

# Transition to Adulthood: A Health Care Guide for Youth and Families

## Introduction

Although approaching adulthood is an exciting time in any young person's life, it is also a time of uncertainty. Like all youth approaching adulthood, people with disabilities and their families need to plan for the future. How can families make sure young adults are prepared to make their own decisions? Who will support them in making those decisions? How can young adults and their families ensure that their basic needs will still be met after they reach adulthood?

Although this sort of planning is important for any family, the planning process may be particularly difficult when the young person has a disability. Benefits programs that the young person needs in order to meet his or her basic needs may be subject to age cut-offs. People with disabilities may need extra support in order to make decisions about their lives and their families may receive myriad and conflicting advice about how to provide such support. People with complex health care or accessibility needs may experience difficulty finding new health care providers who are capable of treating adults.

This guide is intended to help young people with disabilities and their families plan for the transition to adulthood in health care contexts. It includes information on how to ensure that young adults have the support they need to make healthcare decisions, how to access continued healthcare coverage and decide which kind of coverage to get, and how to find an adult-oriented doctor.

## Keeping Health Insurance

Between the ages of 18 and 26, most people with disabilities will “age out” of their original healthcare coverage plans. Keeping continuous health coverage is critically important for good health. Health coverage is not just protection against the chance of getting sick; under the Affordable Care Act, all health care policies must cover certain preventative care services—such as annual

check-ups and vaccines—for free.

The best way to plan for continued healthcare depends on each person's situation. Your options may include:

### Coverage through a parent's insurance plan:

If the youth is currently covered through a parent's health insurance plan – either employer-sponsored or purchased on an exchange – then he or she may continue to be covered under that insurance plan until the age of 26.

This option can be useful when:

- The parent can afford to keep the young adult on the parent's health plan,
- The parent's health plan covers all the health care that the young adult needs,
- The young adult is ineligible for Medicaid or other public health insurance programs, for example due to his or her immigration status, and/or
- The young adult needs a source of health coverage while waiting to be enrolled in another source of coverage, like Medicaid.

It may not be the best option when:

- The parent is unwilling or unable to afford to maintain coverage for the young adult,
- The young adult is approaching the age of 26,
- The young adult needs long-term supports and services that the health plan doesn't cover,
- The young adult has other health needs not covered by the plan – such as maternity benefits in some cases,<sup>1</sup>
- The young adult has access to better or more cost-effective coverage through an employer, the health care exchange, or Medicare/Medicaid.



*The Autistic Self Advocacy Network (ASAN) is a non-profit organization run by and for autistic people. ASAN provides support and services to individuals on the autism spectrum while working to change public perception and combat misinformation. Our activities include public policy advocacy, community engagement to encourage inclusion and respect for neurodiversity, quality of life oriented research and the development of autistic cultural activities.*

For more information on the benefits and drawbacks of this option, see Kaiser Health News' FAQ at <http://www.kaiserhealthnews.org/stories/2013/october/01/faq-on-young-adults-and-the-health-law.aspx>.

## Coverage through an employer

Young adults may be able to get health insurance through an employer. Not all employers offer health insurance, however, and many employers offer insurance only to people who work full-time. Unless a youth or young adult already has a job that offers health insurance, it is best to plan ahead to make sure that he or she has alternative insurance options, such as through the parent's insurance plan, individual health insurance marketplaces, or Medicaid.

## Buying individual coverage

Under the Affordable Care Act, people can purchase health insurance for themselves, their spouse, and/or children through statewide health insurance marketplaces. This insurance is available to everyone who is a United States citizen or qualified resident, even if the insured has a pre-existing medical condition or disability. All plans have to cover a range of services, including mental health treatment and "habilitative" services such as occupational therapy. In addition, although some plans can charge high co-pays and deductibles on top of the monthly insurance premium, preventative care, like annual check-ups and vaccines, is free.

People who earn between 133% and 400% of the federal poverty level, who aren't covered by another plan, and who don't have another affordable source of insurance – like insurance through an employer or through Medicaid – are eligible for tax credits to help them pay for the cost of insurance. Unlike most tax credits, these are available even to those who don't usually earn enough to pay federal income taxes, and can be applied directly to monthly insurance premiums so that people do not have to pay the full cost up front and then wait to be reimbursed.

