

Transition Guidebook

PART B: Whose Life is it Anyway? Leading the Life You Want



For teens with spina bifida

Transition (n) tran-si-tion

A change from one stage to another

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WHAT IS TRANSITION?

Transition is something that all teens go through. It is a process that occurs over many years, especially during high school. If you are a teen with spina bifida or another medical condition, transition may mean taking more responsibility for your health, developing adult life skills, and participating more in your community with friends and family.

Transition involves planning for the changes from pediatric doctors to adult doctors, moving from school to work, and having the skills to be able to achieve what you want as an adult. This can be an exciting and challenging time for you and your parents. It is never too early to start preparing for your future. There are a lot of important topics to think about regarding transition.

We have broken this book into two sections.

Part A: Whose Health is it Anyway? Taking Care of Your Health, talks about becoming more responsible for your health.

Part B: Whose Life is it Anyway? Leading the Life You Want, talks about planning for your future.

Don't forget to speak with your doctor if you have any questions or want to talk about a topic more.

Part B: Whose Life is it Anyway! Leading the Life You Want

Independence Skills

1) Managing Household Chores

Chores are important for all kids, teens and young adults. They build responsibility, teach skills, and let you participate at home while feeling good about your accomplishments. Helping out more with cleaning, laundry, and cooking prepares you for a more independent future.

Household skills should be broken down into smaller steps to make it easier to learn. For example, laundry involves sorting clothes, using the washing machine, using the dryer, folding clothes and putting clothes away. You can start by doing a part of the larger task, and eventually learn how to do all steps. For all tasks, you should participate as much as you can depending on your ability and accessibility in the home.

“Household skills should be broken into smaller steps to make them easier to learn.”

It can be helpful to have a few chores that are always your responsibility, such as feeding a pet, setting the dinner table, or taking out the garbage each week. This builds a pattern. Like taking medications, reminders may be needed at first, but eventually you should start to do them on your own. Reward charts may also be very useful to keep track of completed chores. Talk to your parents to set up a reward program.

Occupational therapy can help teach many household skills and give ideas for various adaptive devices. Speak with your doctor if you are interested in learning more about occupational therapy. The Rehabilitation Institute of Chicago also has a Transition Group for teens to have “hands-on” practice with household skills .

2) Money Management Skills

It is also important to learn to save money for things you want to buy, and to learn how to manage money so that you can go to the store. This may often begin with having an allowance, and learning to save and spend money on small items such as clothing, games, and activities. You can start to practice paying the cashier and learn to give and receive correct change. Around 11-12 years of age, most teens start to carry some small pocket money with them. Eventually, as you get older, you may open up a checking or savings account. This can be a joint account with your parent, so that you can both use the account and they can help you manage it.

There are many skills needed to manage money including understanding the value of money, planning a budget, writing checks, putting money into the bank, and using an ATM card. Like all learning, it will be easier to master these skills if they are broken down into small steps.

Hands-on learning allows you to practice. Schools can help develop these skills and money management can be included in an Individualized Education Program (IEP) if appropriate. Often times, local community agencies have budgeting classes which may be helpful for teens and young adults to practice skills.

3) Safety Tips

As you become older, you may start to spend time alone at home, which is normal for teens. Before spending any time alone, you want to talk with your parent about safety.

✓ *Chore Charts*
<http://www.dltk-cards.com/chart/>

✓ *Children’s Memorial Hospital Occupational Therapy*
312.227.6240
www.childrensmemorial.org

✓ *The Rehabilitation Institute of Chicago Occupational Therapy*
312.238.1000
www.ric.org

These are some safety-related questions to think about:

- Do you answer the door?
- How do you answer the telephone?
- Who do you call in case of an emergency?
- Can you safely leave the house in case of an emergency?
- Can you safely move around the house?
- Can you get a snack?
- How long can you stay home alone?
- Do you need to practice self care skills to stay alone?

These are all questions that should be talked about before staying alone. It is common to begin staying alone for half an hour or an hour, while parents run a quick errand. Then you may begin to stay at home after school for a few hours and eventually longer. Remember, safety is most important no matter how long you are at home alone!

