AASPIRE **Healthcare Toolkit**

Patients and Supporters

Healthcare
Step-by-step navigation of the primary healthcare system, including finding a provider, making an appointment, preparing for a visit, having a visit, and following up on care.

Staying Healthy
Information about nutrition, exercise, recreation, and preventive care.

Your Rights in Healthcare
Information and resources about disclosing an autism diagnosis, getting equal access to healthcare, understanding privacy and decision-making authority in healthcare.

Autism Information
Mostly for adults new to an autism diagnosis, information about autism spectrum disorder, adult diagnosis, therapy and assistive technology, disability rights laws, and Autistic culture and meeting others on the spectrum.

Computer & Internet Access
Resources for accessing computers or the Internet for no or low cost, in order to use this toolkit online.

Medical Information
Links to credible medical information, as well as checklists, worksheets, tips, and other resources from other places online.

Forms & Worksheets
Downloadable checklists and worksheets for making a appointment, preparing for a visit, communicating about symptoms, and following up after an appointment.

www.autismandhealth.org

AASPIRE Healthcare Toolkit

Healthcare

Step-by-step navigation of the primary healthcare system, including finding a provider, making an appointment, preparing for a visit, having a visit, and following up on care.

Contents

- Finding Providers
- Making Appointments
- Preparing for a Visit
- During the Visit
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AASPIRE **Healthcare Toolkit**

Healthcare: Finding Providers

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Healthcare: Finding Providers

www.aaspire.org
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1 What is this topic about?

This section is about how to find a healthcare provider, like a doctor, nurse practitioner, or physician's assistant. If you don't already have a healthcare provider, or if you want to change healthcare providers, this section gives some ideas about how to find a new one. It may not be possible to follow these suggestions in a step-by-step fashion. You may need to go through the steps more than once, or in a different order, before you find a healthcare provider you like. Not all steps or suggestions in this section may apply to you.

2 How do I find names of healthcare providers?

2.1 Option 1: Get referrals from people or organizations you know and trust.

For example, you could ask:

- **Friends, family, or co-workers** - Ask people you trust if they have a doctor they like. Someone you know might be able to give you first-hand information about what a healthcare provider and his or her office and staff are like.

- **Other professionals** - If you go to other healthcare professionals, or if you use a disability service or social service agency, ask them for recommendations.
- **Autism Groups or Communities** - If you are involved with a local autism group or community, either online or offline, you can ask there. These communities might be able suggest providers with experience working with people on the spectrum.
- **Hospitals** - Hospitals may have local physician referral services. Contact your local hospital and ask if it has a physician referral line or someone at its facility who can give physician referrals. Different hospitals may have different words for the people who offer this service. Often they are called referral specialists or health advocates. Ask if the hospital has a physician referral service that you can contact.

> You can ask,*"I'm looking for a healthcare provider. Do you have a physician referral service, health advocate, or someone who can help me find a provider?"*

2.2 Option 2: If you have health insurance, get lists of providers covered by your plan.

Health insurance companies have lists of healthcare providers for you to choose from. These lists can usually be found on a web site, by calling the company on the telephone, or in a booklet sent to you by the company. People with public insurance can contact their state's primary care office to help find possible providers.

> To get a list, you can ask, *"I'm looking for a healthcare provider. Do you have a list of providers I can choose from?"*

2.3 Option 3: What to do if you don't have health insurance.

You don't have to have health insurance to see a doctor. It may require some research to find what options are available in your area. Try asking about or searching for ”free clinics,” ”low-cost clinics,” ”safety net clinics,” ”providers that accept self-pay patients,” and ”clinics that use a sliding scale.” Some ways to search for these options are:

- Information and referral services such as 211.
- Search the Internet.
- Ask at your local hospital.
- If you go to other healthcare professionals, or if you use any disability or social service agencies, ask them for recommendations.
- Contact your state's primary care office to help find possible providers.

> You can ask, *”Do you have any information about free, low-cost, safety net, self-pay, or sliding scale clinics?”*

2.4 Option 4: Online Internet searches

- **Regular Internet searching (e.g., Google)** - Search for 'family practice' or 'general internal medicine' (or whatever specialty you are looking for) and any other keywords that will help you narrow the search. For example, you may want to include the city or county where you live, or the name of a clinic that is convenient to you.
- **Licensing Boards and Professional Organizations** - If your state has a medical licensing board (most do) they may also offer provider lists or searches on the Internet or telephone. Doctors often belong to professional organizations that may offer information and doctor referrals on

their websites. The American Medical Association has a list of both national and state medical licensing organizations.

- **Medline Plus** has an extensive directory to help in locating health professionals, services and facilities.
- **Web Mapping Services** - Many of the popular search engines like Yahoo, Google or Bing offer mapping services. You can use these to locate providers in your area.

2.5 Option 5: Off-line searches

Searches for clinics or providers can be done offline through

- Yellow Pages listings or other directory listings.
- Contacting licensing boards, the American Medical Association, or other professional organizations on the telephone or in person.
- Traveling around your neighborhood and looking for clinics.

If you find a clinic or provider convenient to you, contact them or stop by their front desk and ask if they are accepting new patients at their practice.

> If you're interested in a particular clinic, you can ask, *"I'm interested in becoming a patient at your clinic. Are any healthcare providers at your clinic accepting new patients?"*

> If you're interested in a particular provider, you can ask,*"I'm interested in establishing care with (provider's name). Is (provider's name) accepting new patients?"*

3 How do I know if I can go to a healthcare provider or clinic?

The answers to these questions could change whether you are able to see a particular healthcare provider or not, so it's best to find out the answers before you schedule an appointment. If you find you can't go to a particular provider or clinic, you may have to find another provider or clinic to try.

3.1 If you have insurance, find out:

- Does the healthcare provider or clinic accept your insurance?

  Ask, *"Do you take (insurance company name)?"*

- If yes, is the healthcare provider in-network or out-of-network? An in-network provider is someone who has agreed to see on that company's insurance plan at a reduced cost. The amount you have to pay to see an in-network provider is usually less than the amount you have to pay if you see an out-of-network provider. The insurance company may pay less or not pay anything for services you receive from an out-of-network provider.

  Ask, *"Is (provider's name) in-network?"*

- If out-of-network, find out what your insurance will pay or not pay. Can you afford that? Is it worth it to still see this provider instead of a provider in your network? You will likely have to get this information from your insurance company, not the provider's office.

  Ask, *"How much will be covered if I see an out-of-network provider?"*

- Not all insurance plans cover all treatments. If you need a certain kind of care or treatment, try to find out if your insurance will cover that.

3.2 If you don't have insurance, find out:

- Does the healthcare provider or clinic see patients who don't have insurance (self-pay)?

  Ask, *"Do you see uninsured, self-pay patients?"*

- Is there a sliding scale or other low-cost option?

  Ask, *"Do you have a sliding scale or other low-cost option for self-pay patients?"*

- Can you afford to pay what the provider or clinic is asking?

  Ask, *"How much would it cost for me to see (provider's name)?"*

3.3 Important questions for everyone are:

- Is the healthcare provider taking new patients?

  Ask, *"Is (provider's name) taking new patients?*

- Do you have transportation to get to this healthcare provider or clinic?

  This may be something you just find out on your own, or you could also ask the provider or clinic, *"What is the best way to get to your office (in a car, on a bus, walking from a location, etc.–whatever fits your situation)?"* or *"Can you help me arrange transportation to your office?"*

- Does the healthcare provider or clinic have office hours that work with your schedule?

  This may be something you just find out on your own or you can ask, *"What are your office hours?"* or *"Does (provider's name) have office hours during (time that works with your schedule)?"*

- How long will it be before you can get a new patient appointment? If the appointment will be too far out to meet your needs, you might want to consider looking for a healthcare provider who can see you sooner.

> Ask, *”Will (provider’s name) be able to see me before (date you need to see them by)?”* or *”How long would it take to get an appointment with (provider’s name)?”*

4 How do I know if a healthcare provider is a good choice?

4.1 Do research or ask questions in advance.

You can learn some things about a provider or clinic before your appointment by:

- Looking up the provider or clinic on the Internet.
- Asking people you know for their opinions about the provider or clinic.
- Contacting the office staff and ask them questions.

Some questions you might want answered are listed in the next section Questions to Consider. You might not be able to answer all these questions before your appointment.

4.2 Questions to Consider

These questions can be good to consider when making a decision about whether to see or continue seeing a healthcare provider. Some questions may not be important to you. That’s OK; you can just ignore them. You may not be able to answer many of these questions until you have had one or more visits with the provider.

- Do the healthcare provider and office staff have the right credentials and training?
- Do they have an accessible way for you to communicate with them (example: secure messaging system, alternatives to telephone)?
- Do they have knowledge of autism or experience with people on the autism spectrum?
- Do they have knowledge or experience with your medical problems (if your medical problems are uncommon)?
- Do they have attitudes you agree with about autism or disability?
- Do they have communication skills and style that work well with yours?
- Are they willing and able to make the accommodations you need?
- Do they respect your right to self-determination?
- Are they interested in including you in your care?
- Do you like their approach to medicine?
- Do they have the resources in their office or clinic that you need or want? Examples: care manager, social worker, ”medical home”, secure messaging, on-site lab/pharmacy.

Tip: Doctors in the United States are licensed in the state where they practice. Check your your state’s website to find out what office deals with medical licenses. Many have a place where you can search for a doctor’s license by name. They should also be able to tell you if any complaints have been filed against that doctor. If you don’t have access to the Internet, try your state’s Information and Referral Line (such as 211) or look in the state section of your phone book for an office that handles medical licenses.

4.3 Think about how things are going after the first few visits.

After you've seen the provider one, two, or three times, ask yourself the ”Questions to Consider” again. Sometimes it takes a while to learn if a provider will meet your needs.

5 What if a provider turns out to be a bad fit for me?

If this isn't a good fit, it's OK to switch to another provider. (But, sometimes relationships take time and no relationship is perfect.)

6 Should I disclose my ASD diagnosis to my healthcare provider?

Whether to tell your provider about your ASD diagnosis is your choice. In most cases, the benefits of disclosing a diagnosis far outweigh the risks, but you need to weigh the risks and benefits for yourself to know what is right for you. In general, telling your provider may help them better understand you and make working with you easier (but some providers may also need some education). For more information on the possible benefits and risks of disclosure, see the section in Your Rights in Healthcare on Disclosure.

7 Summary

Finding A Provider - Healthcare providers can be found by:

- Asking people or organizations you know and trust (for example, friends and family, other professionals, autism groups, or hospitals).

- Through listings provided by your health insurance provider (if you have insurance).
- Searching for safety-net or self-pay clinics (if you do not have insurance).
- Searching on the Internet, including using links provided by licensing boards and professional medical organizations.
- Searching off-line, including through Yellow Pages, contacting professional organizations off-line, or looking physically for a convenient provider or clinic in your neighborhood.

Knowing If You Can See a Provider - Make sure:

- The provider takes your insurance (if you have insurance) and that you can pay for the in-network or out-of-network service.
- The provider takes self-pay patients (if you don't have insurance) and that you can pay for the service.
- The provider is taking new patients.
- That you can get to the provider when you need to.

Knowing If the Provider Is a Good Choice - Some ways to figure out if a provider is a good fit for you are:

- Find out information about the provider by looking them up on the Internet, asking people you trust for their opinions, and contacting the provider's office.
- Schedule a ”getting to know you” visit with the new provider.
- See the provider a few more times, and think about how the visits went.
- Use the list of ”Questions to Consider” as a guide to some things that might be important to think about in figuring out if a healthcare provider is a good match for you.

What to Do If the Provider Was a Bad Choice - If after a few visits you don't feel comfortable with a particular healthcare provider, it's absolutely OK to see a different provider.

Disclosure - It's your choice if you want to tell your new healthcare provider about autism. Telling your provider may help them better understand you and make working with you easier (but some providers may also need some education about autism).

8 Links and Resources

- Your Healthcare Information Guide - This site contains a whole host of resources, guides and links to a variety of healthcare topics written in plain language. It was created by a husband and wife team who are currently working in healthcare fields.
- Get Affordable Healthcare - Health Resources and Services Administration (HRSA) is the primary Federal agency for improving access to health care services for people who are uninsured, isolated or medically vulnerable. Their website has a list of resources for the uninsured as well as a search engine that can be used to search for community or safety-net clinics by geographic area.
- 211 - State Information and Referral system for help with food, housing, employment, health care, counseling and more.

AASPIRE **Healthcare Toolkit**

Healthcare: Making Appointments

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- What might I want to know before I schedule an appointment?
- What might I want to know after I schedule an appointment?
- I can't use the telephone or have trouble with scheduling, what should I do?
- What might I say making an appointment?
- Summary

Healthcare: Making Appointments

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1 What is this topic about?

This topic is about how to make an appointment with a healthcare provider. Different providers may have slightly different ways to make appointments. This section gives some basic information about appointments that should be similar for most providers.

2 What might I want to know before I schedule an appointment?

Before you or your supporter contacts the office, you might want to have the following information ready.

1. The contact information for the provider's office (telephone number, address, etc.)
2. The reason why you are making the appointment (for example, new patient visit, sore throat, annual exam, etc.).
3. Your (or your supporter's) contact information in case the office needs to call you back.
4. What days and times you are free.

5. Who to call for a reminder, and that person's phone number.
6. If you have health insurance, who your insurance provider is.
7. Any other questions that you may have about the appointment.

You might not need to know all of these things, depending on the particulars of the appointment.

The Making an Appointment Worksheet has places to organize all of this information.

3 What might I want to know after I schedule an appointment?

By the end of making the appointment, you may have learned some of the following things.

- The date and time of your appointment.
- Where your appointment is located.
- The name of the healthcare provider you will be seeing.
- Anything special you need to bring to the appointment, or do before the appointment (for example, not eat any food eight hours before).
- The answers to any other questions you had about the appointment.

You might not need to know all of these things, depending on the particulars of the appointment. The Making an Appointment Worksheet has places to organize all of this information

4 I can't use the telephone or have trouble with scheduling, what should I do?

Unfortunately, many providers or their offices do not feel comfortable using non-secured text-based ways to make appointments, such as email or text. Here are some ideas if you have difficulty with the telephone:

- Find out if your healthcare provider has an electronic messaging system (for example, MyChart) and use that system for scheduling.
- Ask someone you trust to make the appointment for you.
- Go to the office in person and make the appointment face-to-face.
- Use an online relay or caption service such as AT&T Relay Service, which will allow you to type and/or read.
- Have someone contact the office, or go to the office in person, and make special arrangements.

If you have a hard time with scheduling things, here are some ideas that may help:

- Ask the healthcare provider's staff or front desk people to help you with scheduling.
- Ask someone you trust to help you with scheduling.
- Use calendar software on your computer or mobile device to keep track of appointments.
- Use the Making an Appointment Worksheet which organizes all of the steps for scheduling and gives a sample script you can use.

5 What might I say when making an appointment?

What you say when making the appointment will be a little different depending on the type of appointment you need. Here is a script for how to start the conversation in a few different situations. Each fill-in-the-blank script is followed by an example. When making the appointment, you would put your own information in the blanks, not read the example.

- Establish Care or New Patient visit

  ”Hi, my name is (your name) and I would like to make a new patient appointment with Doctor (the provider’s last name) to establish care.”

