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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.
Part A: Taking Care of Your Health

The spina bifida clinic’s goal is to help you feel comfortable about managing your medical condition and be fully prepared to transfer to adult doctors, once you are older. To make the 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 in the back. This opening is usually seen at birth and closed. Because the spinal cord was exposed, message 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 case it does not empty on its own. Also, some people may need a shunt, which is a valve that keeps from fluid 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 or 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.
<table>
<thead>
<tr>
<th>Condition</th>
<th>Symptoms</th>
<th>Preventative Measures</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Shunt Malfunction</strong></td>
<td>□ Headache</td>
<td>□ See your neurosurgeon regularly</td>
</tr>
<tr>
<td></td>
<td>□ Nausea and vomiting</td>
<td>□ Monitor your health</td>
</tr>
<tr>
<td></td>
<td>□ Blurred vision</td>
<td>□ Call your doctor if there is a problem</td>
</tr>
<tr>
<td></td>
<td>□ Drowsiness</td>
<td>□ Manage constipation</td>
</tr>
<tr>
<td></td>
<td>□ Neck pain/back pain</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Change in bowel/bladder</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Doing worse in school</td>
<td></td>
</tr>
<tr>
<td><strong>Urinary Tract Infections (UTI)</strong></td>
<td>□ Belly pain</td>
<td>□ Drink enough fluids</td>
</tr>
<tr>
<td></td>
<td>□ Nausea</td>
<td>□ Keep catheter clean</td>
</tr>
<tr>
<td></td>
<td>□ Smelly, dark, or cloudy urine</td>
<td>□ Catheterize regularly</td>
</tr>
<tr>
<td></td>
<td>□ Leaking</td>
<td>□ See your urologist regularly</td>
</tr>
<tr>
<td></td>
<td>□ Blood in urine</td>
<td>□ Protect kidneys with medication if needed</td>
</tr>
<tr>
<td><strong>Pressure Sores</strong></td>
<td>□ Redness</td>
<td>□ Changing positions often if you are sitting for a long period of time, called “Pressure Reliefs”</td>
</tr>
<tr>
<td></td>
<td>□ Openings in the skin</td>
<td>□ Check feet and body daily</td>
</tr>
<tr>
<td></td>
<td>□ Drainage</td>
<td>□ Do not let the skin get too dry or too moist</td>
</tr>
<tr>
<td></td>
<td></td>
<td>□ No tight shoes or braces</td>
</tr>
<tr>
<td><strong>Latex Allergy</strong></td>
<td>□ Rash, hives, welts</td>
<td>□ Let your school know that you have a Latex allergy</td>
</tr>
<tr>
<td></td>
<td>□ Itching</td>
<td>□ Avoid products with Latex</td>
</tr>
<tr>
<td></td>
<td>□ Coughing</td>
<td>□ Ask for a copy of the Spina Bifida Association’s Latex Sheet for idea on Latex free products</td>
</tr>
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</table>

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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 cell phones 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 starts 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 medication 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, 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 to 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 be asking 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 to have information in order to make the best decisions for you.

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 you parent is still 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 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 and 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 help you put on your clothes or braces, even though you may be able to do most of it on your own. Someone 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 showered 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 self catheterization. Next, begin helping with getting supplies ready, cleaning the area, and cleaning up afterwards.

Even if can not use the catheter on your own, it is important to know the steps to direct your care. These 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 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 parts daily for sores. A good time to do this is when you are getting dressed in the morning, 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 a 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 the 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 can 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 with someone you trust – such as a teacher, social worker, parent, or friend
- Learn relaxation exercises and breathing
- Role play and practice situations that decrease stress
- Learn coping skills such as breaking larger tasks into small 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 feel sad or very irritable most of the time, have changes in your sleeping or eating, and do not have interest in the activities you enjoyed before, talk with 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 it 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
- A list of all your surgeries, including dates and hospital

You may also want to include the phone numbers for your doctors, social workers, and any clinic coordinators, as well as your 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.

Resources in the Community

- Alexian Brothers - Hoffman Estates: 800-432-5005
- University of IL Psychiatry Dept.: 312-896-7387
- Spina Bifida Association of IL: 773-444-0305
Graduating from Lurie Children's Hospital: Transferring to Adult Care

As you reach your late teen years you will begin to plan to graduate from Lurie Children’s Hospital’s Spina Bifida Clinic to adult doctors. Most young adult 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 Lurie Children’s 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.

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/
- Healthy Transition – http://healthytransitionsny.org
- Health Care Transitions: Web, video, and print resources – http://hctransitions.ichp.edu/hct-promo

MyHealth Passport: http://www.sickkids.on.ca/myhealthpassport

Fashionable Medical ID Bracelets: 800-360-8680
http://www.laurenshope.com

Medical IDs and e.MedTAG: http://www.americanmedical-id.com