

Transition Guidebook

PART A: Whose Health is it Anyway? Taking Care of Your Health



For teens with spina bifida

Transition (n) tran-si-tion

A change from one stage to another

Contributors

Rebecca Boudos, LCSW
Shubhra Mukherjee, MD

Editors:

Suma Rao-Gupta, MPH

The information included in this document is for informational purposes only and is not intended to substitute in any way for medical education, training, treatment, advice, or diagnosis by a healthcare professional. The Children's Memorial Hospital makes no warranties related to the information in this document. A qualified healthcare professional should always be consulted before making any healthcare-related decision.

© 2009 Children's Memorial Hospital. All rights reserved. The information contained herein may not be reproduced, modified, distributed or transmitted without the express written permission of The Children's Memorial Hospital.

TABLE OF CONTENTS

What is Transition?	3
Part A: Whose Health is it Anyway? Taking Care of Your Health	3
Understanding Your Medical Condition.....	3
Managing Medications and Supplies.....	5
Talking with Your Spina Bifida Team	6
Making Your Own Doctor Appointments	6
Managing Self Care	
Hygiene/Dressing.....	7
Bowel and Bladder.....	7
Skin Checks.....	8
Managing Your Mood and Stress	8
Creating a Medical Health Summary	9
Graduating from Children's Memorial Hospital: Transferring to Adult Care	10
Additional Health Transition Resources.....	11

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 A: Whose Health is it Anyway? Taking Care of Your Health

The spina bifida clinic's goal is to help you feel comfortable managing your medical condition and be fully prepared to transfer to adult doctors, once you are older. To make this transition easier, there are various areas that you may want to think about.

Understanding Your Medical Condition

One of the most important things is for teens to understand their medical condition. As a child, it is common to know the name of your condition, but as you get older you may want more information. Doctors can help teach you about spina bifida in a way that makes it easy to explain to a friend, your family, or to other doctors. For example, here is an easy way to explain spina bifida: "Spina bifida is a condition present at birth in which the spine does not close over the spinal column, causing an opening on the back. This opening is usually seen at birth and closed. Because the spinal cord was exposed, messages from the nerves may not reach the legs, bowel and bladder, causing there to be little or no movement and feeling in these areas. So, some people use a catheter to empty the bladder in

Useful Resources:

- ✓ *Spina Bifida Body Manual*
www.hrtw.org/tools/pdfs/spina_bifida.pdf
- ✓ *Who Owns Your Body?*
Glenrose Adolescent Services
[Ask your doctor for a copy]
- ✓ *SpinAbilities: A Young Persons Guide to Spina Bifida*
800.621.3141
www.sbaa.org
- ✓ *Health Guide for Adults Living with Spina Bifida*
www.sbaa.org

case it does not empty on its own. Also, some people may need a shunt which is a valve that keeps fluid from building pressure in the brain. "

It is important to learn about other conditions that can be related to spina bifida. Common ones may include a shunt malfunction (if you have a shunt), urinary tract infections (UTIs), pressure sores, or latex and other allergies. The table below lists some examples of common conditions that you may have and ways to prevent them in order to stay healthy.

Condition	Symptoms	Preventative Measures
Shunt Malfunction	<ul style="list-style-type: none"> • Headache • Nausea and vomiting • Blurred vision • Drowsiness • Neck pain/back pain • Change in bowel/bladder • Doing worse at school 	<ul style="list-style-type: none"> • See neurosurgery regularly • Monitor your health • Call your doctor if there is a problem • Manage constipation
Urinary Tract Infections (UTI)	<ul style="list-style-type: none"> • Belly pain • Nausea • Smelly, dark, or cloudy urine • Leaking • Blood in urine 	<ul style="list-style-type: none"> • Drink enough fluids • Keep catheter clean • Catheterize regularly • See urology regularly • Protect kidneys with medications if needed
Pressure Sores	<ul style="list-style-type: none"> • Redness • Opening in skin • Drainage 	<ul style="list-style-type: none"> • Changing positions often if sitting for a long period called "Pressure Reliefs" • Check feet and body daily • Do not let skin get too dry or too moist • No tight shoes or braces