The application for health insurance through the statewide marketplaces is available at [www.healthcare.gov](http://www.healthcare.gov). Filling out these applications is also a good way to find out whether you are eligible for Medicaid as a result of your low income, pregnancy or parental status (you may need to fill out a separate application to see if you qualify for disability-based Medicaid coverage).

Applying for individual coverage is a good idea when:

- It is no longer possible to stay on the parent's plan, or the parent's plan is no longer affordable;
- The young adult is not eligible for Medicaid or wants a streamlined application that will help them apply for Medicaid and individual insurance at the same time; and
- The young adult works but can't get health insurance through an employer.

People who want to buy individual coverage can only do so at specific times, so it is important to plan ahead. You may apply for coverage:

- During the "open enrollment" period, which is between November 15 and February 15, OR
- Within 60 days of when you:
  - Lose a previous source of insurance (such as by aging out of Medicaid, losing a job, or losing coverage through a parent's health insurance plan);
  - Get married, divorced, or have a child;
  - Move to a new state;
  - Start filing individual tax returns (as opposed to being included on a parent's tax return)
  - Have a major change of income that affects your eligibility for premium assistance tax credits or Medicaid eligibility.

## Medicaid coverage through the Supplemental Security Income (SSI) or "Buy-In" program:

In most states, adults with disabilities who qualify for Supplemental Security Income (SSI) disability benefits also qualify for Medicaid coverage. The SSI program is often a good option for people with significant disabilities who have very little or no income. To qualify for SSI, a person with a disability must prove that he or she is currently unable to engage in "substantial gainful activity" – that is, that he or she cannot currently work enough hours to earn a significant income. In some circumstances, a person who qualifies for SSI can begin working but still maintain Medicaid coverage as long as they earn less than a certain amount per year.

In some states, people with disabilities who are able to work, but who *would* otherwise qualify for SSI as a result of their disabilities, can get Medicaid coverage through a "buy-in" program. There may still be limits on how much money the person can earn or have saved up.

Coverage through SSI or a state Medicaid “buy-in” program may be a good option when:

- The young adult has very low income and very little money in savings;
- The young adult is already applying for SSI in order to receive income support, and/or
- The young adult needs long-term supports and services or home- and community-based services that are not available through any other program.

It is very important to apply early if you plan on getting coverage for yourself or your child through the SSI or buy-in program. These programs require proof of disability, and processing applications can take a lot of time. Many people are initially rejected and must file an appeal before getting benefits and Medicaid coverage. Even if a youth currently receives SSI benefits, he or she still needs to apply for continued benefits through the adult program.

The application for SSI is available at <http://www.ssa.gov/pgm/ssi.htm>.

### **Income-based Medicaid coverage**

The Affordable Care Act of 2010 allowed states to expand Medicaid coverage to all adults under 65 whose incomes are less than 138% of the Federal Poverty Level (FPL). As of 2013 that was \$15,856 per year for a single adult living in the mainland United States, \$19,803 for a single adult in Alaska and \$18,257 for a single adult in Hawaii.<sup>2</sup> Only the person’s “Modified Adjusted Gross Income” (“MAGI”) is counted – this does not include some kinds of income such as scholarships for educational expenses.

Most people who qualify for income-based Medicaid coverage will be enrolled in an “alternative benchmark plan” that may not be the same as “traditional” Medicaid. In some states, the “alternative benchmark plan” is a private managed care plan! However, people with disabilities who qualify for income-based Medicaid coverage can get traditional Medicaid coverage even if they do not qualify for SSI. It may be a good idea to request enrollment in a “traditional” Medicaid plan if the young adult needs long-term supports and services or other home-and community-based services that are only available through the traditional Medicaid plan.

Income-based Medicaid coverage may be a good option when the young adult lives in a state that offers income-based Medicaid coverage and:

- Cannot remain on a parent’s plan, or can’t afford the co-pays that are required by the parent’s plan,

- Works, but lacks access to employer-based insurance and earns less than 138% of the FPL,
- Needs health coverage while waiting for an SSI eligibility determination, and/or
- Needs home- and community-based services but is not eligible for Medicaid through the SSI program.

