Getting ready for adult health care MY CHECKLIST

For people living with spina bifida

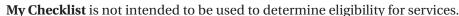
Name:

Date I started My Checklist:



Suggestions for health-care providers:

Please introduce this educational tool to your clients to promote discussion about health-management skills, goals and future planning. Encourage your clients to keep **My Checklist** and review it regularly. Let them know they can discuss questions and goals with you at any clinic visit.





Getting ready for adult health care

MY CHECKLIST

For people living with spina bifida

My Checklist is a list of things that you can do to help you look after your health.

Use this checklist to choose healthy living skills you want to develop or start to do more independently. It's ok if you need or want help with some things.

Keep **My Checklist** in a safe place and bring it with you to your health-care appointments. Talk about **My Checklist** with your family and health-care team.

We suggest that you review **My Checklist** once a year starting from around age 14. Adults can use it too.

It's also helpful to refer to this list when there is a major change in your health. For example, you might want to look at **My Checklist** if your doctor prescribes you a new medication or tells you about a new diagnosis.

The last page of **My Checklist** has a section where you can write down your goals. You might make a goal to learn a new skill, start a new way of doing things, or get more information about a topic. You can use this section to make an "Action Plan" for what you would like to do in the future. You can update or change your goals as needed.

Start with any section. You can do part of the booklet or the whole thing.

- General physical and emotional health
- 6 Allergies
- 7 Medications
- 8 Equipment & supplies
- 10 Bladder & bowel
- 12 Activities of daily living (personal care)
- 14 Pressure sores
- 17 Neurosurgical care
- 19 Health management skills
- 22 Beyond healthcare
- 25 Making an Action Plan

Section 1 General physical and emotional health

I tell my health-care providers about:	Yes	No, someone helps me do this (name)	Does not apply to me	I want to start to do this or learn to do this more independently
My condition and health-care needs				
How the level of my spina bifida affects me (Examples: sensation, movement, risk of injury, wounds, etc.)				
The type of spina bifida I have (Examples: myelomeningocele, meningocele, lipomyelogmeningocele, spina bifida occulta)				
What my other diagnoses are and what they mean for me (Examples: hydrocephalus, learning disability, attention deficit disorder)				
What I normally feel like and how I feel different when I am sick				

Section 1 General physical and emotional health

I talk with my health-care provider about:	Yes	No, someone helps me do this (name)	Does not apply to me	I want to start to do this or learn to do this more independently
How my condition will affect the way I develop through puberty	٥		۵	٥
What my health condition may bring as I get older	۵			
Who will provide my healthcare when I'm an adult	٥			٥
How my condition can be affected by the use of tobacco, alcohol and drugs	۵			
Sexual health (Examples: sexual functioning, safe sex, contraception, family planning, pregnancy)				
How I am feeling emotionally				
Ways to manage stress				
What I can do when I feel anxious or sad and how to reduce these feelings	۵			

Section 1 General physical and emotional health

	Yes	No, someone helps me do this (name)	Does not apply to me	I want to start to do this or learn to do this more independently
I go to my family doctor or to an emergency room when I have a health problem (Examples: infection, fever, injury)				
I follow healthy eating guidelines and maintain a healthy weight				
I exercise regularly				

Section summary

I want to learn more about this topic	☐ Yes	□ No
Start an Action Plan (see page 25)	☐ Yes	□ No
Talk to my family	☐ Yes	□ No
Talk to my health-care team	☐ Yes	□ No
Notes:		

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Section 2 Allergies

	Yes	No, someone helps me do this (name)	Does not apply to me	I want to start to do this or learn to do this more independently
I tell my health-care providers about my allergies	٥			٥
I know when I am having an allergic reaction. I take appropriate action and tell others how they can help me				۵
I avoid things that may contain latex (Examples: medical equipment, condoms, etc.)				
I ask questions about materials that will touch me in health-care appointments (example, "Are those gloves latex?")				۵

