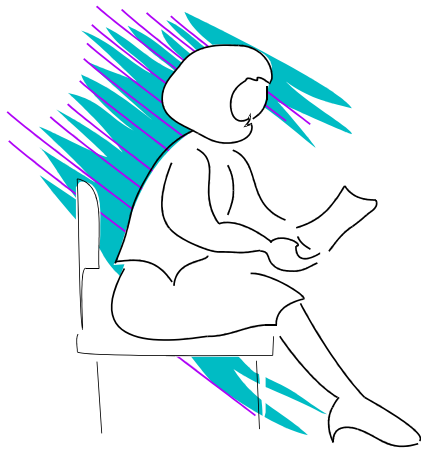


Please call the hospital with any questions at (801) 536-3500. If you are unable to reach the hospital and you feel it is an emergency, call 911 or go to the nearest Emergency Room.

Questions about Transition? Call your Care Coordinator:

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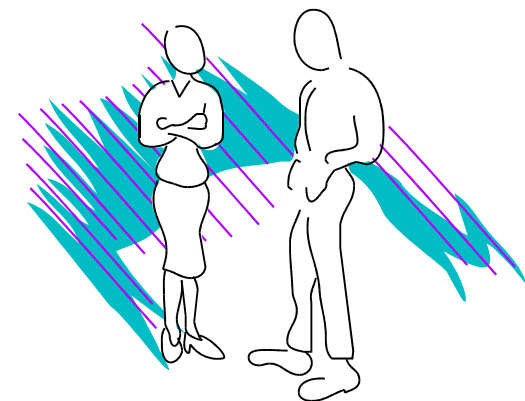
- **Healthy and Ready to Work National Dissemination Center:** This site provides various tools and resources to assist youth with special health care needs in the transition to adulthood. www.hrtw.org
- **Kids As Self Advocates (KASA):** National network of youth with disabilities and their friends that speak out and educate others about issues relevant to youth with special health care needs. www.fvkasa.org/index.html
- **National Center of Medical Home Initiatives for Children with Special Needs:** Provides information on the importance of a medical home and how to obtain an appropriate medical home for children with special health care needs. www.medicalhomeinfo.org/states/index.html
- **National Dissemination Center for Children with Disabilities (NICHCY):** Central source of information on disabilities in children and youth, programs and services for youth with disabilities and special education laws and rights. www.nichcy.org/index.html
- **Parent Advocacy Coalition for Educational Rights (PACER):** This site offers educational materials, information about resources and services, online training and individual assistance for parents of children with disabilities. www.pacer.org
- **University of Wisconsin Family Village:** Information, resources, and communication opportunities for people with disabilities, their families and those that provide them with services and support. www.familyvillage.wisc.edu
- **Youthhood.org:** A dynamic, curriculum-based tool that can help young adults plan for life after high school. www.ncset.org/websites/youthhood.asp



- Watch for signs of depression in your teen such as sleeping too little or too much, changes in eating habits, withdrawal from family and friends and severe mood swings. Teens with disabilities are at a higher risk for depression than their peers. Talk with your teen's primary care provider, school counselor or local mental health center if your teen has these symptoms.

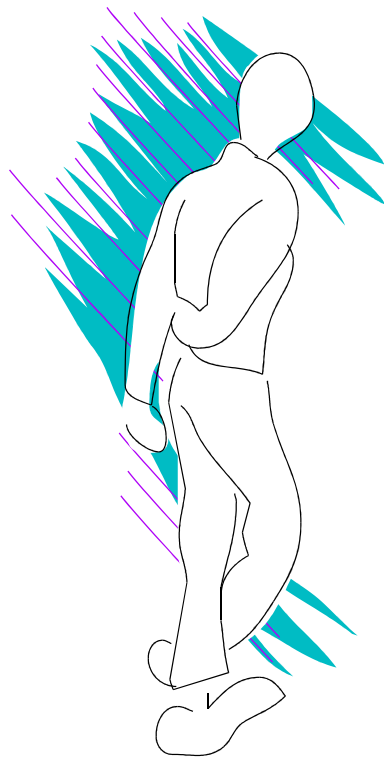
How do I address sexuality with my teen?