  Example: Hello, my name is Jane Smith and I would like to make a new patient appointment with Doctor Connors to establish care.

- Follow-up visit

  ”Hi, my name is (your name) and Doctor (your provider’s last name) wanted me to schedule a follow-up visit (time frame).”

  Example: Hi, my name is Edward Smith and Doctor Jones wanted me to schedule a follow-up visit within the next four weeks.

- Other types of visits

  ”Hi, my name is (your name) and I am a patient of Doctor (your provider’s last name). I am calling to schedule an appointment with my doctor because (describe the reason for the visit).”

  Example: Hi, my name is Jane Smith and I am a patient of Doctor Connors. I am calling to schedule an appointment with my doctor because I went hiking last week and I came back with a rash and it’s not getting better.

The conversation will be a little different each time after this point. The person you are talking to might ask you some questions, or you might want to give information right away like saying when you are available. A script for other things to say is included with the Making an Appointment Worksheet.

6 Summary

Before you make an appointment you may want to know:

- Your provider's contact information,
- The reason for the visit,
- Your contact information and the telephone number for the reminder call,
- When you are free to see the doctor,
- Your health insurance information.

After you make the appointment, you may want to know

- Date, time, and location of the appointment,
- Name of the healthcare provider you'll be seeing,
- Anything special you need to bring to or do for the appointment.

If you have trouble with the telephone some alternatives might be

- Use electronic messaging, if available,
- Have someone help you,
- Make the appointment in person,
- Use a relay service.

To start making an appointment, say *"Hello, my name is (your name) and I'm calling to make a (type of appointment) appointment with (provider's name). The reason I am making the appointment is (reason)."* A more detailed script can be found in the Making an Appointment Worksheet.

AASPIRE **Healthcare Toolkit**

Healthcare: Preparing for a Visit

Contents

- What is this topic about?
- What might I do to prepare for my visit?
- What might my provider want to know about my symptoms?
- What will my provider need to know about my medications?
- What might I need to know about paperwork?
- What might I bring to a visit with my healthcare provider?
- What extra things might I need to bring if it's my first visit, or I haven't seen my provider in a long time?
- How might I prepare for the office and the waiting room?
- I have a hard time with the waiting room, what might I do?
- I have trouble with transportation to the office, what might I do?
- Summary and Tips

Healthcare: Preparing for a Visit

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1 What is this topic about?

This topic is about things you might do to get ready for a visit with your healthcare provider. It includes tips and checklists for knowing what to bring to a visit, how to handle the office and waiting, and how to prepare for interacting with your provider. You do not need to do all of these things to have a healthcare visit.

2 What might I do to prepare for my visit?

2.1 Take Care of Paperwork Before the Visit

You might be asked to fill out an intake form before the visit. Many clinics and offices are willing to mail intake forms before the visit. You can ask about this when you make the appointment, or any time up to a week before the visit. If this will be your first visit to a new healthcare provider, or if you haven't seen your healthcare provider in two or more years, there might be more paperwork to prepare. See the section on ”What do I need to know about paperwork?” for more information.

2.2 Make a List of Topics to Cover

It's not always possible to cover all the things you want to in one visit with your provider. To cover everything, especially if you haven't been to a healthcare provider in a long time, more than one appointment might be needed. Here are some tips for how to make sure the most important things get covered.

1. Make a list of all of the things you would like to cover with your healthcare provider. It's OK if you put more things on the list than you can cover in one visit.
2. After the list is finished, take a look at it and decide which of the things on it are the most important. Here are some questions you can ask yourself that might help in figuring out which things on the list are the most important:
   - ”If we are only able to go over two of the things on this list, which two do I want them to be?”
   - ”Which of the things on this list are giving me the most discomfort?”
   - ”Which of the things on this list am I most worried about?”

   If you aren't sure which things are the most important to cover in the visit, you might find it helpful to talk it over with someone you trust.
3. When you see your healthcare provider, show them the whole list at the start of the appointment and tell them that you don't expect to do everything in one visit. Let them know which of the things on the list are the most important to you. Be prepared to talk about the list a little with your provider and decide together on an ”agenda” for the visit. Also be prepared that your provider may have a different suggestion for what's most important on the list to cover during that visit.

2.3 Prepare for Tests or Procedures

- You may have been asked to prepare ahead of time for a certain test or procedure. Your healthcare provider may ask you to not eat anything for a certain amount of time before the visit (called fasting), take–or not take–certain medications, or follow some other special instructions. Check with your healthcare provider 48 hours before the visit to make sure you are prepared.

- If you are very worried about a test or procedure, contact the office staff and ask if it is possible to come see any equipment first, or to do a ”trial run” of the procedure before doing it for real. This may not always be possible but has been helpful for some. An alternative is to ask for a detailed description of the test or procedure.

2.4 Practice with Role-Playing

Some people may find it helpful to role-play the visit with a supporter or friend to help prepare for a visit. Let your partner know what your health concern is, then have them pretend to be the doctor. Practice explaining your issue to them. Have them ask you questions in response. Here's a short example:

> *Doctor: Hi. So the nurse says you are having problems with your ear?*
> *Patient: Yes.*
> *Doctor: Oh. I'm sorry to hear that. Which ear is it?*
> *Patient: The right one.*
> *Doctor: Just the right one?*
> *Patient: Yes.*
> *Doctor: Does it hurt?*
> *Patient: Yes.*
> *Doctor: How much?*
> *Patient: I'm not sure how to describe it. A lot?*
> *Doctor: That's OK. How often do you notice it?*
> *Patient: All the time.*
> *Doctor: Do you have trouble hearing out of that ear?*
> *Patient: Yes. I also can't sleep on that ear because it hurts.*

Practice until you feel comfortable that you can describe the problem clearly. It's OK to stop and talk about anything you don't understand or get suggestions or clarifications from your partner. There is information about what healthcare providers usually want to know about symptoms in the section ”What might my provider want to know about my symptoms?”

3 What might my provider want to know about my symptoms?

Your provider will likely want a full description of your symptoms to understand what is causing them and how to treat them. When providers ask about symptoms, there is specific information they usually want to know. That information is listed here. Thinking about this information in advance may help you prepare for a discussion with your provider.

If you have more than one symptom, you may need to think about these things for each symptom, or you can group them together if you think they are part of the same problem (for example, a cough, runny nose, and sneezing that all started at the same time). Do whatever works best for you. Not all items apply to all symptoms. You do NOT have to have answers to each item. If you don't have answers, something doesn't apply, or you don't know the answer, that is OK.

What is the Symptom (or set of symptoms)? Examples of symptoms–conditions that you can see or feel–are: pain in a part of your body, tingling, itching, burning, shortness of breath, a cough, diarrhea, fevers, chills, a rash, trouble sleeping, and feeling sad or anxious.

Example: belly pain

Location - Your provider may want to know what part of your body is affected. For example, where does it hurt? Is it your arm? Your abdomen (or belly)? If so, what part of your abdomen? Or where is the rash? Where is the tingling or itching?

Example: right side of belly below ribs

Severity - How bad is it? How much does it hurt? Does this bother you a little bit or a lot? Often the nurse or doctor will ask you to give a number value to the pain. Usually they use a scale of 1 to 10 where 1 is very little pain, 10 is the most pain you can imagine, and 5 is a pain that is midway between least and most pain you can imagine.

Example: it hurts really bad when it's happening, but doesn't hurt at all when it's not happening

Quality - If the symptom is pain, what is the pain like? Is it sharp, dull, stabbing, cramping, burning, throbbing? How would you describe it?

Example: crampy

Duration - How long has it been going on? When did you first notice the symptom? In some cases, you may be able to pinpoint an exact date or time. In other cases, it is OK to give a general idea - for example has it been going on for hours, days, weeks, months, or years? About how many? Sometimes it helps to think about other events in your life. Example: ”My birthday is in July. I remember it started around the time of my birthday.”

Example: started about three months ago

Onset - What were you doing when it first started? For example, did it start while you were exercising or at rest? Did you fall or hurt yourself? Were you in an accident? Did you just wake up with the problem?

Example: it just started happening; I wasn't doing anything special

Frequency or Patterns - Does the symptom come and go or is it there all the time? About how often does it happen? Have you noticed any patterns?

Does it happen at a certain time of day, week, month, or year? What brings it on? Have you figured out any ways that you can predict when it will happen or how bad it will be? About how long does it last each time?

> *Example: It happens right after I eat on most days. It lasts 30 to 60 minutes when it happens.*

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

> *Example: I've had heartburn for years, but this feels different from heartburn. It's in a different place and is more crampy feeling.*

What Makes it Better / Worse - What kinds of things make it feel better? What makes it worse? For example, does it get better or worse when you are lying down? Does it change depending on what you eat? Do certain positions or activities make it better or worse?

> *Example: eating fatty foods makes it worse, eating slowly seems to help*

Related Symptoms - Do you get other symptoms at the same time? For example, when some people get chest pain, they also feel short of breath or dizzy or sweaty. Or when some people get a headache, they also feel nauseated and have blurred vision.

> *Example: nausea, but only sometimes*

Other People - Do other people around you have the same symptoms? For example, do other people you work with or live with have similar symptoms? Is this something that runs in your family? Do other people who interact with you have a similar condition?

Example: I don't know anybody else with similar symptoms.

Effect on Lifestyle or Activities - How has it affected your life? Does the symptom keep you from doing things that you normally do? Does it make it hard to exercise, work, go out, sleep, eat, or read?

Example: It makes it hard for me to eat or for me to leave the house.

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

Example: I've tried Tums and Zantac, but they didn't help at all.

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? Have you noticed that you have had a change in your weight?

Example: It's been getting worse and worse. It used to be just sometimes, but now it's after almost every meal.

Your Thoughts - What do you think is causing the problem? What do you think is going on? Are you worried about something in particular, like that it might be due to a cancer or heart disease?

Example: I'm worried about stomach cancer.

On the Symptom Worksheet these items are listed with blanks that you can fill in to help prepare information about your symptoms.

4 What will my provider need to know about my medications?

Healthcare providers need to know about any medication you are taking, including over the counter medications like aspirin, vitamin, or nutritional supplements. Below is a list of the information providers usually want to know. It's OK if you don't know the information on this list. You can just put your medicine bottles, tubes of ointment, or other medication containers in a bag and bring them with you when you see your healthcare provider. If your healthcare provider wants to know any information about the medications, he or she can then look at the container.

Medication name - The brand or generic name of the medication.

Strength - Some medications have different strengths. The strength is usually listed in a unit of measurement like grams or milligrams. For example, the strength might be 2 grams or 100 milligrams. If your medicine bottle lists two strengths, tell your provider both strengths.

Dose - The dosage of the medication you take. For example, two pills, half a cup, or one tablet. If your medicine bottle lists two dosages, tell your provider both dosages.

Times Per Day or Per Week - How often do you take this medication, and when? For example, someone might take one pill in the morning and one pill after dinner.

How much medication you have left - Do you have a lot of the medication left or are you completely out of that medication?

5 What might I need to know about paperwork?

If you are making a new patient visit, or if you have not seen your healthcare provider in two or more years, you might need to prepare some paperwork. It's best to prepare this paperwork as far before the appointment as possible.

5.1 Patient Intake Forms

Patient intake forms are where you fill out your basic personal and medical information before a visit. Most providers require that all their patients fill these out. Your answers on the forms will help providers know the most important things about your health quickly without having to read through all of your medical records. Ask the office staff to mail you a copy of the forms before your visit. You also have the option to fill out the forms in person before the visit, though this could be stressful. These forms are not usually very accessible. You may want to ask someone to help you with the forms. It is also OK not to fill out everything on the forms. You can leave parts blank if you don't understand them, or aren't sure if they apply to you. Your healthcare provider will ask you for more details during the appointment if he or she wants them. To fill out the forms, answer the questions or fill in the blanks. It is OK to use another piece of paper if you need to. The most important parts of the form are:

- Any major procedures you have had (for example, surgeries)
- Any major illnesses you have had (for example, cancer, or something you had to go into the hospital for)
- Any chronic conditions you currently have (for example, diabetes, allergies, any conditions you're taking medication for)
- Any medications you are currently taking

If you already have a summary of your past health issues that you or someone else has made for you, you may be able to use that to help with the forms. Some people need to ask others to help with their past history information. For example, parents may help you remember important health events from when you were much younger.

5.2 Medical Records

Your medical records are all of the paperwork and electronic records from all of the providers you have seen in your life, including for hospitalizations or emergency department visits. If you are seeing a new healthcare provider for the first time, he or she will want copies of your medical records to learn in depth about your healthcare history and needs. Most healthcare providers have a form they use to automatically transfer medical records from one provider to another. Because your medical records are private, you typically need to give your written permission before the records can be transferred. Ask your new provider's staff ahead of time if they have a form you can send to your previous provider so your records can be transferred. Note: Records transfers can take up to 30, days so it's best to ask for your records to be transferred well before your first visit. If your records can't be transferred in time for your visit, bring the name, address and phone number of any healthcare providers you have seen in the past.

5.3 Medical Information Release Forms

Your health information is private. It typically can not be shared with people who are not healthcare providers without your permission. Medical information release forms let you give your permission for people who aren't healthcare providers to know about your medical information. If there are people in your life who will be closely involved in your healthcare (examples: husband or wife, parent, support staff), you'll need to fill out a medical release form. This form lets the clinic or healthcare provider share information about your medical care with that person. You only need to fill out these forms if you want someone other than your healthcare providers to know your medical information. If you want your healthcare provider to be able to share your medical information with another person, ask your provider's office for the forms to share your healthcare information with others. Most medical information release forms are pretty straightforward to fill out. They ask you to give the name of the person you wish to have information shared with, check off what kinds of information the person can know, and then you need to sign them.

5.4 Autism Healthcare Accommodations Letter

This is a letter addressed to your healthcare provider which lists your customized accommodations information. Sometimes healthcare providers don't understand how to work with people on the autism spectrum. If you have any needs that have to be accommodated in order for you to get good healthcare, the letter may help providers to accommodate you. You can create your own customized Autism Healthcare Accommodations Letter on our web site using the Autism Healthcare Accommodations Report. The online tool for creating the letter works like a normal survey. After you fill out the survey, the tool will create the letter for your healthcare provider based on how you answered the survey.

6 What might I bring to a visit with my healthcare provider?

Listed here are some things that can be helpful to bring with you to any visit with a healthcare provider. Not all things on the list might be useful to you. You can ignore the things that don't apply to your situation.

- Your health insurance card, if you have one. The provider's staff might ask you for your insurance card.
- Something fun to do in case you have to wait (examples: book, puzzle, fidgets, music player).
- Sensory items (examples: sunglasses, chewing gum, head phones).
- A list of questions or things you want to cover with your healthcare provider. More information about this is in "What might I do to prepare for my visit?"

- A completed symptom worksheet or information about your symptoms, if applicable. More information about this is in ”What might my provider want to know about my symptoms?”
- Any logs or diaries you keep about your health problems (examples: blood sugar measurements if you have diabetes, blood pressure measurements if you have high blood pressure, symptom trackers if you use them).
- Containers (bottles, tubes, etc.) of all your current medications, or a list of all your current medications. If you bring a list, see ”What will my provider need to know about my medications?” for what information they will need to know.
- Any instructions or paperwork you have been given by other healthcare providers since your last visit. For example, if you have been to the emergency room, have been hospitalized, or have seen any other healthcare providers since your last visit, you might have paperwork from those visits.
- Name, address, and any directions needed to get to the office.
- Anything your healthcare provider has specifically asked you to bring (if they have asked you to bring anything).

