

A timetable for growing up

For children and young adults with spina bifida and their families.



Starting kindergarten. Becoming a teenager. Graduating from high school. These are some of the changes children go through as they grow up. These changes are called transitions.

This Timetable suggests experiences and activities to help your child grow and learn. It includes topics that are important to people living with spina bifida. The Timetable also helps families and youth think about the future. It's important to start early and plan ahead for transitions.

Each child has unique strengths and abilities. Each child develops at their own pace. As your child grows, continue to add new activities and responsibilities as appropriate for your child.

Encourage your child to make choices, actively participate in their life and achieve their personal best.

Talk to your child's health-care team about how you can use this Timetable to meet your child's needs.

If you are a teenager, start by reading the column marked "Early Teen Years".



General

- Children change and grow and learn new skills and activities at their own pace. Your child is unique. Having spina bifida does not define who your child is.
- Take breaks to renew your energy and accept help from others.
- Inform all caregivers about your child's unique needs.
- Take precautions such as using seat belts and helmets. Be aware of home safety.

Social

- Encourage your child to play with others. Children develop cognitive and motor skills through play.
- Consider joining community activities and connecting with other families.
- Set limits for your child to help develop positive behaviors. Teach your child that there are consequences and be consistent.
- Recognize your child's developing need for independence. Give choices and age appropriate jobs, such as cleaning up toys.

Education

- Stimulate your child's development by introducing activities such as singing and reading. Your child learns by talking and doing things with you.
- Use play activities and picture books to speak with your child about spina bifida. There are some great resources available through the Spina Bifida & Hydrocephalus Association of Ontario.
- Praise your child for cooperating with all care routines, including taking medication properly. Call it medicine, not candy.
- Talk to your child about upcoming clinic visits.

Self-care

- Apply for special funding/drug plan if required. For example, the Easter Seals incontinence grant can be applied for shortly after birth.
- Follow a daily self-care routine with your child.
- Teach your child everyday skills such as brushing teeth and hand washing.
- Familiarize your child with health care needs, including bladder & bowel routines.
- Use simple (but accurate) language to talk about catheterization and other routines.
- Share responsibility for routines by ensuring at least two adults can perform any special care.
- Show your child healthy eating by being a good role model.



Medical

- Learn about your child's medical condition. Become a part of your child's health care team.
- Schedule regular visits with your child's paediatrician or family doctor.
- Keep a record of your child's medical history, treatments and changes in medical condition.
- Know when your child is showing signs and symptoms that require emergency medical attention.
- Help your child avoid latex products, like latex medical gloves.
- Consider ordering a MedicAlert product for your child.
- Plan ahead for travel. Have enough medicine/supplies. Consider bringing clinic notes or letters with you to explain any special care requirements.



General

- Don't let your child's medical condition get in the way of life. Expect and encourage normal childhood experiences. You can be a role model for an active lifestyle.
- Celebrate your child's achievements.
- Teach your child to express needs and wants.
- Teach your child that behavior and choices have consequences. Be consistent.
- Give your child household chores, such as cleaning or tidying. Your child can assist by giving verbal directions instead of physically doing the chore, if appropriate.
- Balance your child's TV and computer time with active play time.

Social

- Encourage your child to participate in activities at school and in the community such as adapted sports and recreation.
- Organize play dates with friends. When your child visits friends, help parents understand about any special needs.
- Help your child recognize their special talents and interests.
- Explore your child's feelings about spina bifida. Talk about ways to answer questions from friends.
- Be aware of your own stress level and ask for support if needed.
- It is common to want to protect your child, however, recognize your child's need for increasing independence and encourage it.

Education

- Work with your child's school to ensure your child participates fully. Provide any special documentation or resources, such as medication information, educational material about spina bifida or descriptions of special needs.
- Ask for a school meeting with previous and current teachers and administration when your child changes classrooms.
- Speak with the school and caregivers about your child's personal health care needs including bowel and bladder routines.