If you are not sure whether your state has income-based Medicaid coverage, visit <https://www.healthcare.gov/what-if-my-state-is-not-expanding-medicaid/>.

If you earn some income and are not sure whether you qualify for income-based Medicaid coverage, you can find out by filling out an application for insurance through [www.healthcare.gov](http://www.healthcare.gov). This site provides access to “one-stop” applications for insurance through the health insurance marketplace or through income-based Medicaid programs.

### **Other sources of coverage**

Depending on the young adult’s situation, other sources of coverage may be available. For example, low-income young adults with children may be able to get coverage through Medicaid even if they don’t qualify for SSI or for income-based Medicaid.

### **Creating a Support Network**

Like all youth preparing to take on the roles of adults, youth with developmental disabilities may benefit from a network of trusted supporters who can help them keep make and keep track of appointments, maintain a file containing important medical records, communicate with doctors, and otherwise help manage their health care.

Support can be very informal. For example, you can always ask your friends or family for advice on many health issues, such as when it’s necessary to see a doctor or what sort of health care coverage you should get. You can also ask friends or family to help you with daily activities, like remembering to take your medication.

Other forms of support may require formal arrangements. For example, if you’d like to choose a person to make health decisions for you during emergencies or when you’re unconscious, you may need to fill out a specific form called a **Durable Medical Power of Attorney** or **Health Care Proxy**. If you want a doctor to give health information about you to another person, you may need to sign a form called a **HIPAA release**. If someone thinks that you can’t make your own medical decisions and wants the

power to make decisions for you, that person will have to ask a court to grant him or her guardianship over you.

## Types of Formal Support Arrangements:

### DURABLE MEDICAL POWER OF ATTORNEY (ALSO KNOWN AS HEALTH CARE PROXY)

Many states allow you to name a person who can make health care decisions for you if you ever become unable to make them for yourself. For example, you might be unable to make a decision if you are unconscious.

Using a durable power of attorney or health care proxy, you can name someone who will talk to doctors, gather health information, make decisions on your behalf, and otherwise act as your advocate in emergencies or other situations when you need extra help to make decisions.

It is important to remember that these agreements give someone else the ability to make health care decisions for you in some situations. Make sure that the person you name is someone you trust to make the decisions you would want them to make. In many states, you can give a person authority to make some health care decisions but not others. For example, you may wish to give someone the authority to agree to emergency medical treatment that you might need, but not the authority to remove a feeding tube that is keeping you alive.

If you appoint someone as your durable power of attorney or health care proxy, it is important that both you and the person you appoint keep a copy of the agreement. You should also give a copy to your doctors, especially your primary care doctor.

### HIPAA RELEASE

You may want to have someone help you understand your medical information and help you talk with doctors. In some situations, such as when you bring a friend to a doctor's appointment to help you talk to a doctor, you might not need to sign a form allowing the doctor to talk to that person. In most situations, however, doctors cannot talk to other people about your health care without your permission. If you would like someone to be able to call a doctor's office for you to ask a question, or to be able to get your health records from the doctor's office, you may need to sign a form.

It is important that your medical information only be shared with the people you intend to share it with. Before you sign a form to release your medical records it is important to make sure the form says the following:

- **HOW MUCH INFORMATION WILL BE SHARED.** You can share your complete record, just one section or information related to a specific medical problem.
- **HOW OFTEN THE INFORMATION WILL BE SHARED.** Will the information be shared once or will information be shared on an ongoing basis? If the information is going to be provided on an ongoing basis then there should be a date when the authorization expires and must be renewed.
- **WHO WILL RECEIVE THE INFORMATION.** This is the person or provider you are sharing the information with (the third party). This should include the person or provider's name, address and telephone number.
- **HOW THE INFORMATION WILL BE SHARED.** There should be a place where you indicate how your records will be sent to the third party. In most cases it should be provided by mail or hand delivery rather than faxed to avoid the information being seen by anyone else.

## Supported Decision-making Agreement

In some places outside the United States, you can appoint someone as a "supported decision-maker." This person will be able to help you make decisions about your health care, but cannot make decisions for you.