If this is your first visit with the healthcare provider, 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:

- A copy of your Autism Healthcare Accommodations letter for your healthcare provider (if you made one, see Autism Healthcare Accommodations Report)

There are some more things you might want to bring with you if this is your first visit or if you haven’t been to see your healthcare provider for two or more years. They are listed in the next section ”What extra things might I need to bring if it’s my first visit, or I haven’t seen my provider in a long time?” Here is a checklist you can use to organize what you might want to bring.

7 What extra things might I need to bring if it's my first visit, or I haven't seen my provider in a long time?

If it's your first visit with a new provider, or if you have not seen your provider in a long time (for example, the last time you saw your provider was two or more years ago), you should try to bring everything listed in ”What might I bring to a visit with my provider?”, plus some extra things. The extra things are listed below. The paperwork parts are described in more detail in the section ”What might I need to know about paperwork?”

- A short summary of your medical history (if you have one)
- Your old medical records, if you have them (This is described in more detail in the section ”What might I need to know about paperwork?”.)
- The names and addresses or fax numbers of your past healthcare providers, or of 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. If there aren't any other people involved in your healthcare, or you don't have some of these kinds of people, that's OK. You only need to bring their information if you have them.
- Your intake form, if you filled one out at home.

Here is a checklist you can use to organize what you might want to bring.

8 How might I prepare for the office and the waiting room?

Here are some things that may be helpful in preparing for the office and the waiting room.

- Have someone take pictures of the office and staff before your appointment. Many offices now have web sites so you may be able to find pictures of the staff there.
- Use Google Street View from Google Maps to view the outside of the facilities and see your route to them.
- Think about how you are getting to and from the office. Are you taking public transportation? Is someone picking you up? Is it a mix of both? You may want to print out directions for how to get to the office. You can also ask the office staff to provide you with a map or directions of how to get to their office. Make sure you have the proper fare, if it's required.
- Make sure you have any maps or directions you need. If the provider's office is in a large hospital or is confusing to navigate, you might want to ask for a map or directions. If maps and directions don't help, ask if someone at the office can meet you and show you where to go.
- Bring something to keep you occupied while you wait. Most providers who see adult patients don't keep games or toys in the office so make sure to bring whatever it is you like to do while you wait.
- Bring anything to help with sensory issues such as light (for example, sunglasses), sound (for example, headphones), or temperature (for example, a blanket or warm clothes). Remember it's OK to self-advocate, or have a supporter advocate for you if you need an accommodation. For example, ask the office staff to adjust the light, music, or temperature.

What else? The list above can get you started, but everyone is different. Think about anything else that might help you make it to the office and to feel more comfortable after you get there.

9 I have a hard time with the waiting room, what might I do?

Here are some things your provider's office and staff can do that might be helpful. Please speak to (or have someone you trust speak to) the office staff to see if they can implement these if you think they will be helpful.

- Request to wait in the exam room or other private area.
- Request to wait in the car or other place outside the office building until it's time to go into the exam room. Make sure the office staff knows how to contact you when it's time for you to go in.
- Request that the office staff turn off the TV, radio, or other things that make noise in the waiting room.
- Request that the lights in the waiting area be dimmed or allow for natural light.
- Ask how long the wait is likely to be, or if there are unexpected delays.
- If you are unlikely to notice when your name is called for your appointment, make sure the office staff knows to come over to you or get your attention in another way.
- Have the office staff show you where the exam room is.

10 I have trouble with transportation to the office, what might I do?

Your healthcare provider's office may be able to help you find local resources for transportation to your appointment. These resources might be special arrangements through your local transportation system (sometimes called paratransit), a volunteer driver program, or some other low-cost or free transportation service. Not all providers' offices have information about transportation. Here is some information about transportation that may be helpful.

- Disability.gov - The U.S. Government has a searchable list of transportation resources both nationally and by state.
- Community Transportation Association - This national advocacy organization focuses on transportation for individuals who do not have access to mass transit or private vehicles. It has a section on medical transportation as well as a section on transportation for people with disabilities
- Project Action - This is a national program for improving transportation for people with disabilities. It is administered by the National Easter Seal Society and funded by the Federal Transit Administration.

11 Summary and Tips

Some things you might want to do to prepare for a healthcare visit are:

- Take care of paperwork (intake forms, medical records transfer, medical release forms, accommodations letter)
- Make a list of topics to cover at the visit
- Prepare for any tests or procedures
- Practice for the visit with role-playing
- Work out what you want to say about your symptoms
- Put together information about your medications
- Make sure you have transportation and directions to the office
- Pack the things you might want for the waiting room and the visit

You may want to prepare information about your symptoms before the appointment. The things healthcare providers usually want to know about symptoms are:

- What is the symptom?
- Where is it happening?
- How bad is it?
- What does it feel like?
- When did you first notice it happening?
- What were you doing when you first noticed it?
- Are there any patterns to it?
- How is it different from what is normal for you?
- What makes it better or worse?
- Do you get any other symptoms at the same time?
- Do other people around you have similar symptoms?
- Has the symptom affected what you do?
- Have you tried to treat the symptom?
- What do you think might be causing the problem?

Some tips for coping with the waiting room are:

- Get familiar with the waiting room in advance, or have someone take pictures
- Ask to wait in a private room or somewhere else
- Ask office staff to turn off things that make noise or to change the lights in the waiting area
- Ask how long the wait is likely to be or to be told if there is an unexpected delay
- Make sure office staff knows how to get your attention

- Ask office staff to take you to the exam room when it is your turn

If you have trouble with transportation, ask the clinic or office if they have any transportation resources, or can help. You can also find transportation resources online, for example, at Disability.gov. Checklists and worksheets:

- Symptoms Worksheet
- What to Bring to a Visit checklist

AASPIRE **Healthcare Toolkit**

Healthcare: During the Visit

Contents

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- What is likely to happen during the visit?
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Healthcare: During the Visit

www.aaspire.org
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1 What is this topic about?

This topic is about things that might happen during a visit to a healthcare provider. It is also about ways to make the visit go more smoothly.

Although different things will happen at each visit, many visits follow similar steps. The steps are outlined in the section ”What is likely to happen during the visit?”. Each of the steps is then described in more detail in its own section.

This topic is about regular primary care visits. It is not about visits with specialists, emergency room visits, or other types of healthcare visits that will likely have different steps to them.

2 What is likely to happen during the visit?

Below is a flow of the steps that often happen during a visit. These steps are not always the same. They may be different for each provider or they may change based on the reason why you are having the primary care visit. However, this is the flow of events that happens at most primary care visits.

1. Check in with the receptionist or front office desk when you arrive. The receptionist may ask you to sign in or wait to be checked in.
2. Wait to be called for your turn to see your healthcare provider.
3. Have the nurse or assistant take your vital signs and guide you to an examination room.
4. Wait for the healthcare provider to come into the examination room.
5. Have a conversation with your healthcare provider about your health and your concerns. Your healthcare provider may ask you some questions.
6. Get an examination by your healthcare provider. Sometimes, especially in teaching hospitals, your healthcare provider may also talk to their supervisor, or their supervisor may examine you or ask you more questions.
7. Have another conversation with your healthcare provider about what he or she thinks is going on with your health, and recommends as next steps. You may want to ask your healthcare provider some questions.
8. Work with the nurse or assistant if they come back after you've talked to your provider. The nurse or assistant may need to do some tests, give you a shot, give you some instructions, or do other wrap-up things.
9. Check out with the receptionist or front office desk before you leave.
10. Consider follow up instructions. You may have been asked to do some follow up things, like make an appointment with a specialist, get some labs or x-rays, fill a prescription, or do something at home. See the After the Visit topic for more information on follow up instructions.

3 What do I need to know about checking in when I arrive?

It is best to arrive a little early for your visit so that you can check in. When you first enter the office, go to the receptionist or front desk and let the person there know you have arrived.

> You can say, *My name is (your name) and I am here to see (your healthcare provider's name).*

If you have any paperwork prepared, give it to the person at the desk.

> You can say, *”This is my paperwork. What would you like me to do with it?”*

The person behind the desk should let you know what to do next with the paperwork.

If you do not have any paperwork prepared–or even if you do–the person at the desk may give you more forms to fill out, or more papers to read. Most of these forms are part of standard care. Unfortunately, some can be very difficult to understand (for any patients). If you are worried about filling out or signing a form, you can ask the office staff, a nurse, or someone you trust to explain it to you.

After you are checked in, the person at the desk will probably ask you to wait until it is your turn to see your healthcare provider.

4 What are some tips for handling the waiting room?

Some tips for handling the waiting room are listed in the section, ”I have a hard time with the waiting room, what might I do” in Preparing for a Visit.

If you think one of the tips might be helpful to you, bring it up to the person behind the desk at the end of the check-in process, and ask if the person can accommodate your needs. Explaining that you are on the autism spectrum can help the person see this as an accommodation and not just a preference. It can also be helpful to include briefly why it's important that you be accommodated, so the person knows you are not just being fussy.

Example #1:

> *I am on the autism spectrum and I have a very hard time handling the waiting room. I worry it may stress me out too much to have a productive visit. Would you be able to text me on the phone when it is my turn, so I can wait outside where it's quieter?"*

Example #2:

> *"I am on the autism spectrum and uncertainty can stress me out too much to have a productive visit. Would you be able to let me know right away if my wait will likely be longer than 15 minutes?"*

If you really don't wish to disclose your autism diagnosis, you can also be specific about the reason why you need to be accommodated without bringing up autism.

Example #3:

> *"I have unusually sensitive hearing and sounds can stress me out too much to have a productive visit. Would it be possible for me to wait in a quieter area?"*

5 What might the nurse or assistant do before I've seen the provider?

You will often see a nurse or assistant before you see your healthcare provider. This is normal in many clinics and offices. The nurse or assistant is an important part of the healthcare team. He or she communicates with your provider, and works together with your provider during your visit. The nurse or assistant has to keep your health information private just like your healthcare provider does. The nurse or assistant will usually show you to the examination room and get some basic health information from you. He or she may ask you the reason for your visit, about any medications you are taking, or for clarifications on some of your paperwork.

He or she will often take your vital signs. This may happen in the examination room or in another part of the office. For example, scales for measuring height and weight are sometimes in the hallway. Vital signs are:

- respiratory rate (how fast you are breathing)
- temperature
- blood pressure
- heart rate
- weight and height

The nurse or assistant will sometimes give you an examination gown to put on, and ask you to change into it. If you need the nurse or assistant to accommodate you with something, it is OK to ask. For example, you can ask him or her to give very specific instructions, or to guide you to the room instead of just pointing.

6 Tips for Staying Comfortable While Waiting for the Provider

It is OK to ask the nurse or assistant for things that will help you feel more calm and comfortable while waiting for the provider to show up. For example, you can ask:

- how long it is likely to be before your healthcare provider shows up
- to be told if your healthcare provider will be delayed and your wait gets longer
- if you can wear your coat or other clothing over the examination gown until the provider comes in
- if the lights can be dimmed, shades opened, or other changes made to the light in the room

- if there is a quieter room available, or if you could wait somewhere quieter for your provider

It can be helpful to include briefly why it's important that you be accommodated, so the nurse or assistant knows you are not just being fussy.

You can say, *"I have a very hard time with (describe what makes you uncomfortable), and worry it may stress me out too much to have a productive visit. Would it be possible (describe the tip that you think will be helpful)."*

Example:

> *"I have a very hard time with being cold, and worry it may stress me out too much to have a productive visit. Would it be possible for me to wear my sweater over my examination gown until the provider is ready for me?"*

7 What might my healthcare provider ask me?

If you have made a list of things you would like to have addressed, share it with your healthcare provider at the beginning of the visit so that you and your provider can set a plan for the rest of the visit. Then the provider will probably ask you questions regarding the issue(s) to be addressed at that visit.

Your provider will interview you about the symptoms of the problems you want to take care of. If you have used a Symptoms Worksheet to organize your symptoms, you might find it useful to refer to your worksheet when your provider asks you about your symptoms. Do not hand your provider the symptoms worksheet unless he or she asks you to see it. The worksheet is just for you to better be able to answer the provider's questions. If your provider is asking a lot of questions, it's not to be nosey or invade your privacy. Doctors are trained to ask questions in a particular way in order to make a proper diagnosis and treatment plan. In addition to asking questions about your health concerns, many providers will ask you for information that may seem very personal. They do this because these things can have important effects on your health or healthcare. They do not do this because they think you are a bad person or the type of person who would do bad things. They ask these questions of everyone. It's best to be honest about this stuff. Personal or embarrassing questions might include:

- Habits - smoking, alcohol, drugs
- Diet and exercise
- Living situation, employment, disability status
- Intimate relationships - sexual preference, sexual activity, how many partners, birth control and STD control, threats, violence, abuse
- Mental health - depression, sadness, mania, anxiety, panic attacks
- Social supports, social life, stressors in your life
- Healthcare Power of Attorney, Guardianship, Emergency contacts
- Preventative health - see ”Prevenative Healthcare” section of ”Staying Healthy”.

8 I have a hard time answering these types of questions, what should I do?

If you have trouble answering your healthcare provider's questions here are some things you can ask your provider to do that might make it easier for you to answer. Not all of these will be useful to every person. Not all of these will be possible. Providers are more likely to do these things if you pick the one or two most important suggestions for you.

- Specific Questions - Have your provider ask very specific, concrete questions and avoid very broad questions.
- Yes/No - Have your provider ask yes and no questions when possible.
- Extra Time - Ask the provider to give you extra time to respond to questions.
- Read written notes - Ask your provider to read notes you wrote before or during the visit.
- Examples - Have your provider give you examples of the types of things people may experience and have you explain if you experience them too.
- Multiple Choice - Ask your provider to give you a list of possible symptoms or answers to choose from.
- Life Events - Have the healthcare provider help with time questions by linking to important events in your life.
- Reword - Ask the provider to reword something if it confuses you.

It's OK to not know the answers to questions the provider is asking. It's also OK to not to be 100 percent exact or confident in your answers.

9 What might my healthcare provider do to examine me?

The provider may need to examine your body to diagnose you and recommend next steps. The provider may examine you with his or her hands or with an instrument. The provider may touch or look in your eyes, ears, nose, mouth, breasts, spine/back, abdomen, extremities, genitals, rectum, or skin. What part of the body, and the kind of examination the doctor will do, depends on the health concern being addressed.

If your healthcare provider has a supervisor (for example, you go to a clinic in a teaching hospital), the supervisor may also examine you or ask you questions.

10 I have a hard time with being examined, what might I do?

If you have trouble tolerating exams or procedures, here are some things you can ask your provider to do that may make them more tolerable for you. Not all of these will be useful to every person. Not all of these will be possible. Providers are more likely to do these things if you pick the one or two most important suggestions for you.

