

Special Topic TeleProgram

How to Prepare for the Doctor-Part 1

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I. What to do before your appointment

A. The more you can do ahead of time, the more productive your visit will be!

- 1. Have important questions ready ahead of time.**
- 2. Arrive 10 to 15 minutes early**
 - (a) If paperwork is difficult ask office to mail it to you ahead of time.
 - (b) Bring a friend or relative to help with paperwork.
- 3. Be sure you are aware of what type of provider you are seeing and questions are appropriate.**
 - (a) Do not ask orthopedics questions to an urologist!
- 4. Make sure your transportation is arranged ahead of time.**
 - (a) Utilize friends, family, or care providers
 - (b) Understand Medicaid transportation options
 - (c) If you have to miss, make sure you cancel. Avoid “no showing” as it may prevent you from rescheduling
- 5. Wear clothes that can be easily removed for a physical exam.**

II. What you need to know about yourself and your health.

A. Pertinent past medical history, but don't overwhelm the new provider.

- 1. Neurosurgical history**
 - a) Hydrocephalus status**
 - (1) Type of shunt***
 - (2) Last shunt revision***
 - (3) Where you have received neurosurgical care***

b) Bring copies of most recent scans

(1) Shunt series disks or reports

(2) CT or MRI disks or reports

c) Chiari status and tethered cord

(1) Last decompression or tethered cord release

(2) MRI of spine disk or report

2. Urological history

a) Bladder care

(1) Do you do CIC, how often, type of catheter

(2) Where do you receive your supplies

(3) Recent Renal Ultrasound or other testing disks or reports

3. General medical history

a) High blood pressure

(1) Any medications

b) Surgeries

(1) General or ortho surgeries

c) Diabetes

(1) Age of onset

d) Wound care

(1) History of pressure ulcers

(2) Current treatment for pressure ulcers

(3) Pressure ulcer prevention

e) Medications

(1) List of current medications

(2) List of past medications with poor results

(3) Medication allergies

B. Family history

1. Know if any diseases run in your family

- a) Diabetes
- b) Cancer
- c) Blood pressure issues
- d) Cholesterol problems
- e) Mental health concerns

C. Social history

1. You will be asked about the following at a first visit

a) Sexually active

(1) Be honest and don't be embarrassed. This is the best place to get guidance and it will help your provider take better care of you if you are honest

(2) This should have been part of your adolescent interview but is always part of the adult interview

(3) Providers do not judge behavior.

b) Smoking status

(1) Include smokeless tobacco

(2) Is a way for providers to see if you are ready for changing some behaviors that may lead to health concerns

c) Drug and alcohol usage

(1) Providers do not report to the police

(2) May guide medication management as some meds are not safe while using other drugs and alcohol

III. What will happen during the visit

A. Interview period first

1. Parents may be in or out of the room

a) Many providers may be cautious with another person in the room

(1) Adults usually attend appointment alone

(2) It is your right to have someone else in the room, make this clear to the provider

(3) Understand that providers will still ask personal health questions even if you have someone else with you

b) Tell the provider if you are uncomfortable

(1) At any point you can stop if you are uncomfortable

(2) Ask caregiver or parent to step out if questions become too personal.

B. Physical exam

1. Parents in or out of the room

a) This is a great time to ask parents or caregivers to leave

(1) If you haven't had a chance share concerns privately with caregiver

(2) Ask for assistance with transfer if needed

(3) May stop at any time if you feel uncomfortable

2. If provider misses something important, please share as not everyone is an expert in Spina Bifida. Teach your provider, we appreciate it.

IV. What will happen after the visit

A. Follow up

1. You will not be called to schedule a follow up

a) Most adult providers will request 1, 3, 6, or 12 month visits

(1) You should schedule before leaving if possible

(2) Mark this down on your calendar and tell a friend to help you remember

(3) Provide email and cell phone as most offices send an email and will text reminders

b) Tests, imaging, blood work

(1) Your provider may order these things. Ask what can be accomplished that day as you are already there. Sometimes blood work can be done. Take the opportunity to do the tests while you are already there and save yourself a trip

(2) Ask provider what time frame these should be done in

c) Referral to other specialist

(1) Your provider may refer you to a specialist. Make sure you have their contact info

(2) Give one week for the referral and if you haven't heard from them call the number to schedule

B. New Medications

1. What if new meds are prescribed?

a) Make sure you know the name and understand the purpose of the new medications

(1) Don't hesitate to ask questions if you don't understand

(2) Make sure you know which pharmacy you use and can tell your provider

C. Parent involvement with follow up

1. Your parents and family members can't call to help with appointment in the adult world

a) If you need their help ask for them to sign a release of information so they can help you

(1) Ask parents to take notes during a visit

(2) Practice making your own appointment with parent or caregiver there for advise