Unfortunately, no state in the United States has a law recognizing supported decision-making agreements right now, but advocates hope that this will change in the future. In the meantime, you can use the form in our **Model Supported Decision-Making Agreement Legislation** to express your intention to have someone act as your supported decision-maker. Even though there is no guarantee that it will be legally recognized, it can be useful as a guide for your relationship with someone who provides this sort of support on an informal basis.

## How to Use Supporters

If someone helps support you with your healthcare – either informally or through a power of attorney or health care proxy agreement – explain (or ask your supporters to explain) the role of your supporters to your healthcare provider. Different people have different ways they like to be supported. For example, some people like to do all the communication with their healthcare provider themselves and have the supporter just take notes. Others may want the supporter to do most of the communication. Your healthcare providers may not understand what role you want your supporters to play in your healthcare unless they are told.

## Do I Need a Guardian?

A guardian or conservator is someone who can act as the legal authority for another person. If someone believes that your disability makes you unable to make your own health care, financial, or other decisions, that person may ask a court to appoint a guardian over you. Depending on what the court decides, the guardian may have the power to make medical decisions for you, even if you do not agree with those decisions, and you may lose the ability to make medical decisions independently.

Before seeking guardianship, it is important to explore all other alternatives, including informal support arrangements and powers of attorney or health care proxies. Guardianships can have serious consequences for a person's ability to make their own decisions. People may think they need guardianship over an adult simply because the adult needs help to understand information and make health decisions. Unfortunately, because a guardian is typically allowed to make decisions for a person with a disability, guardianships can have the effect of preventing people with disabilities from participating meaningfully in their own health care decisions and learning new decision-making skills.

If you are facing a petition for guardianship, or are under a guardianship and do not want to be, you can challenge the guardianship in court. Your state's Protection and Advocacy organization is a good place to look for advice. Visit <http://www.ndrn.org/en/ndrn-member-agencies.html> to find your state's Protection and Advocacy organization.

## Ensuring that health care is included in your middle school and high school education plans

The Individuals with Disabilities Education Act (IDEA) requires that schools provide "transition planning" services for students with disabilities, starting no later than age 16. Where appropriate, transition planning must include strategies to build independent living skills.<sup>3</sup> Because making health care decisions and coordinating care is an essential independent living skill, preparing students with disabilities to take on these roles during adulthood should be a component of any student's transition plan.

Doctors agree that health care transition planning should start as early as possible, and no later than 14. At this age, parents may wish to request that health care decision-making and transition planning be included as a transition goal in their child's IEP. Strategies to achieve this goal could include:

- Enrolling the student in a mainstream health class, with or without modified or supplemental instruction in specific areas;
- Coordinating with the student's health case manager or primary care doctor to identify areas of need; or
- If the student receives health services while at school, such as administration of medication, blood glucose monitoring, or nursing services, using these services as an opportunity to teach specific skills. For example, a student may be encouraged to begin reading his or her own blood glucose monitor or dispensing the correct number of pills while under the supervision of a school employee.

## Maintaining your Personal Medical Records

Whether you are thinking of getting a new doctor or simply trying to remember whether your check-ups are up to date, having a file folder containing your important medical records can come in very handy. Here's how to gather your medical records to create a file:

1. Write a list of the doctors and other health providers you've seen recently. This could include your regular pediatrician and any specialists you see: neurologist, gynecologist or urologist, psychiatrist, dermatologist, cardiologist, dentist, occupational therapist, etc. When making this list, it may help to ask for help from your parent or any other person who helped schedule doctor's appointments for you.
2. Contact each doctor and request your records. *You have a right to these records under federal law.* The one exception is psychotherapy notes – but you still have a right to your therapist's records detailing other things like appointments and medications you've taken.
3. You may be asked to sign a form in order to receive a copy of your health records.
4. Take a look at the records when you receive them to make sure that they are correct and complete. If you need help understanding the records or remembering whether the information in them is correct, you may want to have a trusted friend, family member, or service provider help you.