Section summary

□ Yes	□ No
☐ Yes	□ No
☐ Yes	□ No
☐ Yes	□ No
	□ Yes

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Section 3 Medications

	Yes	No, someone helps me do this (name)	Does not apply to me	I want to start to do this or learn to do this more independently
I keep a list of all my medications, including dosages, times and what each is for				
I reorder my prescription with the pharmacy when I am running low				
I book an appointment to go to the doctor to get a new prescription before I am out of refills				
I use a system to remember to take my medications at the right times (Examples, phone app, calendar, etc.)				
I talk with my pharmacists and doctors about all the medications and supplements that I am taking to make sure that they are safe to take together				
I take appropriate action if I miss a dose				

Section summary

☐ Yes	□ No
☐ Yes	□ No
☐ Yes	□ No
☐ Yes	□ No
	□ Yes

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Section 4 Equipment and supplies

Equipment:	Yes	No, someone helps me do this (name)	Does not apply to me	I want to start to do this or learn to do this more independently
I arrange to get my equipment fixed when needed (Examples, wheelchair, walker, AFO's, etc.)				
I book my own appointments to get new equipment prescribed				
I fill out the applications for funding from government agencies and charitable organizations for equipment that I need	٥			
I have talked to my health-care team about who will prescribe my equipment when I am an adult				
I have talked to my health-care team about how often I can get new equipment funded through the government				
I talk to my health-care provider when my equipment needs to be changed (Examples: needing a power chair instead of a manual, needing orthotics, growing out of equipment)				

Section 4 Equipment and supplies

Supplies	Yes	No, someone helps me do this (name)	Does not apply to me	I want to start to do this or learn to do this more independently
I order and arrange payment for my incontinence supplies				۵
I fill out the forms needed for ODSP or insurance when I need to change the quantity or type of incontinence supplies				٥
I talk with my doctor or nurse about my incontinence products to find out what options are available (Examples: catheter sizes, types of catheters, types of adult protection)	٥			

Section summary

□ Yes	□ No
□ Yes	□ No
□ Yes	□ No
□ Yes	□ No
	□ Yes

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Section 5 Bladder and bowel

	Yes	No, someone helps me do this (name)	Does not apply to me	I want to start to do this or learn to do this more independently
I talk with my health-care provider about my bladder and kidneys. I have picked a safe way to manage my bladder routine				
I watch for signs and symptoms of a bladder infection such as fever, pain, and increased wetness. I take action if needed				
I have ultrasounds yearly so my health-care provider can monitor my bladder & kidney status				
I talk with my health-care provider about my bowel routine and have picked a safe option for my routine				
I talk to my health-care provider about what to do if I become constipated	٥			٥
I talk to my health-care provider about where to access support in managing my cecostomy tube (C-Tube)	۵			
I talk to my health-care provider about where I will go to get my C-tube changed as an adult				
I have a reminder system in place to help me manage my bowel and bladder routines (Example, my phone reminds me when I need to do my catheter)				

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Section 5 Bladder and bowel

Section summary

I want to learn more about this topic	☐ Yes	□ No
Start an Action Plan (see page 25)	☐ Yes	□ No
Talk to my family	☐ Yes	□ No
Talk to my health-care team	☐ Yes	□ No
Notes:		

Section 6 Activities of daily living (personal care)

	Yes	No, someone helps me do this (name)	Does not apply to me	I want to start to do this or learn to do this more independently
I have assistance available if dressing, bathing, or preparing meals is taking a very long time for me to do				
I talk to my health-care provider about how to reduce safety risks in my daily routines (Examples, falls, identifying pressure sores, infections)				
I talk my attendants or PSWs about how to reduce safety risks in my daily routines (Examples, falls, identifying pressure sores, infections)				
I direct my own personal care. I explain my routine to a new attendant, PSW or helper (Examples, bladder/bowel, showers, transfers, meal prep, etc.)				
I talk with my attendants or PSWs about how they can help me notice if I'm having a problem with my health (Examples, bowel, bladder, pressure sores)				
I know who to ask to have my hours of attendant or PSW care increased if needed				
I talk to people I trust if an attendant, PSW or helper makes me feel uncomfortable				