- Who Will Do What - Have the provider explain what parts of the visit the nurse or assistant will do and what parts of the visit the doctor will do.
- Explain First - Have the provider explain what he or she is going to do before doing it.
- Equipment - Have the provider show you the equipment he or she will use before it is used.
- Trial Run - If possible, do a ”trial run” of difficult exams or procedures before they are done for real. For example, practice with the equipment or walk through the steps that will happen.
- How Long - Ask the provider how long something is likely to take.
- Warn - Ask the provider to let you know when they are about to touch you or do something to you.
- Clothes - Ask if you can keep as many clothes on as possible or limit the amount of time you have to be undressed or in a gown.
- Extra Time - Ask for extra time to process things you need to see, hear, or feel before you have to respond (for example, pressing and asking if something hurts).
- Avoid Touch - Ask to be touched as little as possible during the exam.
- Firm and Deep Touch - Ask to be touched with a firm, deep pressure if possible (not a light touch).

- Sit or Lean - Ask if you can sit, lie down, or lean on something during procedures, when possible.
- Signals - Ask if you can use a signal to tell the provider that you need a break.
- Check In - Have the provider ask you from time to time if you are able to handle the pain or discomfort.
- Anesthesia - Ask if anesthesia is an option if you need it to tolerate a procedure.

11 What might I want to ask my heathcare provider?

After your healthcare provider has examined you, they will talk about what they think is going on. You might want to ask your provider some questions about what they think is going on.

Here is a good list of questions you might want to ask your healthcare provider.

- What do you think is causing my problem?
- Is there more than one condition (disease) that could be causing my problem?
- What tests will you do to diagnose the problem and identify which of the possible conditions is present?
- How good are the tests for diagnosing the problem and the conditions?
- How safe are the tests?
- What is the likely course of this condition? What is the long-term outlook with and without treatment?
- What are my treatment options? How effective is each treatment option? What are the benefits versus risks of each treatment option?

- If my symptoms get worse, what should I do on my own? When should I contact you?

(Taken from article on MedicineNet.com by William Shiel, Jr, MD.)

12 What are some tips for understanding diagnoses and recommendations?

Here are some suggestions that might help you make sure you understand your provider's recommendations. Not all of these will be useful to every person. Not all of these will be possible. Providers are more likely to do these things if you pick the one or two most important suggestions for you.

- Restate - Restate what the provider said in your own words to see if you got it right.
- Get Another Explanation - Ask a supporter who communicates well with you to re-explain the things to you.
- Write Things Down - Ask the provider to write things down, or write the things down yourself and have him or her check it.
- Get Names - Ask for the name of your health condition and look it up in a credible source.
- Discuss Options - If a decision about something needs to be made, discuss your options with a trusted person before making a decision.

13 I have trouble being included in decisions about my healthcare, what should I do?

If you are having trouble being included in discussions or decisions about your healthcare, here are some suggestions as to how you can be more involved.

Not all of these will be useful to every person. Not all of these will be possible. Providers are more likely to do these things if you pick the one or two most important suggestions for you.

- Extra Time - Ask for extra time to make a decision. It's OK if that means you need to come back or communicate the decision at a later time.
- Ask for Concrete Information - Tell your provider to be very blunt and concrete with you about what will happen if you do or do not follow your provider's recommendations. If possible, have the provider give concrete examples.
- Get Detailed Information - Ask your provider to direct you to detailed information or resources about your health conditions.
- Involve Others - Have the provider give a person you trust detailed information about your health conditions and choices.
- Discuss - Discuss your healthcare choices with a person you trust and then speak to your provider about what you've decided.

14 What might I do if there isn't time to cover everything I want to cover?

Not all of your concerns can always be covered in one visit. If you're not able to get all of your concerns covered, it is OK to ask for another appointment to finish up. The front office staff or receptionist can usually help with scheduling another appointment.

15 What do I need to know about preventive care?

Preventive care includes things that can help prevent a major health problem, or can help catch a health problem when it is still minor or easier to treat. Preventive care includes things like cancer screening, vaccinations, and dental cleanings.

Some preventive care, such as screening for diseases like cancer or diabetes, needs to be done regularly. You may want to ask your healthcare provider during the visit if you need to make a separate preventive care appointment for anything.

For more information about preventive care, see the topic Preventive Care under Keeping Yourself Healthy.

16 More Tips for Communicating with Healthcare Providers

It is OK to ask your healthcare provider for things that will help you communicate with him or her better. Here are some tips to make it more likely that the provider will understand and give you what you need.

If you ask for accommodations, make it clear that something is a disability-related need, not a preference.

> *Example: ”Even though my speech is fluent, I have a really hard time communicating verbally. May I please write down my answers instead? It will help me give you better information.”*

More information about asking for accommodations is found in ”How do I request ADA accommodations for my healthcare?” in the Equal Access section.

- If someone helps support you with your healthcare, 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, while 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.

- It's OK to ask your healthcare provider to go more slowly. It's OK to ask your provider to re-explain something or write it down.
- Let your healthcare provider know that you respect how tight their schedule may be. One way to do that is bring a list of your health concerns and at the start of the visit discuss which of the issues to address right away, and which may need to be taken care of at another appointment. It is OK to ask for another appointment to get all of your concerns addressed.
- Show your appreciation for the provider's efforts. When the visit is nearing an end, you can simply say, "Thank you for your time and effort."
- Regular preventive care or follow-up visits may strengthen your relationship with your provider because you will see him or her more frequently.

17 What might the nurse or assistant do after I've seen the provider?

The nurse or assistant might come back after you have seen your healthcare provider. He or she might talk to you about things the healthcare provider has recommended. For example he or she might go over any new medications, might show you how to do something you'll need to do at home, or might give you more information about your health condition. He or she might have instructions for you about testing, or about seeing another healthcare provider. The nurse or assistant might also do some tests or draw blood. Use the tips in the sections about I have a hard time answering these types of questions, what should I do?, What are some tips for understanding diagnoses and recommendations?, and More Tips for Communicating with Healthcare Providers for communicating with the nurse or assistant.

18 What about check out and follow up?

After you have seen your healthcare provider and done any other things with the nurse or assistant, you may need to go back to the front desk or receptionist and let them know you are done with your visit. Depending on your situation, there may be some extra steps to checking out. Examples of steps some people might need to take are:

- Schedule another visit with your healthcare provider to cover something that wasn't addressed at this visit
- Schedule a follow up appointment, lab, or other type of visit that the front desk or receptionist can help with (see the topic After the Visit for more details)
- Schedule a preventive care visit
- Pay for something

19 Summary

Most regular visits with a primary care provider follow these steps:

- Check in with the front desk
- Wait to be called for your turn with the healthcare provider
- Have the nurse or assistant take your vitals and show you to a room
- Wait for the healthcare provider
- Talk with the healthcare provider about your concerns
- Get an examination

- Talk with the healthcare provider about what they think is going on with your health
- Work with the nurse or assistant on any final steps
- Check out
- Consider follow-up instructions

During all of these steps, it is OK to ask for things that can help you best participate in your healthcare. You may ask for things you need from front desk staff, nurses and assistants, and from the primary care provider. It is usually easier to get your needs met if you briefly explain why what you need really matters. Otherwise people might misunderstand and think it's just a preference or that you are being fussy.

Healthcare providers like to feel appreciated and respected, just like anyone else. It can improve communication with them to let them know you appreciate their work and respect their time.

If you aren't able to cover all of your health concerns in one visit, it is OK to make another visit to cover the rest of the issues.

AASPIRE **Healthcare Toolkit**

Healthcare: After the Visit

Contents

- What is this topic about?
- What might I do if I have questions after the visit is over?
- What might I do if the provider asked for a follow-up visit?
- What might I do if the provider made a referral to another provider or specialist?
- What might I do if the provider ordered lab tests?
- What might I do if the provider prescribed medications?
- What might I do if the provider asked me to track things, like my symptoms?
- What might I need to know about taking care of my health condition(s) at home?
- If I need assistance to do these types of things, what might I do?
- My provider often seems rushed at the end of visits, how might I get all my questions answered?
- Summary and Tips

www.autismandhealth.org

Healthcare: After the Visit

www.aaspire.org
Last Updated September 29, 2015

1 What is this topic about?

This topic is about things that may need to be done after a visit with a healthcare provider. These things might include:

- Contacting your healthcare provider if you have questions after the visit
- Making a follow-up appointment with your healthcare provider
- Making an appointment with a different healthcare provider or a specialist (a referral)
- Getting a lab, x-ray, or other test
- Filling a prescription, getting or taking a medication
- Tracking your symptoms
- Taking care of your health condition(s) at home

The After the Visit Worksheet has spaces to organize information about these things.

2 What might I do if I have questions after the visit is over?

You might think of questions for your healthcare provider after the visit is over. For example, you might need more information about something that was talked about during the visit. Or you might realize you don't have good instructions for how to do something at home to manage your health. If you have questions that come up after your visit, you can contact someone to get your questions answered. Before you leave the clinic or office on the day of your visit, ask your healthcare provider or the front desk staff who you can contact if you have questions after you get home. Ask how to contact the person. If you are given a contact method that does not work for you (for example, they give you a phone number and you do not use the telephone), ask if there is a different way, and tell them what methods might work better for you. It doesn't matter how long after the appointment you realize you have more questions. What matters is that you get the information and care that you need. Contact your provider's office and tell them that you have some questions about your last visit.

3 What might I do if the provider asked for a follow-up visit?

It is always a good idea to know when your health care provider wants you to come back to see him or her. Often your provider will tell you this information, but you may want to ask if he or she does not tell you first. Follow-up appointments are often made to see if a medication is helping, to see if a problem has gotten better or worse, or to tend to an injury. If a follow-up appointment is needed, make sure you know this information:

- When should I make the follow-up appointment for?
- How do I make a follow-up appointment?

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

You might be able to schedule the follow-up appointment with the clinic or office staff before you leave the clinic or office.

4 What might I do if the provider made a referral to another provider or specialist?

Your healthcare provider might ask you to make an appointment with a different healthcare provider, or with a specialist or a specialty department. Healthcare providers make referrals when your health problem needs the care of someone who specializes in that kind of problem. For example, a healthcare provider might refer you to a dermatologist for an unusual rash. If you were given a referral to another provider, clinic, or department, you may need to make an appointment with the person or department you were referred to or this may be arranged for you. Check whose job it is to schedule the new appointment–yours or theirs. The office staff can tell you. Good information to know is:

- What is the name of the person, clinic, or department I'm supposed to see?
- Why have I been referred to this other provider?
- Do I call them or do they call me?
- Who do I contact to make the appointment?
- How do I make the appointment?
- 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?
- Should I bring anything special with me when I go to this other provider?

If the referral is to someone in the same clinic or facility as your healthcare provider, you might be able to make the referral appointment with the front desk staff before you leave the office. Make sure the provider you have been referred to knows about any accommodation needs that you have. You might also want to ask your healthcare provider to talk to the specialist or department about your needs.

5 What might I do if the provider ordered lab tests?

Your provider may order labs, X-rays, or other tests. Some examples of labs and tests are blood draws, urine samples, or ultrasounds. Some tests might be done the same day as your healthcare appointment and not need any special scheduling. Other tests you might need to schedule later, or with another person or department. It will depend on the test and the reason for the test. If your healthcare provider has ordered labs, X-rays, or other tests, and they are not going to be done right away before you leave the office, make sure you know the information below. Note that not all of these questions might apply to the test or procedure you need.

- 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? If so, 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: do not eat anything for 12 hours before the test (this is called fasting).
- What will the test or procedure be like? Will there be strange sounds or sensations? Will it hurt?
- How will I find out the results of the test?

If you have insurance, you may also want to ask whether or not your insurance will cover the test or procedure. You may need to get this information from your insurance provider. If the lab, x-ray, or test will be done in the same clinic or facility as your healthcare provider, you might be able to make the appointment with the front desk staff before you leave the office. Make sure the people doing the labs, x-rays, or tests know about any accommodation needs that you have. You might also want to ask your healthcare provider to talk to the specialist or department about your needs. Ask your healthcare provider for help preparing for labs or tests, if you need it.

6 What might I do if the provider prescribed medications?

Your healthcare provider might ask you to take a medication or use a medicinal cream or patch. The medication could be prescription only, or it might be something you can buy in stores without a prescription (sometimes called ”over the counter” medicine). For any kind of medication, make sure you feel comfortable with how to use it before you leave the office. You should try to answer all of the following questions:

- What is the name of the medication?
- How many pills or how much liquid do I take at a time? If it’s a cream, how much do I put on at a time? If it is a patch, where do I put it on my skin?

- How many times a day do I take or use the medicine?
- What time or times of day should I take or use the medicine?
- Does it matter if I take the medicine immediately before or after eating?
- Do I take or use the medicine only when I have a symptom or do I take it regularly on a schedule?
- When do I stop taking or using the medicine?
- What side effects should I look out for?
- What do I do if there are side effects?
- Are there risks of interactions (bad reactions) with sunlight, my other medicines, or foods I may eat?
- Should I avoid any particular activities while I'm taking this medication?
- Do I need to refrigerate the medication, or store it in a special way?

If the provider prescribed medications, you will also need to know about the prescription, and about refills. It is a good idea to know the name, address, and phone number of your preferred pharmacy, if you have one. You may want to give that information to your provider. Some things to know before you leave the office are:

- Has the prescription been faxed / e-prescribed / called in to the pharmacy, or do I need a paper copy of the prescription?
- If the prescription has been faxed, e-prescribed, or called in, where is the pharmacy?
- If I am getting a paper copy of the prescription, is there a particular pharmacy I need to take this to, or can I take it to any pharmacy?
- How do I get refills, if I need them?

When you pick up your medication at the pharmacy you can have a short conversation with the pharmacist about the medication. You may want to ask these questions again, or any other questions about the medication:

- Are there any special warnings about this medication?
- What are the side effects?
- What do I do if I experience side effects?

It can also be good to tell the pharmacist what the instructions are for taking or using the medication, in your own words. The pharmacist can help to make sure you have the right instructions. When you start taking a medication, you may want to think about how you might remember to take it at the right times. Here are some ways that people remind themselves:

- Set a daily alarm clock or cell phone alarm
- Use a pill box that has days of the week compartments to remind you
- Put your medicine in a place where you are likely to see it
- Mark your calendar or daily journal when you have taken it
- Make yourself a reminder sign and place it somewhere you are likely to see it
- Ask someone to help remind you

7 What might I do if the provider asked me to track things, like my symptoms?

Your healthcare provider might ask you to track your symptoms. For example, you might be asked to keep a pain diary, a mood diary, or note when your symptoms become better or worse. Symptom tracking is usually used to monitor the progress of a condition, to better understand a condition, or to see if a medication or treatment is working. There are a lot of different options for symptom tracking. You might need to try more than one way, or even invent your own way, in order to find a symptom tracking system that works for you. Here are some ideas:

- Use a paper calendar or day planner
- Use a paper diary
- Use a symptom tracker online. Examples:
  - Symptom tracker at the Mayo Clinic
  - Symptom tracker at WebMD.com
- Use a symptom tracker program on your computer (search the Internet for ”symptom tracker software”)
- Use a symptom tracker app on your smart phone, tablet, or PDA (search your device’s app store for ”symptom tracker”)
- Use an audio or video diary (for example, with a voice recorder, with the recorder and camera on a smart phone or computer)

For many of these kinds of trackers, symptoms can be noted in words (for example ”mild” or ”severe”) or they can be noted with pictures (for example, a smiley face or a sad face). Remembering to keep track of symptoms can be hard for a lot of people. Here are some ideas for how to remember to use a symptom tracker:

- Set a timer or alarm to go off when it’s time to use the symptom tracker.
- Pick a time of day when you are usually not busy, and always track your symptoms at that same time of day (for example, after dinner, before you brush your teeth, or at noon).
- Ask a friend, a family member, or someone you live with to help remind you.