5. Put the records away in a safe place. Keep your records together. Ask help from a trusted friend, family member, or service provider if you need help keeping them organized.
6. It is best to not write on your records or give your only copy of your records to anyone – not even a doctor! If a doctor wants a copy of a record that you brought with you, ask if you can use their copier. If you do not have the copy with you, offer to sign a form that allows your doctor to request a copy from the other doctor’s office.

It can help to keep a table or set of cards that include information about the doctors and your progress getting records. Use a visual scheme that makes sense to you. For example, you could make a table:

<b>Doctor’s Name</b>	<b>Email or Phone Number</b>	<b>Records requested?</b>	<b>Records received?</b>
Dr. Brown (pediatrician)	(xxx) xxx-xxxx	On 2/15/2014	On 3/31/2014
Dr. Ng (neurologist)	Ng123@example.com	On 4/1/2014	Not yet – ask again
Dr. Arroyo (allergist)	(xxx) xxx-xxxx	Not yet – need form	Not yet

Or put each doctor on a separate page or card:

**Doctor Brown, Pediatrician**

(xxx) xxx-xxxx

Records requested 2/15/2014

Records received 3/31/2014

**Doctor Ng, Neurologist**

Ng123@example.com

Records requested: 4/1/2014

Records received: Not yet – ask again

## Other Resources

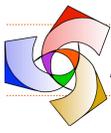
For more resources on how to navigate the health care system, including how to make an appointment, prepare for doctor’s visits, and communicate with doctors about your health, check out the Academic-Autistic Spectrum Partnership in Research and Education (AASPIRE) Health Care Toolkit, available at [www.autismandhealth.org](http://www.autismandhealth.org).

AASPIRE’s worksheets on how to make an appointment, what to bring to an appointment, how to track and describe your symptoms, and what to do after a health-care appointment are included at the end of this resource.

## References

- <sup>1</sup> <http://www.kaiserhealthnews.org/stories/2013/october/01/faq-on-young-adults-and-the-health-law.aspx>
- <sup>2</sup> <http://aspe.hhs.gov/poverty/13poverty.cfm#thresholds>
- <sup>3</sup> 34 C.F.R. § 300.320(b). Discussion of this provision is available at <http://nichcy.org/schoolage/iep/iepcontents/transition>.





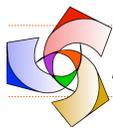
## AASPIRE **Worksheet: Making an Appointment**

This worksheet walks through the steps of making a healthcare appointment. It has lines to write in information that you might want handy while making the appointment. It also has lines to write in information the office staff might tell you, like the day and time of the appointment. The parts in *italic* can be used as a script to be used in conversation, if desired. Some things on this worksheet may not apply to you. That's OK; just ignore those parts.

1. Making an appointment is usually done by telephone, in person, or, if available, through a secure electronic messaging system (example: MyChart). You may also have arranged a special way of contacting the office previously. Start by contacting the office.

The contact information for the provider's office is (use the option that applies to you):

- Telephone \_\_\_\_\_
- Web address and login information for secure messaging system  
\_\_\_\_\_
- Other contact information \_\_\_\_\_
- The provider's name is: \_\_\_\_\_



# AASPIRE **Worksheet: Making an Appointment**

Hello, my name is \_\_\_\_\_ and I'm calling to make an appointment with \_\_\_\_\_.

2. When you contact the provider's office, tell them what the appointment is for. You may need to give details to a nurse, medical assistant or scheduler – they are an important part of a team and will keep your information confidential.

**NOTE:** If you are making your first appointment with a new provider, tell them you want to make a new patient appointment. See section below for additional information you may need.

The reason that I am making the appointment is:

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3. Have your (or your supporters') contact information available in case the office needs to call you back. The office may not ask for this information, but it's good to have just in case.

If the office needs to contact me back, they should contact:

- Name \_\_\_\_\_
- Telephone \_\_\_\_\_
- Other \_\_\_\_\_



## AASPIRE **Worksheet: Making an Appointment**

4. Know your own schedule / availability; if applicable, know the availability of the person who will support you and make sure your schedules work together.

The days and times I am free for an appointment are:

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5. Then there will probably be a conversation next about scheduling. By the end of the conversation, you should be able to confirm the date and time of the appointment, and have an estimate of about how long the appointment is likely to take.