- Learn about how the school system works. Talk with your child's school about the Identification, Placement and Review Committee Process (IPRC) and the Individual Education Plan (IEP).
- Some children who have spina bifida have learning challenges. Keep track of your child's progress in school. Talk with your health care team about assessments, and options to support success at school. Talk to your school about special needs resources. If your child has difficulty with school or social situations, ask your health care provider or principal about a formal assessment.
- Talk about puberty with your child. Sometimes puberty comes earlier for children with spina bifida.

Self-care

- Reapply for the Easter Seals Incontinence Grant at age 6.
- Involve your child in bladder and bowel routines. Have your child gather supplies and wash their hands. Some children may be able to self-catheterize at this age.
- Teach your child about body parts, privacy and personal safety – especially during personal care routines.
- Encourage your child to explain their own care needs to new providers (if they need assistance with personal care).
- Encourage your child to make healthy food choices.
- Teach your child personal information, such as address, phone number and how to call 911.

Medical

- Make sure your child knows the name of their medical condition. Your child should know their allergies too.
- Prepare your child for appointments using play-acting, puppets, dolls or drawing.
- Be honest when explaining a procedure to your child, even if the procedure may hurt.
- Teach your child about symptoms of emergencies such as shunt malfunction, bladder infection or pressure sores. Your child should talk with an adult immediately.



Continue with the suggestions from earlier years.
Add new activities and responsibilities as your child grows.



General

- Recognize your child's increasing need for independence and encourage your child to express needs and wants.
- Set up a bank account for your child. Give an allowance so your child learns about money.
- Help your child manage stress through art, exercise, music and journal writing. Talk to your child's health-care team if stress is a concern.
- Let your child make mistakes. Help them problem-solve. Discuss some of your own mistakes and problems together.
- Help your child to sign up for and attend recreation programs and camps.

Social

- Support your child's participation in at least one activity or hobby outside of the home.
- Encourage friendships with children around the same age as your child. If your child has trouble making friends, ask your school and health-care team for help.
- Teach your child phone skills and internet safety. Practice by talking to family members and friends.
- Support your child as they talk to friends about their condition.
- Ask your child if they would like to meet peers with the same condition. Seek out support groups or ask your health-care team for suggestions.

Self-care

- Involve your child in routine care associated with their condition. Use correct names and set goals for more independent self-care. Your child may be independently managing or directing bladder and bowel routines by now.
- Promote healthy eating. Encourage your child to take part in meal planning and preparation.
- Learn about spina bifida by looking at websites and other resources.

Education

- Some children who have spina bifida have learning challenges. Keep track of your child's progress in school. Talk with your health-care team about assessments, and options to support success at school. Talk to your school about special needs resources.
- Set structured homework time. Encourage your child to do homework as independently as possible, but be available for help.
- Talk about your child's future. What does your child want to be or do?
- Keep talking with your child about puberty. Encourage questions.



Medical

- Ask your child what they know about their medical condition. Help them practice talking about it and fill in any gaps.
- Prepare for appointments by making a list of questions and concerns with your child.
- Have your child practice speaking directly to the health-care team.
- Talk to your child about symptoms that need immediate follow-up. Your child should tell you and the health-care team.
- Go online and create a MyHealth Passport with your child at www.sickkids.ca/myhealthpassport



General

- Speak up for yourself. Talk to your parents, teachers, attendants and health-care team about what is important to you.
- Find role models you can relate and look up to.
- Start to participate in banking and develop your money management skills.
- Practice using public or accessible transit and navigating your community.
- Start volunteering. You will learn about your interests and develop your employment skills.
- Participate in life skills and independence programs.

Social

- Hang out with friends. Join teams and clubs at school. Get involved in activities outside of school such as camps or community programs.
- Talk about puberty, dating and sexuality with your parents or someone you trust.
- You can choose with whom you would like to share the details of your medical condition (example, friends, coaches).

Education

- Talk to your health-care team about high school. Ask if you should update your learning assessments.
- Take part in meetings about your education and get to know your school guidance counselor.
- Talk about career interests and begin to set goals for after high school, such as college, university or employment. Talk to your guidance counselor about aptitude testing.
- Practice explaining your medical condition so that you can advocate for yourself at school and in medical situations. Ask your teachers and family to help you with this.

