

PFA Tips

Healthcare Transition Tips

It's important to have a doctor who knows how to keep you healthy as an adult. Pediatricians are trained to care for babies, children, and teens; they aren't trained to treat the medical conditions that you might have as you get older.

It is important to find your adult doctors early. You should begin seeing an adult doctor around age 18 to 21. Ask your pediatrician to share your records and discuss your history with the new doctor while you are still a patient in case there are questions about your condition or treatment.

The main difference between a pediatric and an adult approach to health care is that you are the only person communicating with your provider and making your health care decisions. You can sign a release of information form which will allow your parents or others to participate in your appointment. The change to an adult approach to care comes at age 18, either while you are still with your pediatric or family medicine providers, or with your new adult provider.

How do I find a new doctor?

- Ask current doctor for a referral – your current pediatrician may have a colleague that he/she has referred before
- Ask your parents or friends for a recommendation
- Ask your insurance company
- Contact local support groups
- Search the Pathfinders for Autism provider database

You must feel comfortable that the doctor you choose will be able to meet your medical needs. When you have a doctor you want to call, ask to speak to a staff member who will be able to take time to answer your questions. You can also make an appointment to speak to the doctor and staff in person.

You've picked the doctor(s) you would like to see, now what? There are things that need to be discussed to move this process forward.

Questions to ask the Doctor

- Is the doctor willing to discuss your health history and special needs with your pediatrician? Can you be a part of that conversation?
- Does the doctor currently see patients with health conditions similar to yours?
- What hospital is used to schedule procedures?
- Does this doctor have any medical or specialty training related to your health conditions?
- Who fills in for the doctor when he/she is away from the office?

Questions to ask the office

- Is the doctor taking new patients?
- Do they accept your insurance?
- What are the office hours?
- What is the procedure for after hours issues?
- How does the doctor communicate with your specialists?
- What services does the office provide?
- How flexible is the office to accommodate your health needs? (service dogs, early appointments, late appointments, times when the office is more quiet).

Questions to ask yourself

- Is the doctor listening to your concerns and answering all of your questions?
- Does the doctor take time explaining things to you so that you can understand what he/she is saying?



Managing your health care

Since you are now the key person making decisions about your care, you are expected to manage your own appointments, medications, and health care payments/insurance. You will also want to be prepared with your own questions at your appointments. Create a healthcare notebook or binder to help you stay organized.

The following documents will help you stay organized: (links are listed at the end under Additional Resources)

- Making an Appointment Worksheet
- Sample Medical Summary and Emergency Care Plan
- Symptoms Worksheet

Things to Bring to a Healthcare Visit

- Health insurance card (if you have one)
- Something fun to do in case you have to wait (examples: book, puzzle, fidgets, music player)
- Sensory items (examples: sunglasses, chewing gum, headphones)
- A list of questions or things you want to talk about with your healthcare provider
- If you plan to talk about a symptom or set of symptoms, a completed Symptoms Worksheet (if you used it)

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- Any logs or diaries you keep related to your health problems (examples: blood sugar measurements, blood pressure measurements, symptom trackers)
- Containers (bottles, tubes, etc.) of all of your current medications. The next best thing would be a list of all current medications, including any new or changed medications
- If you have been to the emergency room, have been hospitalized, or have seen a different healthcare provider since your last visit, any instructions or paperwork that you got
- Name, address, and any directions needed to get to the office
- Anything your healthcare provider has asked you to bring (if they have asked you to bring anything)

If this is a visit with a new provider, if you have not seen this provider in a long time (for example, at least two years), or if any of this information has changed since the last time you saw this provider, also bring:

- A short summary of your medical history
- Your old medical records (if you have them)
- Names and addresses (or fax numbers) of your past healthcare providers or any other healthcare providers that you are still going to (your primary care provider and any specialists)
- Names and contact information of people who may be involved in your healthcare. Examples include the person they should contact in case of an emergency, your Healthcare

Power of Attorney (the person who would make health-related decisions for you if you ever could not make them yourself), a guardian (if you have one), and anyone who helps you communicate between visits.

- Your intake form, if you filled one out at home

Talk to your healthcare provider about accommodation needs or strategies that may help make visits go more smoothly, including:

- Appointment flexibility – typically, first or last patient of the day can be helpful
- Allotted time – a little more time for appointments
- Sensitivity to Light – lower or no lighting in exam room
- Sensitivity to Sound – lower to no music

Additional Resources

Making an Appointment Worksheet

https://www.autismandhealth.org/inc/forms/hc_appointment_worksheet.pdf

Sample Medical Summary and Emergency Care Plan

<http://www.gottransition.org/resourceGet.cfm?id=227>

Symptoms Worksheet

https://www.autismandhealth.org/inc/forms/hc_symptoms_worksheet.pdf

The Parents' Place of Maryland

<https://www.ppm.org/>

Becoming an Adult: Taking Responsibility for your Medical Care

<https://www.youtube.com/watch?v=cjXurYrFMZM&feature=youtu.be>

Got Transition FAQ Page

<http://www.gottransition.org/youthfamilies/index.cfm>

Autistic Self Advocacy Network: Healthcare Toolkit

<http://autisticadvocacy.org/wp-content/uploads/2014/07/ASAN-healthcare-toolkit-final.pdf>

AASPIRE Healthcare Toolkit

https://www.autismandhealth.org/?a=pt&p=main&theme=ltlc&size=small&t=pt_fm

Autism Speaks Transition Tool Kit

https://www.autismspeaks.org/sites/default/files/docs/ttk2_health.pdf

Pathfinders for Autism provider database

<http://pathfindersforautism.org/providers-services/>

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