4) Transportation

When you were younger, your parent/caregiver usually took you places. As you get older you will start to find other ways to get around the community. This might include getting rides from friends, taking public transportation, using transportation services for people with disabilities, or learning to drive. Driving rehabilitation programs can help teach you to drive and suggest adaptations for your car if needed. While it can sometimes feel more comfortable staying at home, exploring options for transportation and getting out in the community has good benefits for young people.

5) Living Independently

As you start to plan for your future, you will also need to think about where you want to live when you get older. Some young adults continue to live at home, others live in a college setting or with friends, and some people live on their own.

One of the reasons it is so important to learn household skills -- such as cleaning, cooking, and money management -- is to prepare to live on your own, if you choose to. Other things to think about are accessibility of your home and whether you need any help while living on your own. There are programs that can provide some additional services if you are living on your own.

A new option for young adults with spina bifida is Anixter Village, which is a 15 unit apartment building in Chicago that offers

✓ **Regional Transportation Authority and ParaTransit**
836.7000 from any area code

www.rtachicago.com

✓ **Driving Rehabilitation**

- Marianjoy, Wheaton
630.909.6080
- Evanston, North Shore
847.570.1260
- Alexian Brothers
847.640.3119

✓ **First Transit: Public Aid Medical Transportation**
877.725.0569

✓ **Anixter Village**
773.440.0305

✓ **Access Living: Housing Team**
312.640.2100
www.accessliving.org

✓ **Progress Center for Independent Living**
708.209.1500
<http://progresscil.org>

✓ **Mayor's Office for People with Disabilities**
Housing Program and HomeMod
312.743.1523

programming for people living on their own for the first time. The goal is to work in the program to become successful while living on your own, and eventually move into the community once you have the skills to live independently.

It is important to talk with your family and doctors about where you may want to live as you get older, so everyone can start planning and you can choose the option that is best for you.

Healthy Lifestyle

1) Nutrition

Eating healthy is an important part of a healthy lifestyle. Hippocrates said, "If we could give every individual the right amount of nourishment and exercise, not too little and not too much, we would have found the safest way to health."

People with spina bifida often tell us that they eat less than their family members but still gain weight. Researchers are looking at the reasons for this. In the meantime, here are some tips that you can follow.

- Eat plenty of fresh fruits and vegetables, about 5 servings a day. Fruits and vegetables are low in calories, high in vitamins, and have fiber (which helps the bowels move).
- Consume whole grains as part of your diet -- they are a good source of fiber and many nutrients. Whole grains can be found in many foods including cereals, barley, whole wheat, quinoa, corn, and rice.
- Protein is important especially if you have a pressure sore, or are healing after surgery. Lean meats, eggs, dairy, nuts, lentils and beans are all good sources of protein.
- Dairy products are a good source of Calcium and Vitamin D. You also get Vitamin D from sunlight on your skin. Calcium and Vitamin D are important to help keep your bones strong and healthy.

We do not have a good way of telling what is the right number of calories for people with spina bifida, but your doctor can let you know if your weight is a healthy one. You should check your weight regularly and make sure that clothes still fit. You may want to meet with a dietician to see if you are getting enough vitamins and nutrients. Some people need extra vitamins and calcium if they eat very little.

“Avoiding junk foods are an important part of the plan.”

✓ ***Children’s Memorial Hospital: Dietician***

Linda Somers, RD

800.KIDS DOC

✓ ***Nutrition and Wellness Center at University of Illinois***

312.740.6574

✓ ***La Rabida Children’s Hospital***

773.363.6700

Avoiding junk foods are an important part of the plan. Soda pop has a lot of sugar, and should be avoided. Foods high in fat, starch or sugar (fries, chips, cakes, chocolate bars, cookies) cause weight gain, and should be eaten rarely. It's OK to have some of these foods occasionally, maybe once a month or once a week, but they should not be part of a regular diet. Try to find healthier options, like microwave popcorn, apple or banana chips, dried fruit, and cut up fruits and vegetables for a snack. People often mention that when they are eating better, they feel much less tired, and healthier!