Self-care

- Participate in healthy meal preparation, grocery shopping, and chores.
- Plan ahead to fit your care routines into your life. For example, take your medications and catheter supplies with you to evening activities or when you go away. If you need help, ask your parents.
- Know your equipment vendors.

Medical

- Keep learning about your condition. Know the reasons for medications, tests and procedures and what symptoms need immediate medical attention.
- Learn how to prevent possible secondary complications of spina bifida, such as pressure sores, infections, weight gain or obesity.
- Avoid common items that contain latex, such as medical equipment, condoms.
- Discuss getting ready to move to the adult health-care system before you turn 18 years old. If you see a paediatrician or you don't have a family doctor, start to look for a new doctor that you can see as a teenager and as an adult.
- Start to make your own medical appointments and keep track of them.
- Attend part of your medical appointments by yourself. Prepare a list and ask questions.
- Discuss birth control, parenthood, sexually transmitted diseases, drugs, alcohol and smoking with your health-care team.
- Create or update your own MyHealthPassport. Carry it in your wallet. www.sickkids.ca/myhealthpassport



General

- Think of yourself as a role model to younger children.
- Learn about the impact of your condition on sexual health and reproduction (for example, genetics).
- Thinking about driving? Speak to your health-care team.
- Review your equipment needs and funding options. Some sources of funding may not be available to you and your family once you turn 18.
- Apply at age 17.5 to the Ontario Disability Support Program (OSDP) if appropriate.
- If you are interested in one day moving out of your family home, talk with your health-care team about what type of supportive housing options are possible and what the waitlists for these options are like.
- Participate in life skills and independence programs.

Social

- Join teams or committees at your school. Participate in community programs that match your interests.
- Talk about relationships and sexuality with someone you trust.
- Talk to someone you trust if you are feeling stressed by school, social experiences or family pressures. Ask your health-care team for help if needed.
- When you go away from home, make sure that someone you are with knows how to get help for you in case of emergency.

Education

- Consider your skills and interests and what you would like to spend your time doing in the future.
- If you are going to college or university register with the disability office at your school.
- Looking for work? Gain skills through programs to support job readiness. Go for aptitude testing, career counseling, shadow someone at his or her job, or attend a job fair.
- Connect with the Spina Bifida & Hydrocephalus Association of Ontario.
- Look into alternative education options after high school including day programs, adult life skills programs and literacy programming.

- If you have a cognitive disability you might be eligible for Developmental Services Ontario supports. Ask your health-care providers about this.
- Ask your health care team if you should update your learning assessment to help you plan for the future.

Self-care

- Learn where your prescriptions are filled and how to get other supplies.
- Keep an up-to-date record of tests, procedures and medicines. Ask for help to do this if needed.
- Make sure your health-care team and support people have your current contact information.
- Update your MyHealth Passport.
- If you feel you want to stop or change a self-care routine, talk to your health-care provider about alternatives.
- Medical complications may happen as you learn to take charge of your care. Know the early warning signs and talk to your family or health care provider immediately when you have a question or problem.

Medical

- Talk to your health-care team about your upcoming transfer to an adult health care facility. Celebrate your “graduation”.
- Learn who your adult health-care team is and how your care will change in the adult system. Know who to call and where to go in an emergency. Once you are 18 you can no longer be admitted to a paediatric hospital.
- Make sure you have enough medication to last until your first appointment with your new adult providers.
- Make decisions together with your health-care team.
- Use a calendar system to track clinic appointments and other tests.



Continue with the suggestions from earlier years.
Add new activities and responsibilities as you grow.



General

- Make sure you get copies of paperwork you might need in the future from your high school and hospitals, such as transcripts, Individualized Education Plans, learning assessments and medical reports.
- You will be meeting new adult service providers in education, health care and independent living settings. Practice what you want to say about your disability and your medical history to new people.
- Talk to family, friends and people from various organizations about your goals. Follow your interests by pursuing further education, volunteering, or working.
- Plan where you would like to live now or in the future. You may want to live with family, live independently, or live with supports.