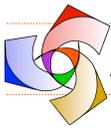
The date and time of my appointment is \_\_\_\_\_.

The appointment will take about \_\_\_\_\_ (hours or minutes).  
Is that correct?

6. Make sure you know the location of the appointment.

The location of my appointment is:

- Street Address: \_\_\_\_\_
- Building: \_\_\_\_\_
- Floor, suite number, or room number: \_\_\_\_\_
- City or Town: \_\_\_\_\_



Is that correct?

7. Make sure you know the name of the provider you will be seeing.

Just to confirm, the name of the provider I'll be seeing is

\_\_\_\_\_. Is that correct?

8. Make sure you know about anything special you need to bring or do.

Examples: 1) If the provider wants to do a cholesterol test at your appointment, you might need to fast before the appointment. 2) If

it's a new patient visit, the provider might want you to bring any medical records you have.

Is there anything special I should do to prepare for this visit, or anything special I should bring with me to this visit?

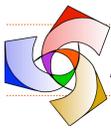
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**If you are making a first appointment with a new healthcare provider:**

The office staff may ask you for additional information. It may be useful to have this information handy in case they do.



9. Who and to what number the reminder call should be directed:

- Name \_\_\_\_\_
- Telephone Number: \_\_\_\_\_
- Other (alternative to telephone) \_\_\_\_\_

10. If you have health insurance, who your insurance provider is:

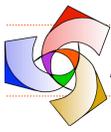
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11. Mailing address for sending forms or other papers through the mail:

- Number and Street: \_\_\_\_\_
- City or Town: \_\_\_\_\_
- Zip Code: \_\_\_\_\_

You may also have some additional questions for the office staff, or things you want to learn about the clinic or provider.

12. If you have any questions about the new provider that haven't been answered, ask them now. Examples: Is the provider taking new patients? Do you accept my insurance? Are you open evening hours? See Tips for Finding a Provider for more examples.



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13. If desired, ask if the office can send you the new patient forms to fill out in advance.

Could you please mail me the new patient forms so I can fill them out in advance?

14. Consider discussing accommodation needs related to facilities, if you have them. For example, exploring waiting room options, accommodating sensory needs, or finding out if it's OK to visit the office before the appointment or to take pictures of the office before the appointment.

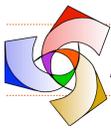
I have a disability that can make it hard to manage the office. I'm wondering if it would be possible to:

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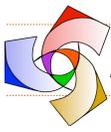
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## Things to Bring to a Healthcare Visit

- 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 Symptom Worksheet (if you used it)
- 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)



## AASPIRE **Worksheet: What to Bring**

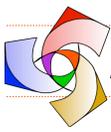
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If this is a visit with a new provider, if you have not seen this provider in a long time (for example, at least two years), or if any of this information has changed since the last time you saw this provider, also bring:

- 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.

If this is a first visit, or if you would like to talk with your healthcare provider about your accommodation needs or strategies that may help make visits go more smoothly, also bring:

- Copy of your Autism Healthcare Accommodations letter for your healthcare provider (if you made one)



## Describing Your Symptoms

This worksheet covers the information healthcare providers (like physicians, physician assistants, and nurse practitioners) usually want to know about symptoms. Not all questions apply to all symptoms. You do NOT have to answer every question. But thinking through some of these questions may help you better describe your symptoms or answer your provider's questions.

Use this worksheet for your own reference. Healthcare providers may become overwhelmed if you ask them to read it. For more information and examples see AASPIRE's Healthcare Toolkit at [www.autismandhealth.org](http://www.autismandhealth.org).

What is the symptom (or set of symptoms)? Describe them.

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Location – What areas of your body are affected?

