THE FAMILY AS ROLE MODELS

Parents and other family members are role models for children at all ages. Remember that your actions (or lack of actions) teach your child. Take good care of yourself and set a healthy example in these areas:

- Fitness and exercise
- Personal care
- Education
- Self-esteem and pride
- Empowerment
- Advocacy for services and equipment
- Educating professionals and practitioners
- Refusing to be a victim

RECORDING MAJOR EVENTS IN YOUR CHILD’S LIFE

Maintain a journal or life record of the major events in your child’s life. Review this record periodically. Share the record with your child, and give it to him or her during adolescence, or at an age-appropriate time. The record should include:

- Health issues or problems
- Developmental milestones
- Changes in family structure
- Therapy and service records
- Equipment and vendors
- Changes in function
- Ongoing concerns
- Assessments and reports, e.g. Individual Education Plans
- Financial & insurance information
- Trust funds and Social Security Insurance
- Legal matters, living wills


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Children can play an active role in their health care.

**WHEN YOUR CHILD IS YOUNG**
- Talk to your child about his/her chronic illness or disability so that they are able to tell others about it.
- Teach your child to take his/her medication (you will still need to track how much they take).
- Teach your child about danger signs associated with their illness or disability.
- Encourage your child to ask questions and talk to the doctor and other health care providers.
- Teach your child basic health promotion such as good eating habits, physical activity, handwashing and personal hygiene.
- Teach your child specific self care for their illness or disability, such as preventing infection, managing pain, and proper nutrition and hydration.

**WHEN YOUR CHILD IS AN ADOLESCENT**
- Assess your teen’s knowledge of their chronic illness or disability—fill in any gaps in understanding.
- Teach your teen to call the doctor if they experience a danger sign and to tell you about any danger sign.
- Teach your teen to take their medication and tell you how much is taken.
- Discuss the long-term course of the illness or disability with your teen, and what they might expect in the future.
- Teach your teen to go to doctor visits without you. Encourage your teen to communicate (e.g. ask questions) directly with the doctor and health care providers.
- Teach your teen to take his/her own temperature and manage specific self-care.
- Encourage your teen to attend a teen support group, talk to a genetic counselor if appropriate and keep you informed about what they are doing and feeling.

Teaching your child basic life and independent living skills

It’s never too early to start teaching your child these problem-solving and management skills. It’s important to give your child opportunities to practice skills. Life skills must be rooted in knowledge, attitudes, and behavior.

![SKILLS Diagram]

**Introducing work, responsibility and earning money**

Keep in mind that work may be either volunteer or paid employment. Vocational training and employment for your child will depend on support services available in your area, availability of assistive technology, accommodations made by employers, and local economic climate.

Teens going on to post-secondary education should be aware that colleges have services for students with disabilities. These services can help students identify accommodations they may need to be successful in college.

**TIPS FOR PARENTS**
- Assign chores at an early age, appropriate to your child’s ability level.
- Help your child learn independent living skills early.
- Be aware of your child’s interests and abilities (though ever changing).
- Talk to those who have training in employment issues.