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Section 6 Activities of daily living (personal care)

Section summary

I want to learn more about this topic	☐ Yes	□ No
Start an Action Plan (see page 25)	□ Yes	□ No
Talk to my family	☐ Yes	□ No
Talk to my health-care team	☐ Yes	□ No
Notes:		

Section 7 Pressure sores

I prevent pressure sores by:	Yes	No, someone helps me do this (name)	Does not apply to me	I want to start to do this or learn to do this more independently
Scheduling frequent changes if I have bladder or bowel incontinence				۵
Checking my skin regularly for pressure sores. I have someone help me see the areas I can't check on my own				۵
Contacting a health-care provider if I have a red mark that doesn't go away after 20 minutes				٥
Shifting my position frequently, especially when in my wheelchair or bed				۵
Asking for turns at night if needed				٥

Section 7 Pressure sores

When I have a pressure sore:	Yes	No, someone helps me do this (name)	Does not apply to me	I want to start to do this or learn to do this more independently
I seek medical attention as soon as possible				
I know the signs and symptoms of infection and I see a health-care provider right away (Examples, fever, redness, hot to touch)				
I look for what is causing the pressure with support from others and try to fix it				
I ask my health-care provider for a referral to an occupational therapist or orthotist to check my equipment (Examples, bed, wheelchair, clothing, orthotics)	٥			
I problem solve with my case manager IF the times nurses are arriving for my wound care are not matching my schedule				
I ask my health-care provider what my attendant or PSW should do if I get urine or feces on my bandage				
I ask my health-care provider what to do if my bandage gets wet or how to shower with my bandage				
I problem solve with my attendant or PSW IF the schedule for my showers needs to be coordinated with my dressing changes				

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Section 7 Pressure sores

Section summary

I want to learn more about this topic	□ Yes	□ No
Start an Action Plan (see page 25)	☐ Yes	□ No
Talk to my family	☐ Yes	□ No
Talk to my health-care team	☐ Yes	□ No
Notes:		

Section 8 Neurosurgical care

	Yes	No, someone helps me do this (name)	Does not apply to me	I want to start to do this or learn to do this more independently
I explain to health-care providers what a shunt is and where mine is located				
I watch for symptoms that would mean that there is a problem with my shunt (Examples, dizziness, headaches)				
I ask my health-care provider if I have a Chiari malformation and what this means for me	۵			
I know the symptoms of tethered cord and talk to my health-care team or neurosurgeon if I am worried (Examples, changes in bowel and bladder, changes in foot position, new pain in the back or head)				
I keep a list of when my neurosurgeries were. I take my list to health-care appointments (Examples shunts, decompressions, tethered cord release)				
I know who my neurosurgeon for adult care is and I have their contact information	٥			

Section 8 Neurosurgical care

Section summary

I want to learn more about this topic	□ Yes	□ No
Start an Action Plan (see page 25)	☐ Yes	□ No
Talk to my family	□ Yes	□ No
Talk to my health-care team	□ Yes	□ No
Notes:		

Section 9 Health management skills

	Yes	No, someone helps me do this (name)	Does not apply to me	I want to start to do this or learn to do this more independently
I organize and keep track of my health information (Examples, names of doctors, medications, test results)				
I book my health-care appointments (Examples, calling doctor's office to book an appointment, calling seating clinic)				
I use an agenda or calendar to keep track of when my appointments are (Examples, using an application on my phone, using a paper agenda)				
I know how to use public transportation, accessible transit or how to drive to get to a health-care appointment (Examples, TTC, accessible transit, driving)				
I speak up for myself and tell others what I need during health-care visits				
I ask and answer questions during health-care appointments	٥			
I express my concerns about treatment and health-care plans to my health-care provider (Example, I would say if I did not want to take a medication because of side effects)				