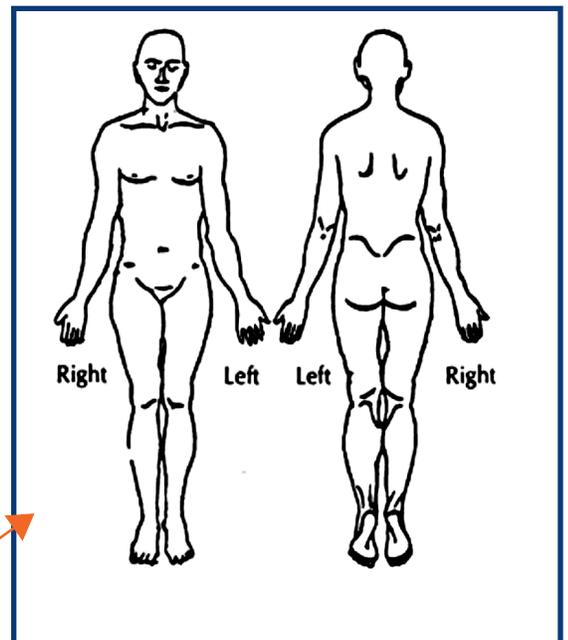
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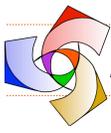
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**Optional:** Put an X or shade in the areas of your body where the symptoms are.





# AASPIRE **Worksheet: Symptoms**

Quality - If the symptom is pain, what is the pain like?

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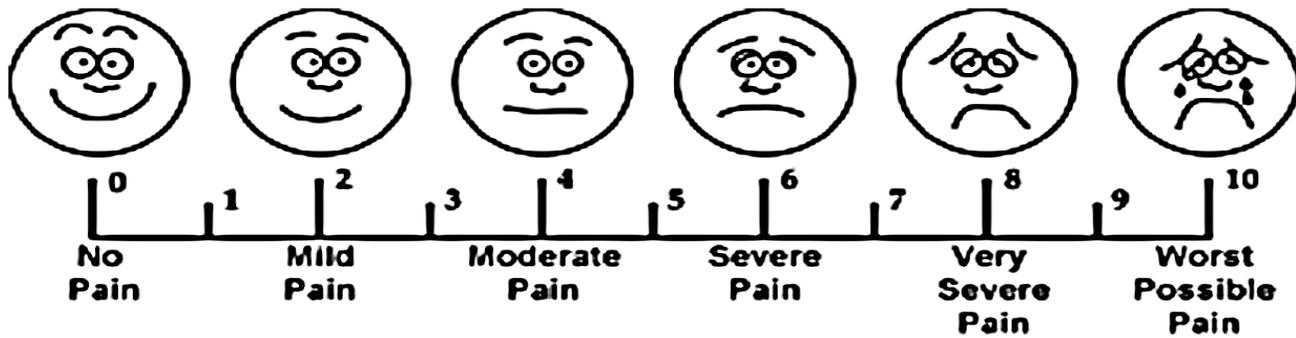
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Severity - How bad is it? Does it bother you a little bit or a lot?

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**Optional:** You may want to use a pain scale to describe how bad your pain is. Some people like these scales; others don't. If you are having pain, your provider may ask you to use a pain scale, so it may help to think about it in advance.



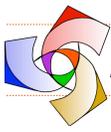
Duration – How long has it been going on? When did you first notice the symptom?

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Onset - What were you doing when the symptom first started?

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Frequency and Patterns – Does the symptom come and go or is it there all the time? Can you predict anything about it?

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Change from Baseline - What is normal for you? How is this problem different from how you usually feel?

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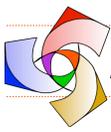
What Makes it Worse/Better - What makes the symptoms feel better?  
What makes them worse?

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Related Symptoms – Do you get other symptoms at the same time?

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Other People – Do other people around you, like family and friends, have the same symptoms?

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Effect On Lifestyle or Activities - How have the symptoms affected your life?  
Do they keep you from doing things that you normally do?

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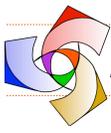
Treatments – What have you tried doing to treat your symptoms so far?  
Has it helped? What happened when you tried the treatment?

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Why now? If this problem has been going on for a long time, what made you come in to see your healthcare provider now? Has anything changed recently?

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Your thoughts – What do you think is causing the problem? Are you worried about something in particular?

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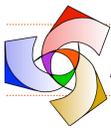
Other important details – Is there anything else that you think may help your provider understand what is going on?

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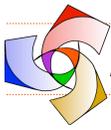
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## Things to Know Before You Go Worksheet

Your provider may ask you to do something after the appointment. This worksheet has a page for each of the main things your provider may ask you to do.