- If you keep a daily planner, a visual schedule, reminder notes, or a daily to-do list, add working on your symptom tracker to it.

8 What might I need to know about taking care of my health condition(s) at home?

Your healthcare provider may ask you to do things at home to manage your health condition or conditions. For example, you may be asked to keep a pain diary, to eat a special diet, or to use some kind of medical equipment like a crutch or a splint. Before you leave the office, make sure you have instructions that you understand for what to do at home. The instructions might be given to you by a nurse or someone else in the office or clinic who is not your primary healthcare provider. It can be helpful to do a ”teach back” with the person who gives you the instructions. In a ”teach back,” first someone explains or shows you how to do something. Then you explain or show them how to do that same thing, in your own words. Teaching often helps people to learn.

9 If I need assistance to do these types of things, what might I do?

Your provider’s office may be able to help you with some of the things you need to do after the visit. Ask the nurse, care manager or the front desk staff if they can help you. Not all offices will be able to help you with these things, but it is always worth asking. Some things your provider’s office may be able to help you with are:

Scheduling Appointments - If your follow-up, referral, test, or pharmacy pickup is in the same office, clinic, or medical facility as your healthcare provider, they probably can schedule the appointment for you. You can also ask if the office has an online appointment tool or other ways to make setting up appointments easier. Some providers’ offices will call you and remind you when it's time to set up a follow-up or other appointment. Each office has different tools and policies, so ask what is available for help with scheduling appointments.

Reminders - Ask the office staff if they do reminder calls or emails. If they do, ask them about any accommodations you might need regarding reminders for your appointment. Some offices or clinics may have people who can help with reminders to pick up a medication from the pharmacy.

Social Services - Some providers work with social workers or can help you network with other social services like vocational rehabilitation, food stamps, housing or other health and human services. If you have basic needs that are not getting met in your daily life, talk about that with your healthcare provider. They may have some resources or ideas.

Transportation - Ask your healthcare provider's office if they can help you connect with transportation options through your regional transportation system or volunteer driver programs.

Directions - Your provider's office may have information sheets that offer directions to get to places you'll need to go for referrals or tests. If the office or clinic is large enough, like a clinic that is part of a major hospital, it may also have a map of the whole facility. Someone from the office may also be able to help guide you to a place you need to go in the building, like the X-ray or radiology department.

10 My provider often seems rushed at the end of visits, how might I get all my questions answered?

There are a lot of questions to be answered about follow-up care like labs, medications, or at-home care. Sometimes providers may run out of time at the end of a visit and need to go see other patients. If it seems like the provider is in a rush or if the provider is ending your visit without answering all your questions, make it clear you still have more questions. Find out what the best way would be to get your questions answered. For example, you might say:

> *”I know you don’t have much time now, but I still have some important questions about my follow-up plans. What would be the best way for me to get them answered? Is there someone in your office who could help me or is there a way I can be in touch with you later? Thanks.”*

11 Summary and Tips

If you have questions after your visit, it is OK to contact your healthcare provider and ask them. Before you leave the medical office, get information for who to contact if you have questions, and how to contact them. Things your healthcare provider might ask you to do after your visit are:

- Make a follow-up appointment to see how things are going
- Go see another healthcare provider or specialist
- Have a lab, x-ray, or other test done
- Take or use a medication
- Keep track of your symptoms
- Do something at home to take care of your health condition

Try to get all of the information you need about any of these things you’ve been asked to do before you leave the office. Make sure you understand any instructions for taking medication, preparing for labs, or doing things at home. If you think you will need help doing any of the things you have been asked to do, talk to your healthcare provider or to the nurse about it. Your healthcare provider’s office may be able to help in other ways besides medical care.

Ask your provider's office if they can help you with directions, transportation, reminders, social services, or making appointments. If your provider seems too rushed at the end of a visit to answer your questions properly, ask them what the best way will be for you to get them answered later. The After the Visit Worksheet has spaces to organize information about these things.

AASPIRE **Healthcare Toolkit**

Staying Healthy

Information about nutrition, exercise, recreation, and preventive care.

Contents

- Nutrition
- Exercise
- Recreation
- Preventive Care

AASPIRE **Healthcare Toolkit**

Staying Healthy: Nutrition

Contents

- What is this topic about?
- What kind of diet is healthy for me?
- How do I eat healthy on a budget?
- Tips for Using the Grocery Store
- Cooking is hard for me, what are some ideas to make it easier?
- How do I cook safely?
- Someone else makes my food, how can I make sure it's healthy?
- I don't like or can't eat most food, what should I do?
- Special Diets for People with Health Conditions
- Eating Disorders
- Links

Staying Healthy: Nutrition

www.aaspire.org
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1 What is this topic about?

A healthy diet can help improve or keep up good health. A healthy diet may also lower the risk for some chronic health problems such as heart disease, diabetes, and cancer. A healthy diet means eating the right amounts of the right nutrients, and drinking the right amount of water. Nutrients can come from many different foods. Everyone's bodies are a little different, and there are many ways to have a healthy diet. This section gives some links to basic information about healthy diet and nutrition.

2 What kind of diet is healthy for me?

There is no single diet that is best for all people. Some people like to stick to a particular diet, like a vegan, low carbohydrate, paleo, anti-inflammatory, or Mediterranean diet. It's okay if you do not want to follow are particular diet. Following some general healthy eating guidelines is all you need to do.

General Guidelines
Vegetables - Try to make about half your plate be vegetables at every meal.
Variety - Eat a variety of types of food, especially vegetables

and fruits. Different foods have different amounts of nutrients that you need. If you only eat a couple types of foods you may be missing several important nutrients.

Whole Grains - If you eat something with grains (breads, pasta, rice, etc.) choose ”whole grain” options when possible (whole grain bread, whole grain pasta, brown rice, etc.)

Beverages - It is easy to get extra calories from things you drink. This can cause weight gain. Drinks like soda, coffee based drinks, milk shakes, juice, and alcohol all have lots of added sugars and fat. Healthier options are to drink water, black coffee, or unsweetened tea.

Juice - Many of us were told that juice is healthy because it is from fruit. Unfortunately this is not true. Juice can have more sugar than a candy bar! Sugar is often added to fruit juice. Also, by drinking the juice, you are only getting the sugary fluid from the fruit. This means you are missing many important nutrients, like fiber, from the rest of the fruit. If you do drink fruit juice, try to find labels that say, ”100% fruit."

Snacks - If you know you are going to need a snack before your next meal, try to keep a healthy snack easily available. This helps you stay away from chips or candy as snacks. Here are some quick healthy snack ideas:

- Nuts (unsalted, not candied) - Nuts are good sources of healthy fats, protein, and minerals. Eat up to a handful a day.
- Fruit - a piece of whole fruit is a good way to have something sweet and healthy. Whole fruits have lots of fiber, vitamins, and minerals. If you are hungrier, try putting some type of nut butter on your fruit, like peanut or almond butter.
- Hard boiled eggs - these can last a week in the refrigerator. You can take them to school or work. When you’re ready to eat, you can peel the shell off. Eggs are good sources of protein, B-vitamins, phosphorus, and selenium. Here’s how to cook them.

Sweets - Sweet foods, breads, and pastas are mostly made of carbohydrates. Carbohydrates are important for your body to get quick energy. This also means that carbohydrates are digested faster and you will feel hungry again sooner. Eating meals mostly with carbohydrates can also spike your blood sugar. To avoid this, try to include healthy fats and proteins any time you eat something with a lot of carbohydrates. This makes sure you get your short-term and long-term energy sources at each meal.

Planning Ahead - In general, eating meals you make at home are healthier than meals you buy at restaurants or fast food places. This is because you can control the ingredients that are in the foods you make yourself. Often we eat out or get fast food when we haven't prepared something already at home or are busy and stressed. One way to avoid this is to plan ahead. Pick a day to make your meals for the rest of the week and freeze them. That way you only have to cook once! This way you know that you have a quick meal ready that you made. This also helps save you money from eating out. Examples: make large batches of stew, curry, burritos, and stir-fry. These things are easy to store in the fridge or freezer and eat later in the week.

Read Labels - Read the labels of the foods you eat. Just reading the nutrition labels and ingredients lists helps you know what you are eating and can help you make better food choices.

Specific Healthy Diets *Mediterranean Diet* This is one of the best researched diets for reducing the risk of chronic disease and maintaining health. The basic concepts are:

- Base your meals on fruits, vegetables, whole grains, olive oil, beans, nuts, legumes, and seeds.
- Use seafood, poultry, and other lean meats as your main sources of meat.
- Limit the amount of red meats and sugars.

Ornish Diet (Ornish Spectrum) -The Ornish diet was developed by Dean Ornish, MD based on different nutrition research. Foods are categorized into 5 groups. Foods in Group 1 are consid-ered the healthiest. Foods in Group 5 are considered the least healthy. These categories help you decide how much of healthy or unhealthy foods you want to eat. Learn more at ornishpectrum.com.

Links to other guidelines and general information about nutrition and healthy diets:

Recipes for Healthy Living created by the American Diabetes Association has tools and tips for people with and without diabetes including: Information on how to make a healthy meal, recipes with nutrition content, healthy and budget-friendly meals, customizable food plans with grocery lists. The American Heart Association has diet and lifestyle recommendations to reduce the risk of heart disease including: how many calories to eat, blood pressure and cholesterol advice, and information on individual food groups, fish, and sugar. The Harvard School of Public Health Nutrition Source has information on healthy foods, beverages, and exercises, as well as a ”healthy eating plate” to visualize food group portions. LiveStrong.com has a lot of different tools and articles to help with diet, nutrition, and exercise, including:

- Detailed information about nutrition Livestrong
- A page where you can browse recipes for healthy food based on your own food preferences (includes detailed nutritional information)
- A food tracker where you can keep track of what you eat

Online and phone apps to track what you eat: MyFitnessPal, My Food Diary, My Net Diary.

3 Where can I find specific details on individual foods or nutrients?

NutritionData.com has tools and information to understand and analyze nutrition, including

- Information about what nutrients are in which foods

- A daily nutritional needs calculator based on your sex, age, weight, and activity level
- Detailed information about special health diets such as diabetic or heart diets

The Linus Pauling Micronutrient Information Center has detailed, technical information on many nutrients found in food, as well as symptoms from not getting enough–or getting too much–of a nutrient. It also has summaries about research on nutrition in specific medical conditions. *NOTE: This site has a lot of information, but is not written in a way that is easy to understand. The information is very technical and uses a lot of jargon.*

4 How much water do I really need to drink?

It is hard to know how much water people need to drink. Many people have heard that you should drink 8 glasses of water a day. Some people may need more or less though depending on how big they are. Also, the food you eat gives you some water, so how much extra you need to drink depends on what you are eating. The Institute of Medicine estimates that adult men need to drink an average of 3.7 liters (125 oz) daily and adult women need to drink about 2.7 liters (91 oz) of water daily. A different way to figure out how much water you might need is to take your body weight in pounds, divide it half, and that's the number of ounces you should drink (for example, a 150 lb person would drink 75 oz of water a day: 150/2=75). Exercise, hot weather, or illness: There are a number of things that can cause you to need more fluids. One is exercising. Another is being in hot weather conditions. Illnesses can also make you lose fluids if you have diarrhea, vomiting, or a high fever with sweats. In those situations, you need to drink more fluids and replace your electrolytes (the salts that are naturally in your body). Some examples of drinks with electrolytes are Gatorade or Poweraid. One way to know if you are drinking enough water is to check your urine. It should be a clear or pale/light yellow. If it is darker you may need to drink more water. Certain medications and medical conditions can also make your urine look darker.

5 What should I do if I want to lose weight?

A goal of losing 1 pound a week is recommended for most people who wish to lose weight. Losing more weight is not sustainable for most people because it requires more drastic lifestyle changes that you might not be ready for. In general, to lose weight, you need to either eat less or exercise more. For many people this means:¡p¿

- eating 500 less calories per day, or
- exercising enough to use up an extra 500 calories per day.

You can talk to your doctor more about safe ways for you to lose weight.

6 How do I eat healthy on a budget?

A lot of people think they can't afford healthy food. It is possible to eat healthy on a budget. Finding simple meals with a protein source and some vegetables can be an easy, quick, and cheap meal.

Quick tips to save money:

- Use coupons and check for sales. Buy in bulk when possible.
- Protein - Meat is an expensive protein source. Decreasing your meat intake and using cheaper protein can help save you money. Eggs, beans, tofu are good sources of protein that tend to cost less.

- Produce - Buy what you know you'll eat. If you are buying fresh fruits and vegetables only get enough for what you know you will eat in the next couple of days. If you buy a lot of fresh fruits and vegetables they may go bad before you get a chance to eat them. This means wasted money. Buying only a few fresh items at once may mean more trips to the store, but it can also save you money.
- Frozen produce - If you do not think you will eat fresh produce before it goes bad, frozen vegetables and fruit are a good option. They are just as good nutritionally and will keep longer in the freezer. Many frozen vegetables are also pre-cut, which can save you time and steps while cooking.
- Many packaged snacks and prepared dinners are actually more expensive than making your own meal. If possible, learn how to make basic meals and make larger batches that can last for several meals. Cooking your fresh vegetables can often make them last longer.

These resources give some ideas for how to eat healthy even when money is tight. Not all of these ideas may be useful to you. You can ignore any that aren't.

The United States Department of Agriculture has a section of its web site that includes articles on shopping on a budget. Foodstamped.com offers some recipes and tips on how to eat healthy on a food stamp budget.

Zenhabits.net has an article called 50 Tips for Grocery Shopping that has a lot of tips for saving money at the grocery store, as well as for having a more calm experience at the grocery store.

7 Tips for Using the Grocery Store

The grocery store can be an extremely stressful experience for some people. Some tips that may be helpful are:

- Plan the shopping before you go, both by making a list and by making a plan of how you will navigate through the store.
- Get very familiar with just one neighborhood grocery store. A smaller one may be easier to get to know well. (But pick a store that is large enough to have the things you need.)
- Bring a friend with you.
- Develop a routine around grocery shopping: for example, visit the same aisles in the same order, use the same checkout - anything that can help reduce the need to process all the bustle of the store.
- Learn where the aisles are that you never use and then just ignore them (for example, there is no need to pay attention to the meat counter if you're a vegetarian).
- Stick to the perimeter of the store. Most grocery stores put the healthier items on the perimeter, like the produce and meat counter, or the frozen aisles. Most of the packaged and snack items are in the center of the store.
- Go grocery shopping during less crowded days and times, for example at 1:00 PM on a Tuesday, or, if you're a night person and have a 24-hour grocery, at 2:00 AM. The *busiest* times at the grocery store are usually:
  - Friday, Saturday, and Sunday mid-morning to late afternoon
  - Weekdays 4:00 PM to 6:00 PM
  - Around major holidays or events like Thanksgiving, Christmas Eve, and Super Bowl Sunday
- Some grocery stores may have online shopping or a delivery service.
- Protect your senses–it's OK to use things like sunglasses, hats, headphones, or ear plugs in the grocery store.
- If your grocery store has them, the self checkouts can be a good way to avoid having to interact with sales people.

- Remember that you can always leave the store at any time if it gets overwhelming.