2) Physical Activity

Exercise is important for all teens, and especially for teens with spina bifida, who can be at an increased risk of being overweight. Most teens will have to attend a gym class while they are in school. Your doctors can talk to your school about ways to adapt your gym class or give you other exercise suggestions. Even if you attend gym class, it is helpful to get in the habit of doing some exercises that you like in order to make this a lifelong habit!

It is important to set realistic goals for yourself. You do not need to exercise seven days a week, but three to four days a week may be a good goal. Once you reach your first goal, you will have more confidence and can set new goals. It is recommended to do regular exercise three to five times a week, for 30-60 minutes, with at least 20 minutes spent getting your heart rate up. You may want to set a schedule or exercise at the same time each day to make this a habit.

There are many adaptive sports programs that have basketball, soccer, sailing, swimming, sled hockey, karate, yoga, tennis, track and field, and much more. If you are interested in finding a sports program or fitness center in your area, speak with your doctor. Many programs can offer scholarships and some may provide transportation. We recommend that everyone find some type of physical activity that they enjoy whether it be home exercises or playing on a sports team.

3) Community Participation

As you get older, you will start to have new interests. Being involved in after school and community activities is important for everyone. Recreation activities are not only fun, but help you increase your self-esteem, meet new people, and stay active.

The Spina Bifida team recommends that everyone participate in an organized school or community activity *at least once a week*. It is

✓ *National Center on Physical Disability*

800.900.8086

www.ncpad.org

✓ *Special Recreation Cooperatives*

www.specialrecreation.org/

✓ *Teens on the Move: An Exercise Video for Teens with Spina Bifida*

www.ncpad.org

✓ *Great Lakes Adaptive Sports (GLASA)*

847.283.0908

www.glasa.org

✓ *Rehabilitation Institute of Chicago: Fitness Center and Sports Programs*

312.238.5001

<http://ric.org/conditions/community/fitness/index.aspx>

✓ *Chicago Park District Adaptive Sports*

312.742.5670

www.chicagoparkdistrict.org

“The Spina Bifida team recommends that everyone participate in an organized school or community activity at least once a week.”

important to find activities that you enjoy. Activities may include sports programs, church activities, school clubs, support groups, art and music programs and many more. If you do not have information about community programs in your neighborhood, talk with your doctors. Each summer Camp Independence at the YMCA offers a week long sleep-over camp for kids, teens, and adults with spina bifida. It is a great way to meet people, try new activities, and work on independence.

Sometimes there are things that may prevent someone from participating, such as health concerns, money, time, transportation, motivation or lack of information. It is our goal to help you and your family decrease these barriers. Sometimes it can be scary to try an activity for the first time; however community participation offers an opportunity to meet new people and the chance to succeed!

4) Friends and Dating

It is normal for teens to start spending more time with friends and hanging out a few times a week. As you get older you should start to call friends and arrange plans to see each other. You might talk with friends on the phone, the internet, or in person. If you use the internet, your parents may monitor your use to make sure that you stay safe and do not give out personal information to strangers.

A good way to make new friends is by being involved in school or in community activities so that you can meet other teens. You may want to ask for their phone number and email to keep in touch outside of activities.

You may also start to have an interest in dating. It is important to first have healthy friendships before dating. As well, it is important to understand boundaries between your self and others, in order to stay safe. As you get older, you will also start to learn about your body and may begin to talk with your parents and doctors about dating and sexuality. It is important to be honest with these questions.

Here are some resources that may be helpful:

- **Sexuality and the Person with Spina Bifida**
Sloan, S. (Dec 1995) (Book) www.sbaa.org
- **Sexuality After Spinal Cord Injury: Answers to Your Questions**
Ducharme, S.H., & Gill, K.M. (1997) (Book)

- ✓ **Access Living**
800.613.8549
<http://www.accessliving.org/>
- ✓ **Centers for Independent Living**
<http://www.ilru.org/html/publications/directory/illinois.html>
Find your local agency
- ✓ **Chicago Park District**
312.742.PLAY
<http://www.chicagoparkdistrict.com/>
- ✓ **Rehabilitation Institute of Chicago: Caring For Kids**
312.238.5010
www.ricsports.org
- ✓ **Camp Independence at YMCA Camp Duncan**
847.546.8086
<http://www.ymcachgo.org>

Contact your local park district and school for activities like Boy Scouts, Girl Scouts, Clubs and more!