- During your teen's routine doctor visits, help your teen ask the doctor or nurse about how her health condition may affect puberty, sexuality and reproduction.
- Talk with your teen about how her body is changing during puberty. Use developmentally appropriate materials to teach her about puberty.
- Bring up the issue of sexuality with your teen. She may be uncomfortable bringing this topic up herself. Share your beliefs and values about sexuality. Listen as she shares her anxieties, beliefs and values.
- Talk with your teen about abstinence, safe sex and birth control options.
- Talk with your teen about her hopes and fears about dating, marriage and parenthood.



How do I help my teen stay emotionally healthy?

- Encourage your teen to seek out friends with and without disabilities.
- Encourage your teen to be involved in school activities, sports, clubs and church groups.
- Look for activities or groups in your community specifically for teens with disabilities.
- Help your teen make and keep friends by inviting her friends to your home or giving your teen a ride to activities.
- Give your teen choices, responsibilities and permission to make mistakes.
- Support your teen's efforts to dress and fit in with her peers.
- Assure your teen that most people experience teasing, being left out, body image and self-esteem problems at some point during the teenage years. These are not just issues for teens with disabilities.
- Teens need positive role models. Look for magazines, movies, and books that show people with disabilities in a positive light.
- The Internet can be a useful tool for your teen to learn more about her disability and to connect with others. Teach your teen Internet safety skills such as not giving out personal information, not arranging to get together with people she has "met" online and reporting to you any people or messages that make her feel uncomfortable. Set rules with your teens about when she can be online and what sites she can visit.



- Adaptive recreation programs provide sports and other forms of recreation to people with disabilities. Programs may include skiing, horseback riding, sled hockey, bowling and team sports, among many others. Contact your local Parks and Recreation, Disabled Sports USA www.dsusa.org, Special Olympics www.specialolympics.org or Care Coordinator for more information



What websites are available to teens with disabilities and their parents?

- **Ability Online:** A free and monitored online support community that links youth ages 11-24 with disabilities or illness to other kids and adults who care. www.ablelink.org/public/new/index.html
- **Band-Aids and Blackboards:** Site for youth growing up with any type of medical problem or disability. Includes poetry, stories, art, photos and essays by teens and for teens with special health care needs. www.lehman.cuny.edu/faculty/jfleitas/bandaides
- **Bright Futures for Families:** Developmentally focused information for infancy, childhood, adolescence and transition. <http://brightfuturesforfamilies.org/home.htm>
- **DisabilityInfo.gov:** Federal government website that serves as a starting point for all government services and information sites. www.disabilityinfo.gov
- **Health Finder:** Key resource for finding the best government and nonprofit health and human services information on the Internet. www.healthfinder.gov

What resources should I be aware of for my teen?

- Developmental disabilities programs offer a variety of services to youth with severe developmental and/or physical disabilities including respite care, family assistance and support and Medicaid waivers. Check with your state's Department of Human Services via www.healthfinder.gov or NICHCY's state resource sheets www.nichcy.org/states.htm for contact information.
- The Maternal and Child Health Bureau contracts with each state to provide specialized medical services and care coordination to youth under age 18 with special health care needs. Services vary by state and may include cleft lip and palate, neurology, genetics, physical and occupational therapy evaluations and orthopedics. https://perfddata.hrsa.gov/mchb/mchreports/link/state_links.asp
- State Children's Health Insurance Programs are low cost health insurance programs for children of working families who are uninsured and meet income guidelines. www.insurekidsnow.gov
- Supplemental Security Income (SSI) pays monthly benefits to parents of children under age 18 with disabilities who qualify based on income and severity of disability. www.ssa.gov
- Medicaid is government funded medical insurance available to children from families with limited income. Most children receiving SSI are automatically eligible for the program. Children with severe disabilities who do not meet income guidelines may still be eligible via Medicaid waiver programs. www.cms.hhs.gov/apps/contacts
- Independent Living Centers offer classes and activities to help people with disabilities to become more independent. Sometimes they can help fund equipment or assistive technology that will help with independence. www.irlu.org/html/publications/directory/index.html
- Parent Training and Information Centers are federally funded programs offering information and referral, peer support, training and advocacy to parents of youth with disabilities. www.taalliance.org/centers/index.htm