Condition	Symptoms	Preventative Measures
Latex Allergy	<ul style="list-style-type: none"> • Rash, hives, welts • Itching • Difficulty breathing • Coughing 	<ul style="list-style-type: none"> • Let your school know you have a Latex allergy • Avoid products with Latex • Ask for a copy of the Spina Bifida Association's Latex Sheet for ideas on Latex free products

Managing Medications and Supplies

Now is the time to start learning the names and purposes of your medications, how to fill prescriptions, and start remembering to take your medications at the right time. It may be easier to remember medications if you take them along with another activity, such as breakfast or dinner.

There are cellphones and watches that vibrate or beep with alarms as reminders. Pill cases can help keep you organized and plan ahead. There is also a new website that will send text messages to your phone or email reminders to you.

At first, you may need reminders from your parent, but eventually they should remind you less often as you take on more responsibility. Even if you are unable to take medications on your own, it is still important to learn the names and purposes of your medicines.

Reward systems and charts may help younger teens stay motivated with organizing and taking medications. For example, you may get a star once a day for remembering to take medications. Ten stars could equal choosing a special reward such as an outing with a friend or parent.

As you get older, you may start to help your parents order your supplies, like medicine or catheters. This means that you have to know when you need more supplies. How many pills are left? How many catheters do you have? How long will one order of supplies last?

Ordering supplies and medications can be done on the phone or online, and delivered to your home. It is important to know the name and phone number of your pharmacy and supply company. When you practice filling a prescription or ordering supplies for the first time,

There is also a new website that will send text messages or email reminders.

www.MyMedSchedule.com

✓ *MyMedSchedule*

www.mymedschedule.com

✓ *MedActionPlan*

<http://medactionplan.com>

✓ *Vibrating Watches*

800.214.9605

www.bedwettingstore.com

have a parent with you to help answer any questions that you do not know. Little by little, you can start to do more on your own. The best way to learn is to practice.

Talking with Your Spina Bifida Team

Now that you are a teen, you may also begin to take more responsibility for your doctor visits. The doctors may start to speak directly to you and ask you to answer some questions about your health. Parents may still add information to the visit, but it is important for you to have a chance to answer. It is important for you, your family, and doctors to be patient during this learning period.

As you build a relationship with your doctors, they may ask to meet with you alone for part of the visit. This gives you some privacy and lets you ask questions one-on-one with your doctor. As you get older, you may spend more time alone with the doctor, and eventually meet with them on your own.

Your doctor may also begin to ask you questions about being a teen. Some of these may be about dating and sexuality, drinking and drugs, and your mood. These questions may feel embarrassing or uncomfortable to answer, but it is important to be honest. Your doctors are not judging you. They want you to have information in order to make the best decisions for yourself.

Making Your Own Doctor Appointments

As you become a young adult, you should also start to make your own doctor appointments and call your doctors. You can start by calling for appointments or checking out from a visit while your parent is there to help. In order to make a doctor appointment, you must know the name of your doctor and the reason you need to see the doctor. It helps to have a cell phone, organizer or calendar to write down the date and time of your next visit.

In adult health care, the doctors may not be able to speak directly to your parents without your permission, because of privacy laws. Therefore, it will be helpful for you to practice talking directly with the doctors and clinical staff who work in the spina bifida clinic when you call about how you feel, want to make an appointment, or have a question.

Managing Self Care

Learning to do your self care is important in order to stay healthy and spend time away from home. At times, it can be overwhelming to think

✓ *Talking With Your Doctor: Video*

<http://video.ichp.ufl.edu/twyd.php>

✓ *Talking with Your Doctor and Other Health Care Professionals Website*

<http://hctransitions.ichp.edu/gladd/>

about managing all of your self care. It may help to break each task into smaller steps. You should be participating as much as you can in your self care. Even if you are unable to do something completely on your own, it is important to know the steps and direct your care to someone else, so that they can help you correctly.