Three Friendship Facts:

1. **Everyone wants to have a friend.**
2. **The best way to make friends is to be one.**
3. **Friendships are give and take.**

(Lutkenhoff, M. & Oppenheimer, Sonya. Spinabilities.)

School and Work

1) Organization Skills

Organization can sometimes be difficult for some people with spina bifida. Teens may have difficulty organizing school work, keeping a schedule, and planning ahead. If you are having trouble staying organized, you may want to talk with your parents and school, to see if they can do some testing which can help identify your strengths and areas to work on improving.

It is often useful to keep calendars, schedules and reminders to help organize your daily responsibilities. Occupational therapists can help you work on these skills as well. Speak with your medical team for a referral or for other hints to stay organized. Here are some tips to get you started.

- Keep a calendar
- Use alarms or vibrating watches as reminders
- Use pill and supply organizers
- Break large tasks into smaller tasks
- Plan ahead
- Keep post it notes as reminders
- Keep all medical things in one place
- Keep catheter/medical supplies in a backpack

2) Individualized Education Program

Some teens may have an Individualized Education Program (IEP) if they have special education classes. If you have an IEP, the school will add a transition plan that includes long term goals when you turn 14 years old. It is important for you, your parents, the school and your medical team to be in communication in order to make the best plan for you. Sometimes it is helpful to bring a copy of your IEP to your clinic visits. This helps the doctors understand your educational goals. The spina bifida transition coordinator is also available to go to your IEP meetings if requested. There are several resources available to help support you in the IEP process and to make sure that your educational rights are met.

✓ *“A Parent’s Guide. The Educational Rights of Students with Disabilities.”*

http://isbe.net/spec-ed/html/parent_rights.htm

✓ *Family Resource Center on Disabilities*

312.939.3513

<http://www.frcd.org/>

✓ *Chicago Public Schools: Office of Specialized Services*

773.553.1800

✓ *Special Ed Advocacy Center*

847.736.8286

<http://www.specialedadvocacycenter.org>

3) After High School Plan

All teens should begin talking with their school, family, and medical providers about what they want to do after high school. Everyone should set realistic expectations and goals. Some people will plan to attend a local community college, while others may leave home to go to college. Others may choose to work or volunteer. There are also community programs that focus on developing adult life skills. Everyone should develop an after high school plan around 17 years of age. Speak with your school counselor about your plan.

If you plan to attend college, it is important to talk with your high school about accommodations that you may need. For instance, will you need a note taker or extra time for a test? Colleges have a student disability office, which can provide accommodations for classes, private dorm rooms, and other services for students with disabilities.

It is also important to understand what accommodations you may need if you plan to work. The better you understand your own needs, the better you can advocate for yourself. For example, people may ask for a stool if it is difficult to stand all day on the job or someone may need to ask for a longer bathroom break to make sure they have time to catheterize if needed. There are programs that can help you ask for reasonable accommodations.

If you plan to attend a community program, volunteer, or work after high school there are several employment and vocational training programs. They can evaluate your strengths and look for areas of improvement, provide job shadowing, practice resume and interview skills, and other services.

- ✓ **HEATH Resources: College**
202.973.0904
<http://www.heath.gwu.edu/>
- ✓ **Department of Rehabilitation Services**
800.843.6154
<http://www.dhs.state.il.us>
- ✓ **Rehabilitation Institute of Chicago: Vocational Rehabilitation**
312.238.6807
www.ric.org
- ✓ **Mayors Office For People with Disabilities**
312.744.6673
www.cityofchicago.org/disabilities
- ✓ **Anixter Center**
773.973.7900
<http://www.anixter.org/>
- ✓ **Jewish Vocational Services**
312.673.3462
www.jvschicago.org
- ✓ **Job Accommodation Network**
800.526.7234
<http://www.jan.wvu.edu/>

Planning for Your Future: Topics to Discuss with Your Parents

1) Insurance

As you become an adult, there may be changes in your insurance. Contact your insurance company to find out how long you will be covered if you are under your parent/guardian's insurance. This may depend on your age, disability, and if you decide to take college classes. If you receive public aid, check with your case manager to make sure that your plan will still be in place once you turn 18 years old.