- Bullying is a serious issue for many teenagers. Your teen may not want to tell you if she is being bullied so watch for signs such as suddenly not wanting to go to school, claiming illness on school days and doing less well at school work.
- If you think your teen might be being bullied, talk with her and her teacher or principal. Most schools have an anti-bullying policy and will eagerly work with you and your teen to stop the problem. You may want to include bullying prevention steps and solutions in your teen's Individualized Education Plan (IEP), if bullying is an ongoing problem for her.

How do I help my teen succeed in school and work?

- Schedule medical appointments after school to reduce time out of school when possible.
- If your teen is receiving any special services at school, require the school to document them as part of an official 504 or Individualized Education Plan (IEP).
- Have your teen attend part or all of her IEP or 504 meetings. Encourage your teen to speak up for what she feels is needed to succeed in school. This will remind the IEP/504 team that they are talking about a specific person, not just a name on a sheet of paper
- Talk with your teen's IEP/504 team about transition. Ask about graduation requirements, how the school will address independent living skills, what vocational testing is available, when your teen will be referred to vocational rehabilitation and the availability of recreation opportunities and socialization activities.
- Teach your teen to take care of her healthcare issues at school. This will be good preparation for managing healthcare issues independently in the work place. Teach her how to take care of bowel and bladder issues, how and when to access medications and what to do in a medical emergency.

- Talk with your teen about what types of jobs and careers interest her. Discuss the training needed to reach employment goals such as college or vocational school. Help your teen to select classes in high school that are relevant to the types of jobs that interest her.
- Encourage your teen to meet with, interview or job shadow someone who is employed in a job that interests her.
- Arrange campus tours of the colleges your teen wishes to attend. Meet with the Disability Resource Center on campus to find out what services are offered to students with disabilities.

How do I teach my teen to manage his own health care?

- Encourage your teen to learn more about his health condition. Good resources include his doctors and nurses, the public library, disability organizations and foundations and relevant Internet sites.
- Help your teen to make a list of questions to ask the doctor at each appointment and remind him to bring the list to appointments.
- Encourage your teen to talk directly to the doctor and to answer the doctor's questions directly rather than having you talk for her.
- Allow your teen to spend time alone with the doctor during appointments so she can ask questions that maybe uncomfortable to ask in front of parents.
- Help your teen to create a "portable medical summary" that includes a list of her diagnoses, medications, allergies, prior surgeries and contact information for his healthcare providers.
- Teach your teen how to request that a copy of her medical record be sent to her and his primary healthcare provider at each appointment.
- Teach your teen to make her own doctor appointments, call in prescription refills, carry his insurance card and know how it works, plan for medical emergencies and sign consent forms for treatment (parent signature will also be required until patient is age 18).

- Always ask for your teen's input when making major decisions about surgeries, medical treatments and hospitalizations. Although you as a parent have the final say, your teen deserves to have her thoughts and feelings taken into consideration.

How do I help my teen become more independent?

- Give your teen chores and responsibilities at home and in the family. Giving young people responsibilities sends the message that you feel they are competent.
- Help your teen find a way to "get around" independently. This may include riding the bus, getting a driver's license or arranging for rides from friends or family members.
- If you think your teen may be able to drive safely, talk with the school counselor or your Care Coordinator about driver's education, adaptive equipment and driving evaluations for people with disabilities.
- Encourage your teen to volunteer or to find a part-time job. Call upon your resources such as your employer, friends or religious organization for help in finding employment or volunteer opportunities.
- Encourage your teen to take an independent living skills class at school or in the community. Independent Living Centers offer a variety of classes including cooking, riding the bus and money management (See page 7).
- Encourage your teen to take "safe risks" like riding the bus with a friend, joining a school club or spending the night away from home.
- Teach your teen goal setting skills. Help her to set goals, break goals down into small steps and to reward herself when goals are met.