Your provider may only ask you to do one or a few of these things, or your provider will not ask you to do any of these things at all. Just use the parts of this worksheet that apply to your situation and ignore the rest. You do not need to fill out every line on every page.



## Getting Help After the Visit

Who do I contact if I have questions after I leave the office?

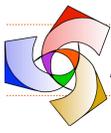
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How should I contact them?

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If you have a hard time using the healthcare system or advocating for yourself, tell your healthcare provider. Your healthcare provider or their staff might be able to help you. Examples of things they might be able to help you with are: arranging transportation, using the pharmacy, getting the accommodations you need in order to work with a specialist or have a lab test done, and filling out forms.



## Making A Follow-Up Appointment With Your Healthcare Provider

If you were told to make a follow-up appointment with your healthcare provider, make sure you know this information before you leave the office.

When should I follow up? \_\_\_\_\_

How do I make a follow-up appointment?

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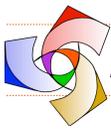
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Is there anything special I should do before the follow-up appointment or bring to the follow-up appointment?

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## Making An Appointment With Another Healthcare Provider or Specialist (Referral)

If you were referred to another provider, clinic, or department, make sure you know this information before you leave the office.

What is the name of the person, clinic, or department I'm supposed to see?

\_\_\_\_\_

Do I call them or do they call me? \_\_\_\_\_

Who do I contact to make the referral? If so, how?

\_\_\_\_\_

How quickly do I need to be seen by this other provider?

\_\_\_\_\_

When should I expect to hear back from this other provider?

\_\_\_\_\_

What should I do if I don't hear back from this other provider, or if they cannot see me in time? \_\_\_\_\_

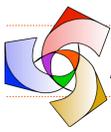
Why have I been referred to this other provider? \_\_\_\_\_

\_\_\_\_\_

Should I bring anything special with me when I see this other provider?

\_\_\_\_\_

**TIP:** Make sure the provider you have been referred to knows about any accommodation needs that you have.



## Getting A Lab, X-Ray, or Other Tests

If your healthcare provider has ordered labs, X-rays, or other tests, make sure you know this information before you leave the office.

What is the name of the test or procedure? \_\_\_\_\_

Where do I go to have the test or procedure done? \_\_\_\_\_

\_\_\_\_\_

Do I need to do the test or procedure at a special time or day? When?

\_\_\_\_\_

Do I just show up for the test or procedure, or do I have to schedule an appointment? \_\_\_\_\_

Who do I schedule the appointment with, and how do I do it?

\_\_\_\_\_

Are there special instructions? (Example: Fast for 12 hours before the test.)

\_\_\_\_\_

\_\_\_\_\_

What will the test or procedure be like? Example: will there be strange sounds or sensations? \_\_\_\_\_

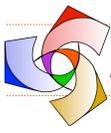
\_\_\_\_\_

How will I learn the results of the test? \_\_\_\_\_

\_\_\_\_\_

**Tip:** Make sure the people who will be doing the labs or tests know about any accommodation needs.

**Tip:** Ask your healthcare provider for help preparing for labs or tests.



## **Taking a Medication**

If the provider prescribed medication, make sure you know this information before you leave the office.

What is the name of the medication? \_\_\_\_\_

Has the prescription been sent in to the pharmacy, or do I need a paper copy of the prescription? \_\_\_\_\_

Where is the pharmacy? \_\_\_\_\_

How many pills or how much liquid do I take at a time? \_\_\_\_\_

How many times a day or week do I take it? \_\_\_\_\_

What time or times of day should I take it? \_\_\_\_\_

Do I take it before or after eating? \_\_\_\_\_

Do I take it just when I have a symptom or on a schedule? \_\_\_\_\_

When do I stop taking it? \_\_\_\_\_

How do I get refills, if I need them? \_\_\_\_\_

Are there interactions with sunlight, medication, or foods?

\_\_\_\_\_

What side effects should I look out for? \_\_\_\_\_

\_\_\_\_\_

What do I do if there are side effects? \_\_\_\_\_

Should I avoid any particular activities? \_\_\_\_\_

Do I need to store the medication in a special way? \_\_\_\_\_