The Division of Specialized Care for Children (DSCC) provides services for eligible youth with special health needs until 21 year of age. If you do not have DSCC, ask your doctor to see if you can apply.

Start to make a plan for your future insurance. Will you have private insurance, Medicaid, Medicare, or insurance through a university? If you are working when you are older, based on your disability, you may be eligible to apply for Health Benefits for Workers with Disabilities. These are all questions that you should discuss with your parent/caregiver and medical team.

2) Supplemental Security Income (SSI)

Also, some teens who are eligible may choose to apply for Supplemental Security Income (SSI) once they turn 18 year old, even if they did not receive it as a child. SSI provides monthly payments to people with a disability and limited income and resources. Once you are 18 years old, your family's income is no longer considered when determining your financial status.

Contact your local SSI office to set up an interview or for more information.

3) Guardianship

Once you turn 18 years old you become your own guardian, and are legally responsible for your own decisions. However, sometimes it can be difficult to make all your medical and financials decisions on your own, and your parents or doctors may have concerns about your ability to make decisions independently. With guardianship, a parent or trusted relative or friend, helps make important decisions with you.

- ✓ *HealthCare.gov*
www.healthcare.gov
 - ✓ *Department of Human Services*
800.843.6154
<http://www.hfs.illinois.gov/medical/apply.html>
 - ✓ *Division of Specialized Care for Children (DSCC)*
800.322.3722
www.uic.edu/hsc/dsc
 - ✓ *Children's Memorial Hospital's Business Office*
773.880.4273
www.childrensmemorial.org
 - ✓ *Health Benefits for Workers with Disabilities (HBWD)*
800.226.0768
<http://www.hbwdillinois.com/>
 - ✓ *Health and Disability Advocates*
312.223.9600
hda@hdadvocates.org
-
- ✓ *Social Security Office*
800.772.1213
www.ssa.gov
-
- ✓ *Illinois Guardianship and Advocacy Commission*
866.274.8023
<http://gac.state.il.us/guardfaq.html>

4) Are You a Member of The Spina Bifida Association of Illinois?

The Spina Bifida Association of Illinois (SBAIL) offers several programs for patients and families. Each year they have a holiday party and a family picnic. In the spring, young adults attending college can apply for the scholarship program. In addition, they provide an emergency fund for families in need. There is also a support group called First Saturday, which meets once a month, and is for young adults ages 19 and up. There are various programs for families and the free quarterly newsletter is a great way to network with other families and friends. Contact the SBAIL to become a member today.

Additional Health Transition Resources

There are several websites dedicated to teens, young adults, and transition. They have different handouts, checklists, and resources you can print to help you plan for your transition. Here are a few that may be helpful for you and your family.

- **Adolescent Health Transition Project**
<http://depts.washington.edu/healthtr/>
- **Healthy Transitions**
<http://www.healthytransitionsny.org>
- **Health Care Transitions: Web, Video and Print Resources**
<http://hctransitions.ichp.edu/hct-promo>
- **Healthy and Ready to Work**
<http://www.hrtw.org/index.html>
- **Children's Medical Services**
<http://www.cms-kids.com/kids/teens/transitions.html>
- **DSCC Transition Information and Resources**
<http://internet.dsccl.uic.edu/dscclroot/parents/transition.asp>

✓ *The Spina Bifida Association of Illinois*
773.444.0305
www.sbail.org

Spina Bifida Clinic Contacts:

- *Rebecca Boudos, LCSW*
Transition Coordinator
312.227.6391
- *Roseann Greene, RN*
Nurse Coordinator
773.880.4523
- *Tanga McGee*
Clinic Coordinator
773.880.4430
- *Shubhra Mukherjee, MD*
Physiatrist/Teen Clinic
312.227.6517



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