Shopping Tours Some grocery stores like New Seasons and Whole Foods, and some dieticians offer ”tours” of grocery stores to help you select healthy foods or find foods to follow a particular diet (like if you need help finding gluten-free foods if you were diagnosed with Celiac disease or gluten-sensitivity). They can also help you find lower cost items to help save you money. Contact your local stores to see if they offer this service, or contact local dieticians, nutritionists, college health programs, and local health departments and ask.

About.com has a nice article on how to shop for groceries and how to navigate a grocery store.

Food Issues for Independent Autistic Adults is a website created by Patricia E. Clark that includes tips to help with shopping.

8 Cooking is hard for me, what are some ideas to make it easier?

There are a lot of cooking resources on the Internet. These three are particularly clear with a lot of steps and photographs, and no confusing phrases like ”until it looks good to you.” Step-by-Step Cook offers in-depth, detailed, start-to-finish instructions on a wide variety of recipes. This site assumes that the users have no prior cooking experience, and includes photos of what each step should look like. Cooking for Engineers breaks recipes down very concretely with tables showing which steps are done in order and which are done at the same time. It also has information on cooking gadgets. Cooking With Autism has some step-by-step sample recipes, and offers a book for purchase. If following recipes or cooking a lot of different things just isn't going to happen for you, here are some ideas:

- Learn how to cook one kind of thing and then do variations on it. For example, learn how to use a rice cooker to make rice and steamed vegetables. Then you can just change the kind of vegetables you steam in it.

- Find healthy frozen dinners or other prepared foods that can be heated in a microwave.
- Learn what kinds of raw foods or pre-cooked foods will give you a healthy diet and then just make plates of them. For example, raw vegetables, canned beans, canned fish, fruits, bread, nuts, and cheese are all things that can be eaten without needing to touch a stove or put ingredients together.
- Make one day a week be ”cooking day” and make all of your meals for the week on that day. Reheat them in the microwave or oven, or eat them cold the other six days.
- Trade with someone for cooking. If there’s something you’re good at but someone else finds hard, maybe you can trade with them. For example if you like programming computers, maybe you could build a web site for someone and keep it updated, and in return they could cook for you a few days a week.
- Keep some ”emergency food” stocked so you don’t go hungry on days when preparing food isn’t manageable. For example, nuts and dried fruits are nutritious, high in calories, and can last a long time.

Food Issues for Independent Autistic Adults is a website created by Patricia E. Clark that includes tips to help with cooking.

9 How do I cook safely?

The U.S. Fire Administration has tips on cooking and fire safety.

Keepingitkleen.com has a lot of information about sanitation and food safety. If you have trouble with forgetting that things are cooking, some kitchen devices run on automatic timers and will shut off by themselves. Examples are microwaves, some toaster ovens, some rice cookers or steamers. If you have trouble with cutting things up, you can get food pre-cut up in a few different ways.

- Some supermarkets carry pre-cut produce, usually in a cooler by the uncut produce.
- Some supermarket workers at meat or fish counters or in delis will cut up your meat, fish, bread, or deli items for you if you ask them to, including removing skin and bones.
- Frozen or canned produce often comes pre-cut.
- Special cooking tools can sometimes help with cutting. Some tools help by making cutting safer and easier (like a bagel slicer). Other tools help by doing the cutting for you (like a food processor).

10 Someone else makes my food, how can I make sure it's healthy?

If you have a good relationship with the person who makes your food and you feel comfortable communicating with him or her, discuss your wish to eat a healthier diet. You can then brainstorm realistic ways that you can eat healthier foods. If you don't feel comfortable talking with your caregiver about wanting healthier food, you might ask for help from someone you trust. If you receive disability services, you can bring up your desire to eat healthier food at your person-centered care conference. You may want to talk to someone you trust first and invite him or her to the meeting so that he or she can help advocate for you.

11 I don’t like or can’t eat most food, what should I do?

Some people on the spectrum have trouble eating a variety of foods. Sometimes it is because of sensory reasons, for example trouble tolerating certain tastes, smells, temperatures, or textures. Other times it may be due to the desire for sameness and not liking changes in routines.

Although it is good to eat a variety of foods, the number of different types of foods is less important than making sure you have a balanced diet with all the nutrients you need. You can find detailed information about the nutritional value of different foods at NutritionData.com.

Some tips for getting the nutrients you need, even if you have a restricted diet, include:

- Look for foods you can tolerate that have each of the important nutrients.
- Talk to your healthcare provider about what vitamins or supplements you should take daily.
- Try a different form of the food - for example, some people who can’t tolerate the texture of a vegetable may be able to drink it as a juice or smoothie.
- Prepare the food in a different way. Some people may not like raw broccoli, but they may like steamed or boiled broccoli.
- Change the temperature of a food and see if it works better for you that way.
- ”Hide” foods - for example, you can put vegetables in a blender and then mix them into pasta or pizza sauce.
- Try something new on a day when you think you can handle it. Even if you don’t like it at first, make sure to try it at least three different days before you reject it–you might find you like it after you have had it a few times.

- Try new foods when you're really hungry.
- Try adding spices you like to food.

Food Issues for Independent Autistic Adults is a website created by Patricia E. Clark that discusses some of the dietary issues adults on the autistic spectrum face including tips on coping with food phobias.

12 Special Diets for People with Health Conditions

People with some types of health problems need special diets. For example, you may need to eat a special diet if you have diabetes, kidney disease, heart disease, or Celiac disease, or if you take medications such as Coumadin. Your healthcare provider can give you information about what types of foods you should or should not eat to help take care of your health problems. In some cases, your healthcare provider can give you a referral to a nutritionist so that you can get more detailed counseling. Ask your provider if your health insurance would pay for a visit with a nutritionist.

13 Eating Disorders

Eating disorders are very common, both in general and among people on the autism spectrum. The National Eating Disorders Association is a good place to start for information about eating disorders.

14 Links

General Nutrition

- The US government's fitness site has information and recommendations about healthy eating.
- Livestrong is a health resource website. The nutrition section of this website has a comprehensive list of suggestions, advice, activities, and tools.
- Mayoclinic.com maintains useful and up-to-date information and tools to help people stay healthy. Their nutrition section has articles, tools, recipes, shopping tips, and other resources related to healthy eating.
- Some general information about what's in food can be found at nutrition.com.
- Food Issues for Independent Autistic Adults by Patricia E. Clark addresses a variety of topics.
- The American Heart Association has nutrition and diet information that focuses on heart health.
- MedlinePlus has a section on nutrition.

Food Safety

- Fire safety
- Food safety

Shopping

- How to grocery shop
- Meal planning and budgeting
- Shopping on a food stamp budget
- 50 tips for Grocery Shopping

Cooking

- Step-by-Step Cook
- Cooking for Engineers
- Cooking with Autism

See the National Eating Disorders Association for information on eating disorders.

AASPIRE **Healthcare Toolkit**

Staying Healthy: Exercise

Contents

- What is this topic about?
- What counts as exercise?
- How often should I exercise?
- How do I pick exercise that's right for me?
- I don't like or can't do most exercise, what should I do?
- Someone else controls my daily schedule, how do I get exercise included?
- What changes in my body can I expect if I start exercising more?
- Do I need to change anything about my diet if I start exercising?
- How can I make sure I'm safe when I'm exercising?
- How do I know if I've hurt myself exercising and what might I do about it?
- Links

Staying Healthy: Exercise

www.aaspire.org
Last Updated September 29, 2015

1 What is this topic about?

Different sources will tell you different things on how to exercise properly. With so many different activities to choose from, figuring out what to do can be difficult. The most important thing about exercise is just to do it, do it in moderation, and do it regularly.

2 What counts as exercise?

Exercise is anything that makes your heart beat faster, your skin sweat, and your joints and muscles get used. Cardiovascular exercise, like walking, biking, running, and swimming makes your heart beat fast and hard. Resistance exercise like weight lifting, yoga, or pilates puts weight on your muscles, bones, and joints. It's good to get both cardio-vascular and resistance exercise, but it's more important to get any kind of exercise.

Exercise doesn't have to be complicated, or involve special equipment. A 30-minute brisk walk three to four times a week is exercise. If walking doesn't seem to be making your heart pump very fast, try running, or try putting heavy things in a backpack and going for a walk with the extra weight.

Exercise doesn't have to be a "sport." Martial arts or dancing–even dancing by yourself alone in your room as long as it gets your heart beating faster–is exercise. So is walking up and down the stairs in your house over and over. So is bouncing on a trampoline or jumping rope in the yard.

Exercise can be done alone or with other people. Some people like to take classes with others to motivate them to exercise. Others don't want to be watched at all. The important thing is to find an exercise you like to do, and do it regularly.

3 How often should I exercise?

If it's important to exercise regularly, what does "regularly" mean? Different resources have different answers to that question. How much you should exercise will also be different depending on whether you have any exercise goals, for example, if you are trying to lose weight or trying to train for a sports competition. In general, it's good to exercise three to five times per week. You should also take at least one day or two days a week off from heavy exercise.

Livestrong.com has an article on how much exercise to get if you're trying to lose weight. San Diego University has tips on how to know if you are getting too much exercise. Zenhabits has tips for how to make exercise a daily habit. The US government has recommendations for exercise in the be active section of fitness.gov

4 How do I pick exercises that are right for me?

Here are some things to think about when picking an exercise:

- Are you physically able to do it well enough so that you can get started? For example, if you haven't exercised in a long time, you might want to start with walking before you try out running. Pick something that you can succeed at.

- Is it easy to get set up for it and/or get to it? Can you just do it without having to make a lot of difficult arrangements? For example, find something you can do in your home or near where you live or work. Or if you're someone who has trouble with fine motor skills, don't pick something that requires buckling and lacing on a lot of complicated safety equipment–or, pick something with equipment that will do fine motor work for you, like using weight machines instead of free weights.
- Is it in your budget? Some exercises like skiing might require a lot of expensive equipment, while others like walking around the neighborhood with a heavy backpack are free.
- Do you like doing it? This is really important! If you like music and dancing, do that. If you enjoy feeling deep pressure in your muscles and joints, weight training might be perfect. If you love slow-paced things, try yoga; for fast-paced nervous energy burn, try sprinting around the track at the local high school when no one else is using it.

5 I don't like or can't do most exercises, what should I do?

If you really don't like any kind of exercise, at least not well enough to be able to do it regularly, or can't do most regular types of exercises, here are some tips for how to get exercise by doing every day things in creative exercise-focused ways. HappyLists has a list of 20 creative ways to get some quick exercise. Fitwatch.com has a list of 9 ways you can slip exercise into your daily routine.

6 Someone else controls my daily schedule, how do I get exercise included?

If you have a good relationship with the person who makes your schedule and you feel comfortable communicating with him or her, discuss your wish to add a new exercise routine. You can then brainstorm realistic ways that you can fit it into your weekly schedule.

If you don't feel comfortable talking with your caregiver about adding exercise to your schedule, you might ask for help from someone you trust. If you receive disability services, you can bring up your desire to exercise at your person-centered care conference. You may want to talk to someone you trust first and invite him or her to the meeting so that he or she can help advocate for you.

7 What changes in my body can I expect if I start exercising more?

Some people experience a lot of changes in their bodies when they start exercising, while others do not. Changes some people might experience are:

- Weight loss or weight gain
- A change in distribution of muscle and fat
- Differently-shaped muscles or more muscles
- Increased appetite or hunger, particularly after workouts
- More energy
- Normal muscle aches

8 Do I need to change anything about my diet if I start exercising?

Exercising causes sweat, which means you need more fluids to replace the ones you sweat out. If you have trouble remembering to drink fluids, you might want to make a rule that you have to drink at least eight ounces of water before you start exercising and again after you finish exercising. Some people may find exercise increases their appetite and they need a bit more food. However moderate amounts of exercise should not require a big change in diet. If you are doing special physical training–for example, if you want to run marathons–you may need to make changes in your diet. That information is outside the scope of this introductory article.

9 How can I make sure I'm safe when I'm exercising?

There are two big kinds of safety with exercise. One is keeping yourself from getting injured from the exercise. The other is being safe from others while exercising, particularly in public places like parks and gyms. Harvard Medical School has 10 Tips for Exercising Safely. These tips were not written for people on the autism spectrum, so some might make bad assumptions like that "listen to your body" is helpful advice. The University of Chicago has some tips for keeping safe while walking in the community.

MedlinePlus has a section on sports safety.

10 How do I know if I've hurt myself exercising and what might I do about it?

It is normal to feel some muscle aches after exercising, especially if you haven't been exercising regularly, if you are trying a new exercise, or if you are pushing yourself to do more than you are used to doing. You can learn more about managing sore muscles and joint pain from exercise at WebMD.

Sometimes, though, pain can be a sign of an injury. It may be hard for some people on the spectrum to tell the difference between normal soreness and pain from an injury, especially if they have difficulty with body awareness. One way to know that you may have injured yourself is if the pain is keeping you from doing something that you ordinarily can do. For example, it might be normal to have achy legs after running, but you should not have to limp when you walk. Or it may be normal to for your arms to be sore after rowing, but if you could lift them over your head before exercising, you should still be able to lift them over your head afterwards. If you think you may have injured yourself, contact your healthcare provider and ask if you need to come in for an appointment.

MedlinePlus also has a section on sports injuries.

11 Links

DareBee has a large number of exercise routines that can be done for free on your own time. There are short and long routines. There are routines that have RPG-type stories with them to make them more interesting. All of the exercises have instructions drawn in black and white illustrations. General Fitness

- The US government's fitness site has information and recommendations about exercise.
- A nice checklist and guide to exercise, both for people just starting out and for people who want to increase their current exercise practice, can be found in this PDF from health.gov.

- Livestrong.com is a health resource website. The fitness section of this website has a comprehensive list of suggestions, advice, activities, and tools for those who are already active or are wishing to get active.
- Mayoclinic.com maintains useful and up-to-date information database and tools to help people stay healthy. Their fitness section has articles on a wide range of topics from basic exercise, to exercise for specific conditions.
- The American Heart Association has fitness recommendations for different ages, and other resources on their website.

Developing Routines

- 20 ways to get quick exersise
- 9 ways to slip exersise into your daily routine
- Tips for making exercise a daily habit

Exercise Safety

- MedlinePlus on sports safety and sports injuries.
- Tips for how to know if you're exercising too much from San Diego University
- 10 Tips for Exercising Safely from Harvard Medical School
- Tips for keeing safe while walking from University of Chicago.

AASPIRE Healthcare Toolkit

Staying Healthy: Recreation

Contents

- What is this topic about?
- What is recreation and why is it important?
- How do I pick recreational activities that are right for me?
- I can't afford the kind of recreation I like, what should I do?
- I need assistance with the kind of recreation I like, what should I do?
- Someone else controls my daily schedule, how can I get recreation included?

Staying Healthy: Recreation

www.aaspire.org
Last Updated September 29, 2015

1 What is this topic about?

Recreation, leisure and play are important for everyone, including adults on the spectrum. Recreation can increase independence, offer a chance to be around peers, or just help people burn off stress. This section describes suggestions for recreational activities.

2 What is recreation and why is it important?

Recreation is something you do that refreshes you. It is something enjoyable that improves your health. It might help you to burn off stress, or just make you happy. Recreation is important for physical and mental health.