Social

- Keep in touch with your old friends from high school, camps and recreation. Be open to developing new friends that you might meet in school, work and community programs.
- Develop an adult relationship with your family. If you live with family members, take responsibility for household tasks. This could include cleaning, helping with shopping or planning meals.
- Talk to your health-care provider about sexuality and healthy relationships.
- Ask your health-care provider to refer you to a social worker or agency if you cannot find programming, supportive housing or services to meet your needs. You may also find options by contacting the Spina Bifida & Hydrocephalus Association of Ontario.

Self-care

- Learn as much as you can about the services and supports that are available to you as an adult. Ask questions and network with people with disabilities. Self-care attendant services are available at home, school, work and in the community.
- Ask your health-care provider for help finding equipment and funding. Getting the right equipment and funding may take time.
- Check with your medical suppliers regularly about new products. Request samples if appropriate for your needs.
- Most medical expenses are covered by OHIP and ODSP (if you are receiving ODSP) but some are not. Look into private health-care insurance for when you are no longer covered under your parent's plan.

- You will go through times of change in your self-care needs, routines and caregivers. Keep practicing your communication skills such as explaining your routine in steps, and being assertive about what is important to you. Write the steps out if it's easier for you.
- Ask your caregivers to let you know if they notice anything unusual that could indicate a problem such as skin or wound issues, bladder infections or constipation. That way you can seek medical treatment early.

Education

- Be aware of options in your community for continuing education. These may include college, university, adult education courses through your local school board, literacy programs and community programs specifically for people with learning challenges.
- If you have a learning disability practice explaining how you learn best to others. This may help you to get accommodations at work, school and volunteer positions. MyEducation Passport (www.sickkids.ca/myedupassport) can help you explain.

Medical

- Keep the names and phone numbers of your old and new health-care providers handy in your phone or wallet. Your MyHealth Passport can help you keep all this information in one place. Update it when you make major changes in your care providers or treatments.
- Book appointments at least once a year with your health-care providers. It is important for people with spina bifida to see health care providers regularly even if they feel well. Book an appointment with your family doctor for a yearly physical exam.
- Ask your health-care provider questions about what to expect in the future as you age.
- Develop a system of supportive people that you can talk to about health issues, especially if problems with your health make you feel anxious. This can include family, friends, attendants, support workers, doctors, nurses, and others.
- Ask your doctor for advice on how to manage lifestyle changes. For example, you may want to change your bowel and bladder routines to match a new work schedule.
- If you have learning difficulties you may want to ask for information to be written down for you to take home or you may want to bring a friend or family member with you to appointments.
- If you need help booking appointments, remembering information and following up with recommendations, let your health-care provider know and ask for help from your support system.

Resources

Spina Bifida & Hydrocephalus Association of Ontario

Website: www.sbhao.on.ca

Phone: 800-387-1575

The Anne Johnston Health Station

Website: www.ajhs.ca

Phone: 416-486-8666

Easter Seals Ontario

Website: www.easterseals.org

Phone: 800-668-6252

March of Dimes Canada

Website: www.marchofdimes.ca

Phone: 800-263-3463

MedicAlert

Website: www.medicalert.ca

Phone: 800-668-1507

Ontario Disability Support Program

Website: www.mcsc.gov.on.ca/en/mcsc/programs/social/odsp

MyHealth Passport

www.sickkids.ca/myhealthpassport/

MyHealth Passport is a customized, wallet-size card that gives you instant access to your medical information. It's free and easy to create.

Ask staff at your local Children's Treatment Centres (in Toronto it would be Holland Bloorview Kids Rehabilitation Hospital) about:

- adapted sports
- recreation options
- volunteer and employment programs
- life skills programs and independence programs.

Acknowledgements:

Timetable adapted from Help them grow...so they're Good 2 Go! with permission from the Good 2 Go Transition Program, Division of Adolescent Medicine at The Hospital for Sick Children

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Content developed by: The Anne Johnston Health Station; Good 2 Go Transition Program, The Hospital for Sick Children; Holland Bloorview Kids Rehabilitation Hospital; Spina Bifida & Hydrocephalus Association of Ontario.