Hygiene/Dressing

During the teen years, being clean becomes even more important, as you spend more time with friends. It is important to shower and brush your teeth regularly. At first you may need reminders. It may be helpful to set up a schedule, such as showers take place every evening after dinner. Sometimes, parents may be in the habit of helping you put on your clothes or braces, even though you may be able to do most of it on your own. Sometimes they may help because it is faster. However, it is important for you to practice too. Try practicing on the weekends when you may have more time. Occupational therapists can give you ideas or devices to help with showering and dressing, including shower chairs, hand mirrors, sock aids or a dressing stick.

Bladder and Bowel

Some teens with spina bifida need to have a bladder and bowel program, such as using a catheter. Bladder and bowel programs can be complicated and take a lot of time, especially when you have a busy schedule. However, you may need them in order to stay healthy and dry when out in public. As you get older, you may want more privacy over your body, which means becoming more independent in bladder and bowel programs.

If you use a catheter, you first must learn the steps and be able to explain each step of self catheterization. Next, begin helping with getting supplies ready, cleaning the area, and cleaning up afterwards.

Even if you can not use your catheter on your own, it is important to know the steps to direct your care. There are various catheters available that may make the process easier. Speak with your urologist if you are having trouble using your catheter or want to practice being more independent.

Bowel programs also involve many steps depending on the method you use. Several common programs involve using an enema/suppository, digital stimulation, or the MACE procedure. Many people with spina bifida set up a schedule for their bowel program. If you have accidents or end up leaking, speak with your doctors to talk

✓ *Vibrating Watches*
800.214.9605
www.bedwettingstore.com

about ways to improve this. It is your body and we want you to feel as comfortable as possible. Being able to manage your bladder and bowel program gives you more freedom and chances to get out with friends and attend other social events.

Skin Checks

Pressure sores that cause redness or open wounds on your skin can be common, but there are several ways to prevent them. When you are younger, your parents might check your body for sores. This will be something that you should start doing on your own. It is your body, so now is the time to start keeping yourself healthy.

Check your feet, legs, butt, and other body parts daily for sores. A good time to do it is when you are getting dressed or getting ready for bed. If you have trouble seeing parts of your body, you may want to use a hand mirror. Talk with your doctor if you need other tips for checking your body.

It is important to do pressure reliefs, lifting up your butt from the seat every 15-20 minutes, if you spend most of the time sitting. Make sure your braces fit well and there are no areas of pressure that need to be fixed. Keep skin clean and dry feet well before putting on braces. If you notice redness or the beginning of a pressure sore, come in to see your doctor. It is easier to heal a small sore than a big one.

Managing Your Mood and Stress

Being a teenager can be both fun and stressful. During these years there are more demands in school and with friends. You may also begin to feel like you disagree with your parents about certain things. It is important to have ideas of healthy ways to deal with stress, as all teens will experience stress at some point.

People deal with stress in different ways. Here are some things that you can do to get rid of stress:

- Exercise
- Eat regularly
- Get enough sleep
- Listen to music, draw, or read a good book
- Talk with friends, take a stroll, or spend time with a pet
- Write in a journal about your feelings
- Talk to someone you trust -- such as a teacher, social worker,

Resources in the Community:

- ✓ *Children's Memorial Hospital Psychiatry Department*
773.975.8771
- ✓ *Alexian Brothers: Hoffman Estates*
800.432.5005
- ✓ *University of IL Psychiatry Department*
312.896.7387
- ✓ *Access Living Support Groups: Fe Fes*
800.613.8549
<http://www.accessliving.org/>
- ✓ *Spina Bifida Association of IL*
773.444.0305
www.sbail.org

parent, or friend

- Learn relaxation exercises and breathing
- Role play and practice situations to decrease stress
- Learn coping skills such as breaking larger tasks into smaller parts
- Avoid tobacco, alcohol, and illegal drugs
- Talk with someone who has been through a similar situation