Different people find different things recreational. What is recreational may also depend on your mood. Some examples of healthy recreational activities are:

Arts recreation

- drawing, painting, sculpting, taking photographs, making visual art
- singing, composing, playing a musical instrument

- writing stories, poems, non-fiction, plays
- acting in plays, doing comic routines, making movies
- sewing, knitting, building furniture, crafting
- going to live theatre, live music shows, movies

Science recreation

- making machines out of circuit boards, building robots, building radios
- playing with microscopes, chemistry, examining geology, ecosystems, star-gazing
- doing math problems
- programming computers
- going to a science museum, zoo, lecture, aquarium

Sensory recreation

- touching things that are soft/hard/rough/smooth–whatever you like to touch best
- listening to music, sounds that are entertaining or relaxing
- watching spinning things, shiny things, colored lights, things that are entertaining and relaxing to look at
- rocking, swinging, dancing, going on slides, moving in ways that are entertaining

Quiet recreation

- reading a book
- spending quiet time outside in nature just sitting

- watching a movie
- snuggling quietly with a friend
- doing puzzles

Exciting recreation

- white water rafting, hiking, bungee jumping, skiing, water skiing
- going to a party, a club, or a dance
- traveling, visiting new places
- working with animals
- exploring national parks and public lands (see Recreation.gov for some more information)
- playing exciting computer games

Recreation and interests

- Find an online or in-person group that shares your special interest and see about getting involved with it. Meetup.com is a resource for in-person groups; google groups and yahoo groups both offer big lists of online communities dedicated to specific interests.
- Allow yourself to spend time studying, building, doing whatever it is that you love most

Recreation and Self-Advocacy Self-advocacy groups may have recreational activities. Some places to contact to get hooked up with local self-advocacy groups: your state's Council on Developmental Disabilities, the Autistic Self Advocacy Network (ASAN), Self Advocates Becoming Empowered (SABE).

Anything that refreshes you can be recreation. It's OK if the things you like to do for recreation are unusual or related to your special interests. It's OK if the things that you like to do for recreation are the same things you liked to do as a child.

3 How do I pick recreational activities that are right for me?

Here are some things to think about when picking a recreational activity:

- Do you enjoy doing it?
- Does it make you feel refreshed and centered?
- Does it make you feel good about yourself?
- Is it safe for you?
- Do you have time in your schedule to do it?
- Is it in your budget? Some recreational activities can get very expensive, while others are free. Some more expensive activities might have low cost options. See the section on ”I can't afford the kind of recreation I like, what might I do?” for some ideas.
- Is it available where you live? It might be harder to do nature activities in the middle of the city, or to go to a museum or a live symphony if you live in the wilderness. (Although there are books, films, and the Internet...)

4 I can't afford the kind of recreation I like, what should I do?

Some kinds of recreation can cost money. Some can cost a lot of money. Here are some ideas for how to get access to less expensive or free recreation that often costs.

- Theatre companies will often let people come see their dress rehearsals for a reduced rate or for free. Some theatre companies will have special reduced rate nights.
- Some recreational facilities, like museums, zoos, and aquariums have reduced rates for people with disabilities. Some have reduced rate days or times (although they can be crowded on those days).

- City, state, and national parks will often have recreational activities for free, or on a sliding scale.
- Sometimes rates for recreational activities are lower if a group attends. If you know other people who would also enjoy the activity, maybe you could pool your money and get a group rate.
- Some places have ”second run” movie theaters where you can see a movie that’s been out for a while for a low price.
- Some expensive recreational activities can be done in less expensive ways. For example, if you like to travel but don’t have the money to go very far or to exotic locations, try exploring new places in your own city.
- Ask at your local library. Some libraries offer reduced rate tickets for attractions like museums to library card holders.

5 I need assistance with the kind of recreation I like, what should I do?

If you have a friend or family member who you enjoy spending time with, ask them to help you out. If you get developmental disabilities services, ask your case manager or personal agent if you can get any recreation assistance through your services. If you don’t have those things, try contacting the chapter of Autism Society of America in your state. Sometimes they organize recreation or know of resources that can help.

6 Someone else controls my daily schedule, how can I get recreation included?

If you have a good relationship with the person who makes your schedule and you feel comfortable communicating with him or her, discuss your wish to add recreation. You can then brainstorm realistic ways that you can fit it into your weekly schedule.

If you don't feel comfortable talking with your caregiver about adding recreation to your schedule, you might ask for help from someone you trust. If you receive disability services, you can bring up your desire to have more recreation at your person-centered care conference. You may want to talk to someone you trust first and invite him or her to the meeting so that he or she can help advocate for you.

AASPIRE **Healthcare Toolkit**

Staying Healthy: Preventive Care

Contents

- What is this topic about?
- How do I know when I need preventive care?
- How might I schedule preventive care?
- I have a hard time tolerating some types of preventative care, what might I do?
- I have a really hard time with blood draws, what might I do?
- What are some other ways I can minimize risks to my health?
- Links

Staying Healthy: Preventative Care

www.aaspire.org
Last Updated September 29, 2015

1 What is this topic about?

Preventive care includes things that can help prevent a major health problem, or can help catch a health problem when it is still minor or easier to treat. Preventive care includes:

- Checking blood pressure, cholesterol levels, and weight
- Screening for cancers, such as cervical, breast, colon, prostate, and skin cancer
- Screening for other diseases like diabetes, osteoporosis, thyroid disease, HIV and other sexually transmitted infections
- Screening for mental health conditions such as depression or anxiety
- Screening for substance abuse such as alcohol, tobacco and drug abuse
- Asking about life situations that can affect health, such as domestic violence
- Getting vaccines to prevent conditions such as tetanus, the flu, or cervical cancer
- Getting eye exams, dental exams, and dental cleanings
- Getting advice about exercise, diet, or other things you can do to stay healthy

2 How do I know when I need preventive care?

What kinds of preventive care you need, and when you need them, will depend on your age and sex. The Mayo Clinic has a tool that gives a personalized list of recommended screenings based on your age and sex. The Centers for Disease Control have a number of quizzes and schedules for helping to figure out what vaccines are recommended based on your age and sex. Your healthcare provider can also help you figure out what kinds of preventive care you need and when.

You might ask, *”Am I due for any preventive care?”*

Whether or not it’s a good idea to get certain kinds of preventive care isn’t always an easy decision. If you’re not sure what kinds of preventive care you need, or not sure if a certain kind of preventive care is right for you, discuss it with your healthcare provider.

3 How might I schedule preventive care?

Your primary care provider can talk to you about ways to keep yourself healthy and can help you decide what types of preventive care you need. Some types of preventive care (such as getting a tetanus shot) can happen during a normal office visit. Other types may need a special appointment (such as getting a Pap smear). Yet other types have to be done outside of the office and may need a referral from your provider (for example mammograms to screen for breast cancer or colonoscopies to screen for colon cancer).

See the section on ”Making an Appointment” for detailed information on how to make an appointment with your primary care provider. When making an appointment, tell the office staff that you are interested in a preventive care visit. If you think you may need a Pap smear, also mention that to the office staff because many offices schedule longer visits for Pap smears.

Once you are at your visit, your provider can help you decide what preventive care you need and can give you referrals for tests that have to happen outside of the office. You can use the After the Visit Worksheet to help make sure you know how to follow up on these referrals. Your primary care provider can order vaccines for you and give them to you in the office. You can also get some vaccines, such as the flu vaccine, by going to local pharmacies or health fairs.

You will need to go to a dentist for preventive dental care (like getting your teeth cleaned) and to an optometrist for preventive eye care (like checking to see if you need glasses).

4 I have a hard time tolerating some types of preventive care, what might I do?

Many of the tips for being examined by your healthcare provider also apply to preventive care situations.

5 I have a really hard time with blood draws, what might I do?

If you have a very hard time with blood draws, here are some things that might be helpful.

- Ask your provider to only order blood tests when absolutely necessary and group them together to avoid having to get stuck more than once.
- Use a numbing spray or cream on your skin so that you can't feel the needle as much.
- Ask the person drawing blood to be very patient and use a calm voice.
- Ask to lie down or lean on something.

- Get a very detailed explanation of what will happen, including how many tubes of blood will be filled.
- Ask your healthcare provider if it would be a good idea to use an anti-anxiety medication before the blood draw.
- Ask the person drawing the blood to give you a lot of advance warning so you can prepare yourself emotionally.
- Have the person drawing the blood warn you before they stick the needle.
- Ask the person drawing the blood not to tell you when they will stick the needle.
- Bring something, or have someone do something, to distract you.

6 What are some other ways I can minimize risks to my health?

Some other things that can be done to help prevent major health problems are:

- Eat a healthy diet
- Exercise five or more times a week
- Do things you like and that make you happy every day
- Get enough rest and relaxation
- If you drink alcohol, don’t have more than one alcoholic drink per day
- Don’t do drugs
- Don’t smoke cigarettes (here’s some information on quitting if you do)
- Use seatbelts and helmets
- Use sunscreen or other protection from the sun

- If possible, avoid people who make you feel bad about yourself
- Find out how to get help if someone is scaring or hurting you. More information is available at The Hotline.

7 Links

- Mayo Clinic screening tool
- CDC schedules
- Help for abuse at The Hotline

AASPIRE **Healthcare Toolkit**

Autism Information

Mostly for adults new to an autism diagnosis, information about autism spectrum disorder, adult diagnosis, therapy and assistive technology, disability rights laws, and Autistic culture and meeting others on the spectrum.

Contents

- About ASD
- Adult ASD Diagnosis
- Therapy and Assistive Technology
- Disability Rights Laws
- Meeting Others on the Spectrum

AASPIRE **Healthcare Toolkit**

Autism Information: About ASD

Contents

- What is this topic about?
- What are the diagnostic criteria for autism spectrum disorder (ASD)?
- What's the difference between autism, Asperger's, PDD-NOS, and ASD?
- What might ASD look like in adults?
- I was just told about the possibility of ASD and I am having mixed feelings.

Autism Information: About ASD

www.aaspire.org
Last Updated September 29, 2015

1 What is this topic about?

This topic gives very basic information about autism spectrum disorder (ASD). It is meant for people who are first learning about ASD. This topic focuses on ASD in adults.

2 What are the diagnostic criteria for ASD and what might they look like in adults?

Autism spectrum disorder (ASD) is a condition described in the Diagnostic and Statistical Manual of Mental Disorders: DSM 5.[1] It is diagnosed based on observation by a diagnostician or team of diagnosticians (e.g. neuropsychologist, psychologist, psychiatrist, licensed clinical social worker, etc.). If you're interested in learning more about diagnosis, see the topic Adult ASD Diagnosis .

The table below lists the current diagnostic criteria for ASD, along with examples of what they may look like in adults.[2]

¡table border="thin black solid" cellspacing="0" cellpadding="5" summary="DSM5 broken down by critera and examples"¿ ¡tr¿ ¡th colspan="2"¿DSM5 Criteria for ASD¡/th¿ ¡th¿Examples of how critera may manifest in adults¡/th¿ ¡/tr¿ ¡tr¿

¡td rowspan=”3”¿A. Persistent deficits in social communication and social interaction across multiple contexts. (Diagnosis requires person meets all three criteria.)¡/td¿ ¡td¿1. Deficits in social-emotional reciprocity¡/td¿ ¡td¿Difficulty initiating or sustaining back and forth conversation; tendency to monologue without attending to listener cues; unusual response to greetings or other social conventions.¡/td¿ ¡/tr¿ ¡tr¿ ¡td¿2. Deficits in nonverbal communicative behaviors used for social interaction¡/td¿ ¡td¿Lack of eye contact; difficulty understanding non-verbal communication; unusual tone of voice or body language.¡/td¿ ¡/tr¿ ¡tr¿ ¡td¿3. Deficits in developing, maintaining, and understanding relationships¡/td¿ ¡td¿Challenges adapting behavior to match different social settings such as when interacting with family, friends, authority figures, or strangers; difficulty developing or sustaining friendships; greater than usual need for time alone.¡/td¿ ¡/tr¿ ¡tr¿ ¡td rowspan=”4”¿B. Restricted, repetitive patterns of behavior, interests, or activities. (Diagnosis requires person meets at least two of four criteria.)¡/td¿ ¡td¿1. Stereotyped or repetitive motor movements, use of objects, or speech ¡/td¿ ¡td¿Repetitive movements or ”stimming” (e.g., rocking, flapping, pacing, or spinning for enjoyment or as a coping mechanism); arranging objects in a very precise manner; echolalia; continuously repeating sounds, words, or phrases.¡/td¿ ¡/tr¿ ¡tr¿ ¡td¿2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior ¡/td¿ ¡td¿Greater than expected degree of distress with changes in routines or expectations; difficulty transitioning between activities; need to do the same thing in the same way each time; greater than usual reliance on rituals for accomplishing daily tasks.¡/td¿ ¡/tr¿ ¡tr¿ ¡td¿3. Highly restricted, fixated interests that are abnormal in intensity or focus¡/td¿ ¡td¿Intense special interests (e.g., looking at spinning objects for hours, learning the detailed schedules of an entire public transportation system, or becoming an expert in seventeenth century art) while having significant difficulty attending to topics outside of one’s areas of special interest.¡/td¿ ¡/tr¿ ¡tr¿ ¡td¿4. Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment¡/td¿ ¡td¿Being hyper- or hypo-sensitive to sounds, lights, smells, or textures; having an abnormally high or low pain threshold; difficulty processing more than one sense at a time (e.g., not being able to understand spoken language while looking at someone’s face); tendency to become confused or overwhelmed by sensory stimuli; challenges with body awareness or separating different types of sensations.¡/td¿ ¡/tr¿ ¡tr¿ ¡td colspan=”2”¿C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life)¡/td¿ ¡td¿Though characteristics should have been present throughout one’s lifetime, a change in circumstances can disrupt coping strategies and make characteristics more pronounced; alternatively, environmental facilitators, supports, and coping strategies may make characteristics less noticeable. ¡/td¿ ¡/tr¿ ¡tr¿ ¡td colspan=”2”¿D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.¡/td¿ ¡td¿Characteristics lead to difficulty obtaining or sustaining employment, doing basic or instrumental activities of daily living, maintaining social life, or integrating with community. For example, there may be significant mismatch between educational attainment and occupational history.¡/td¿ ¡/tr¿ ¡tr¿ ¡td colspan=”2”¿E. These disturbances are not better explained by intellectual disability or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.¡/td¿ ¡td¿N/A¡/td¿ ¡/tr¿ ¡/table¿ Though the DSM-5 conceptualizes ASD primarily as a social-communication disorder, there is a growing literature supporting the hypothesis that ASD is primarily characterized by differences in information processing.[3] See, for example, the intense world theory of ASD.

Adults on the autism spectrum may display autistic traits very differently from children. Most people, whether or not they are on the autism spectrum, mature and behave differently as they get older. As such, adults on the spectrum may not fit society’s images of autistic children. Also, adults often find coping strategies that help them function in the world, but that may make autistic traits harder to recognize.

Among adults who meet the diagnostic criteria for ASD, autistic traits may look very different. While anyone on the spectrum would be expected to have challenges with social communication, these challenges can show up in many different ways. For example, a person may not be able to speak, may misunderstand facial expressions and body language, or may take language too literally. A person may have difficulty starting a conversation, may need more time alone than most people, or may feel uncomfortable socializing with others without a planned activity.