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Section 9 Health management skills

	Yes	No, someone helps me do this (name)	Does not apply to me	I want to start to do this or learn to do this more independently
I ask my health-care provider to explain a procedure or plan before they start to touch me				
I ask for an explanation or example when I don't understand				
I tell my health-care provider that I need information in writing as well as verbally				
I tell my health-care provider to include specific steps and instructions when they make recommendations, make a referral, or prescribe a medication				
I ask my health-care provider to discuss major decisions with me over several conversations so that I have time to think about my options and talk to important people in my life (Examples, surgery, medication side effects, housing)				
I make a list of things that helped me at school that could also help me with my healthcare				
I share the results of psychoeducational assessments and other reports with my health-care team				
I bring someone that I trust with me when I have an appointment and I'm feeling anxious or think I may need support				

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Section 9 Health management skills

	Yes	No, someone helps me do this (name)	Does not apply to me	I want to start to do this or learn to do this more independently
I ask my family members or friends for support when I need it in all parts of my life (Example, if I am experiencing difficulties with my healthcare)				
I request copies of my medical records when I need them. I know it is my right to have my records if I want them				
I know that I can switch health-care providers if someone makes me uncomfortable or frightened. I know that it is my right to ask for a different provider	٥			

Section summary

I want to learn more about this topic	□ Yes	□ No
Start an Action Plan (see page 25)	□ Yes	□ No
Talk to my family	☐ Yes	□ No
Talk to my health-care team	☐ Yes	□ No
Notes:		

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Section 10 Beyond healthcare

	Yes	No	Not sure	Does not apply to me
I am attending school regularly or have a job				
I am involved in clubs, groups, sports or activities that I like				
I hang out with friends who support me or who are good to me				
I have healthy relationships (Examples, family, friendships, sexual partners, attendant/PSW services, acquaintances, etc.)	٥		٥	
I know the importance of having personal boundaries and I respect other people's boundaries. I understand that every relationship is different (Examples, attendant/PSW services, friends, acquaintances)				
I am happy with my current housing situation				
I know about supportive housing options in my community				
My family and I have talked about plans for the future including changes in who will support me as my parents age				
My family and I know about attendant/ PSW service options and services available through Community Care Access Centres				
My family and I know about financial options for adults with disabilities (Examples, ODSP, Henson Trust, RDSP, etc)				

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Section 10 Beyond healthcare

Section summary

I want to learn more about this topic	□ Yes	□ No
Start an Action Plan (see page 25)	☐ Yes	□ No
Talk to my family	☐ Yes	□ No
Talk to my health-care team	☐ Yes	□ No
Notes:		

Section 11 Now what?

- Discuss My Checklist with your family and your health-care provider.
- You may have identified many things that you want to work on.
- To get started, pick one thing that is important to you or your family. Start an Action Plan.
- Keep this checklist so that when you have finished working on your first goal, you can pick another one.

Notes:	

Action Plan

	Pick a goal:
	1 thing I want to work on is
	(My family wants to plan for)
	Break your goal into steps. Ask your family to help or plan a meeting with your health-care
	provider to discuss this.
	C4 1.
	Step 1:
	Step 2:
	Step 3:
	Step 6.
	Step 4:
h	

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Section 11 Now what?

Talk to people	who can support	you with this go	oal or plan. List t	hem here.	
Talk to people	who can support	you with this go	oal or plan. List t	hem here.	
Talk to people	who can support	you with this go	oal or plan. List t	hem here.	
Talk to people	who can support	you with this go	oal or plan. List t	hem here.	
Talk to people	who can support	you with this go	oal or plan. List t	hem here.	

Section 11 Now what?

) .	Ask yourself: What will success look like?				
	I will know I have achieved this goal when				
6.	How long do you think it will take to start seeing progress towards your goal? Decide with your health-care provider when you should meet again to follow up on your goal and see how things are going.				
	I will see my health-care provider again on(date) to talk about my goal.				

Acknowledgements:

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