For more ideas talk with your doctor (Adapted from the American Academy of Pediatrics, www.aap.org)

Depression, anxiety and other mood issues are common for teens. It is important to be open with your medical providers about your feelings. If you find you feel sad or very irritable most of the time, have changes in your sleeping or eating, and do not have an interest in the activities you enjoyed before, talk to your doctor. Sometimes teens like talking with someone other than a parent or friend about their feelings. The clinic can make referrals to social workers, psychologists, and psychiatrists.

Creating a Medical Health Summary

At times, it may seem difficult to remember all of your medical information. That is why it is important to have a written summary to share with your doctor or to use for an emergency. The spina bifida clinic encourages all patients to have a medical health summary.

Medical summaries organize important information about you! You can hand write it on paper or make one on the computer. They even have ones you can save to a memory stick and carry with you. Your medical summary should include:

- your name
- date of birth
- emergency contact information
- a list of medical conditions
- allergies
- current medications and doses
- your immunization records
- all of your surgeries with the dates and hospital

“The spina bifida clinic encourages all patients to have a medical health summary.”

✓ ***MyHealth Passport***

<http://www.sickkids.on.ca/myhealthpassport>

✓ ***Care Notebook***

http://www.medicalhomeinfo.org/Tools/care_notebook.html

✓ ***Fashionable Medical ID Bracelets***

800.360.8680

<http://www.laurenshope.com>

✓ ***Medical IDs and e.MedTAG***

<http://www.americanmedical-id.com/>

You may also want to include the phone numbers for your doctors, social workers and any clinic coordinators, as well as your insurance information. Include any other information that you want to share with your doctors. Bring a copy to your doctor and carry a copy with you. There are a number of outlines for these medical summaries that you might use to get started. Some of these are listed below.

Some teens also may want to have a medical alert bracelet, which lets people know about specific conditions, such as allergies, seizures, or other precautions. As you start to spend more time away from home, this is something you might want to talk to your parents about getting.

Graduating from Children's Memorial Hospital: Transferring to Adult Care

As you reach your late teen years you will begin to plan to graduate from Children's Memorial Hospital's Spina Bifida Clinic to adult doctors. Most young adults transfer their care when they are around 20-21 years old. Not only will you begin to see adult specialists, but it is also important to have an adult primary care doctor. The adult health care system can be different from pediatrics, and you must take more responsibility for your care.

We understand that it may feel different going to an adult clinic and you may miss some of the people and services at Children's Memorial Hospital. These are normal feelings that many young adults experience. This is why it is helpful to plan early, have time to say goodbye to your pediatric team, and feel prepared to successfully work with adult doctors. It is never too early to begin planning.

✓ *Spina Bifida Clinics*

[800.621.3141](tel:800.621.3141)

www.sbaa.org

✓ *The Rehabilitation Institute of Chicago: Adult Clinic*

[312.238.1000](tel:312.238.1000)

http://www.ric.org/conditions/Spina_Bifida/index.aspx

✓ *This is Health Care Transition: Video*

<http://video.ichp.ufl.edu/tihct.php>

✓ *Envisioning My Future: A Young Person's Guide to Health Care Transition*

<http://hctransitions.ichp.ufl.edu/hct-promo/>

Additional Health Transition Resources

There are several websites dedicated to teens, young adults, and transition. They have various handouts, checklists, and other 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/>
- DSCC Transition
<http://internet.dsc.uic.edu/dscroot/parents/transition.asp>
- 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>

Spina Bifida Clinic Contacts:

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



Children's Memorial Hospital
2300 Children's Plaza
Chicago, IL 60614
childrensmemorial.org