Likewise, anyone on the spectrum would be expected to have restricted or repetitive patterns of behaviors, interests, or activities, but that can be different for each person. For example, a person may look at spinning objects for hours, learn the detailed schedules of an entire public transportation system, or be an expert in seventeenth century art. Many people on the spectrum appreciate structure and can find routines very helpful in understanding or coping with the world. For example, they may always need to take the same route to get somewhere or may use a very complex organizational system to function at work or remember to eat. Unplanned events or changes in routines may cause anxiety for people on the autism spectrum.

People on the autism spectrum may experience sensory input differently from other people. For example, a person might have very sensitive hearing whereas another might have an extremely high pain threshold. Often people may have a very hard time coping with certain sensations, such as fluorescent lights, loud sounds, light touch, or particular textures or smells. They may not be able to process more than one sense at a time; for example, they may not be able to understand spoken language while looking at someone's face. They may also get overwhelmed when there are a lot of sensory stimuli happening all at once.

Some people on the spectrum may have difficulty with motor skills. Examples may include difficulty with handwriting, catching a ball, or planning out complex, multi-step actions like learning a dance sequence.

Autistic traits can potentially be strengths or challenges, or sometimes both.

Not all people on the autism spectrum have stereotypical positive traits such as being good at memorizing things or using computers. Similarly, people on the autism spectrum do not all shy away from social interactions, and many can maintain strong friendships or relationships.

3 What's the difference between autism, Asperger's, PDD-NOS, and ASD?

The Diagnostic and Statistical Manual (DSM) is the book that defines these terms. Different versions of the book define different terms. The DSM-IV has a category called Pervasive Developmental Disorders (PDD) with different sets of criteria for autistic disorder, Asperger's disorder, and pervasive developmental disorder - not otherwise specified (PDD-NOS). The Centers for Disease Control (CDC) has posted the DSM-IV criteria. The differences between these three terms have not always been very clear to people, including the people who need to diagnose them. Sometimes the same person would be given different labels from different clinicians. To try to get rid of some of this confusion, the most recent version of the DSM, the DSM-V, has defined only one set of criteria and term which is autism spectrum disorder (ASD).

4 I was just told about the possibility of ASD and I am having mixed feelings.

It is normal to feel a wide range of emotions when you are told about possibly having a medical label, especially if you are not familiar with the condition. Many individuals who have received an Autism Spectrum Disorder (ASD) diagnosis have reported feelings such as anger, confusion, embarrassment, but also relief, validation, and belonging. For some Autistic adults, finding out why they have always felt different from others provides them with a sense of relief and direction. Other newly diagnosed Autistic individuals might feel angry about the diagnosis, especially if they do not have support from their parents, friends, or other relatives. A lot of people become very interested and focused on learning about autism when they first find out; it can become a temporary or permanent special interest. Some people find it helpful to work through their doubts and feelings with others who have had a similar experience. See the section Meeting Others on the Spectrum for more information about how to find peers and support groups. Some people can find therapy helpful. Whatever your feelings, it is OK to feel them. Over time most people find a balance. Working through all the feelings is a natural process and it takes time.

5 References

[1] American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders, Firth Edition (DSM-5). Washington, DC: American Psychiatric Association; 2013.

[2] Nicolaidis, C., Kripke, C.C., Raymaker, D.M. (2014) Primary Care for Adults on the Autism Spectrum Medical Clinics of North America. 98;1169-1191.

[3] Kapp, SK (2013). Empathizing with sensory and movement differences: Moving toward sensitive understanding of autism. Frontiers in Integrative Neuroscience. 7(38)

AASPIRE **Healthcare Toolkit**

Autism Information:
Adult ASD Diagnosis

Contents

- What is this topic about?
- Why might I think about being evaluated for a formal diagnosis?
- How can I get evaluated for a diagnosis?
- What if I don't have health insurance that covers diagnostic testing for ASD?
- What usually happens during a diagnostic evaluation?
- How might I prepare for an evaluation?
- Should I tell my friends, family, and acquaintances that I have a diagnosis of ASD?
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- Summary

Autism Information: Adult ASD Diagnosis

www.aaspire.org
Last Updated September 29, 2015

1 What is this topic about?

This topic is about getting evaluated for an autism spectrum diagnosis as an adult. It covers reasons for being evaluated, how to get evaluated, and a little bit about telling friends, family, and other people you know about your diagnosis if you get one.

2 Why might I think about being evaluated for a formal diagnosis?

Getting a diagnosis as an adult has been helpful to many people, though it can sometimes be a mixed or negative experience. Not everyone may need a formal diagnosis. Many things that are helpful to people with a formal diagnosis, like the information in this toolkit, are also available to people who are self-diagnosed. Also, being evaluated for a diagnosis does not mean you will get one.

2.1 Ways a formal diagnosis may benefit you:

- You would have legal rights to accommodations in school, at work, in healthcare, or in other settings.

- You may get a better understanding of yourself.
- Your healthcare providers, including mental health professionals like counselors and therapists, may be able to provide better service to you.
- You may get peace of mind from a professional confirmation of your experiences.
- You may get new ideas for how to make better use of your strengths to handle your challenges.
- It may help your family members, friends, and other people you know to understand and support you better.
- You may qualify for benefits and services for people who have an ASD diagnosis.
- You may qualify for special programs for people with disabilities, such as scholarships or incentives to increase workplace diversity.

2.2 Common risks associated with being evaluated for, or getting, an ASD diagnosis:

- The evaluation process may be stressful or may make you feel bad about yourself.
- You may have a negative experience with an evaluator who does not treat you well.
- You may not get a diagnosis, even if you meet criteria. Different evaluators may interpret criteria in different ways.
- Other people may not believe you or be supportive, even if your diagnosis is official.
- Some people might assume problems you are having are because of autism, rather than for other reasons that need attention in your life.
- Simply having a diagnosis may not be enough for you to qualify for services.

3 How can I get evaluated for a diagnosis?

Typically the first step is to find someone who can make the diagnosis in adults. Here's a list of kinds of professionals who can diagnose individuals on the autistic spectrum.

- Psychiatrists or other medical doctors (MDs) with expertise in ASD
- Psychologists and neuropsychologists
- Licensed clinical social workers

If you need help finding someone who can make a diagnosis, here are some ideas:

- Ask your primary care physician
- Ask someone you know and trust
- Contact a local autism related group (for example, your local Autism Society of America branch)
- Search the Internet (for example, if you live in Portland, you might type into a search engine: autism adult diagnosis Portland)
- Contact your student health services department if you're a student
- Contact your state's Department of Vocational Rehabilitation to help you with getting evaluated for a diagnosis, especially if you are having trouble finding or keeping employment
- Check if there is an autism clinic or autism center in your area. If so, call or check their web site to find out if it has services for adults.

If you have any family, friends, or acquaintances (people who you know a little bit) whom you trust, you might ask them if they can recommend a psychologist or other professional who can diagnose autism. Many people find it helpful to mention that they are especially interested in seeing a professional who has a good reputation for working with adults on the autism spectrum.

You can ask, *”I am wondering if you know of any professionals who diagnose autism and have a good reputation for working with adults?”*

4 What if I don’t have health insurance that covers diagnostic testing for ASD?

Being uninsured or unable to afford a diagnosis can be distressing. If you’re in this position, here are some possible resources:

- Check with your state’s Department of Vocational Rehabilitation (VR), to see if it can be of assistance, especially if you are unemployed or are searching for a job.
- Check with your local Department of Human Services (DHS), to see if it offers medical assistance.
- Check with your student health department if you attend a college to see what options it has for students who need to be evaluated for a diagnosis.
- Check out university psychology clinics to see if your local university offers a clinic, and ask if they evaluate for ASD diagnoses. If so, find out the cost of evaluation, and ask if they have a sliding scale fee. A sliding scale fee means that the cost goes down the less able you are to be able to afford it.
- Check if your state offers low-cost health insurance options for people who do not have access to insurance plans via employment, or other means. For example, if you live in Columbus, Ohio, you might type into an Internet search engine such as Google: low-cost insurance plans Columbus Ohio.

- Check with your parent(s), if you have a good relationship, and see if they might be willing to help fund part or all of the cost of evaluation.
- Explain your situation directly to the diagnostician or provider, and ask whether he or she offers a sliding-scale fee.

5 What usually happens during a diagnostic evaluation?

Your provider's evaluation of you might take anywhere from two days to two or more months, depending on the method your provider uses, and how busy he or she is. The provider doing your assessment may do the following:

- Ask you questions;
- Ask you to take a series of tests (tests often include an IQ test, adaptive skills tests, and the Autism Diagnostic Observation Schedule);
- Ask you to complete questionnaires about your autistic traits such as sensory issues, or other things that may relate to autism;
- After getting your permission and if possible, interview your parents, other family members, or close friends who know you well or can give information about your childhood development (for example, using the Autism Diagnostic Interview-Revised);
- Explore other possible diagnoses, for example, ADHD, social anxiety, obsessive compulsive disorder, or learning disabilities.

6 How might I prepare for an evaluation?

Spend some time listing your autistic traits before your appointment. For example, list the types of difficulties you have with social interactions, what your special interests are, and any of your sensory sensitivities. A list can help you a great deal if you get overwhelmed or anxious and forget what you want to share with a provider. Lists are also a helpful way to open and direct the conversation with the evaluator. If possible, talk with the people you would want your provider to interview about your life or childhood development. Make sure that they know that you are considering an evaluation for diagnosis of ASD, and that they are comfortable talking with a provider about you. Note that you can still get an evaluation even if there is no one who can report on your early childhood.

7 Should I tell my friends, family, and acquaintances that I have a diagnosis of ASD?

Disclosure is very personal. When it comes to sharing an ASD diagnosis, each person will have different boundaries and needs that they must consider. Disclosing your diagnosis can strengthen relationships with people. It can also cause tension, especially when you disclose to people who do not understand autism or are not interested in learning about it. While there is always a risk when you choose to disclose, there is also the possibility of reassurance, better communication, and new understanding. Keep in mind that negative attitudes and perceptions, as well as misunderstandings, are at the root of most unsuccessful disclosure scenarios. In any situation where you need to disclose your diagnosis, try to maintain a sense of confidence and strength.

7.1 Questions to ask yourself before you disclose:

- What might be good for this person to know about my diagnosis?
- Will disclosure improve communication and understanding between this person and me?
- Could my disclosure bring about any negative effects?

- Is this the best time for me to disclose my diagnosis?
- How might this person react to my disclosure, and will I be able to cope with the reaction?

7.2 Reasons some people choose to disclose their diagnosis:

- A friend or family member is confused by a certain need or request, and mentioning an ASD diagnosis might help resolve the confusion (For example, perhaps holiday gatherings are very hard for you. You want your family and friends to know that you care about them, but need to limit the number or length of gatherings you attend.);
- A person who mentions he or she is seeking an evaluation for ASD might benefit from your support, guidance, and commonality;
- People might be more likely to understand you and stop misinterpreting your behaviors.

7.3 Ideas to help disclosure go smoothly:

- Be precise and specific.
- Share your strengths.
- Share your challenges and some solutions you are working on.
- Remind family and friends that you are still the same you and that the only thing that has changed is that you now have an official diagnosis.
- Stay strong if people do not respond in a way that you had hoped for. People often come to understand things better after they have some time to think. Try to be patient and persevere in educating others about yourself and your needs, even if you only do so a little bit at a time.

8 What can I do if people who are important to me react badly to my diagnosis?

Some people may react with disbelief, hostility, or other negative feelings when someone discloses either their plans to pursue evaluation, or when they disclose their diagnosis. This can be hurtful or even traumatizing for the person who has disclosed. There's not always an easy way to get through the tough situation of having a negative response to disclosing. That makes it especially important to find sources of encouragement and strength. Ideas:

- Seek counseling from a trusted counselor or therapist.
- Seek support from a trusted friend or family member.
- Seek guidance from a trusted pastor, priest, rabbi, or other religious or spiritual figure.
- Seek support from other people who have had experiences similar to yours. You might wish to join an autism listserv or forum where you can meet other autistic adults, or you might look for a support group for autistic adults in your area.
- Seek out other members of the Autistic community.
- Seek books written by autistic adults or self-help books that focus on helping people get through hard times.
- Keep a journal or blog of your daily feelings so that you can have a safe way to vent your hurts or frustrations.
- Offer to give the person more information about ASD.
- Write a letter to, or have a conversation with, the person about your experiences and why you think you are on the autism spectrum.
- Give the person time to think about it. Disclosure may take others by surprise.

9 Summary

- Adult diagnosis is possible, and seeking evaluation for it has both potential benefits (for example, increased understanding, access to services, legal rights) and potential risks (for example, stress, not receiving the diagnosis).
- Diagnosis is typically done by psychiatrists or other medical doctors (MDs) with expertise in ASD, psychologists, neuropsychologists, and licensed clinical social workers. You can search for them, or ask others to find them.
- If you don't have health insurance that covers diagnostic testing for ASD, there are free or low-cost options such as Vocational Rehabilitation, universities, and providers with sliding scale fees.
- A diagnostic assessment typically includes interviews of you and people who know you well, a series of tests (like IQ tests), questionnaires about your autistic traits, and looking at other possible diagnoses.
- To prepare for an evaluation, it can be helpful to list your autism-related experiences and to talk with the people you would like the evaluator to interview.
- Disclosing an adult diagnosis to friends, family, and acquaintances is a personal choice, with both possible risks (like not being believed) and possible benefits (like being better understood).
- If someone does react badly to your disclosure of an adult diagnosis, you can discuss it with someone else, offer the person more information about autism to help better understand, or give the person time to think about it.

AASPIRE **Healthcare Toolkit**

Autism Information: Therapy and Assistive Technology

Contents

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- Why might I be interested in therapy or assistive technology?
- Mental Health Therapy
- Occupational Therapy
- Speech and Language Therapy
- Assistive Technology for Communication
- Other Types of Assistive Technology that May Be Useful
- Service Animals
- What qualities might I look for in a therapist?
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- Consent and Self-Advocacy in Therapy
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Autism Information: Therapy and Assistive Technology

www.aaspire.org
Last Updated September 29, 2015

1 What is this topic about?

This topic is about therapy and assistive technology. Therapy includes things like speech and language therapy, occupational therapy, and mental health counseling. Assistive technology helps people do things they could not do without the technology. Speech devices, wheel chairs, and electronic reminder programs are examples of assistive technology. Whether or not to have therapy should always be your choice. Therapies and assistive technologies are not always perfect solutions to address disability-related challenges. The therapies and assistive technologies discussed on this page are not meant to cure or stop someone from being autistic. They are instead meant to provide ideas for ways to accommodate or relieve challenges that are common among individuals on the autism spectrum.

2 Why might I be interested in therapy or assistive technology?

Therapy or assistive technology might help with certain autism-related challenges. Examples of reasons someone on the autism spectrum may choose to explore therapy or assistive technology include:

- Sensory integration or sensory sensitivity

- Motor skills and motor planning
- Communication difficulties
- Challenges with typical social interaction
- Difficulty with sequencing or planning activities
- Assistance with self improvement and achieving personal goals

3 Mental Health Therapy

Life can be challenging and stressful for anyone, and especially so for many individuals on the autism spectrum. Mental health is a person’s emotional and mental well-being. Mental health therapy is used when a person is having difficulty with emotional or mental well-being, or when a person wants to feel more satisfied with life but doesn’t know how. A person might seek mental health therapy for a mental health problem, like anxiety, depression, pervasive fears (for example, fear of leaving the house), obsessive compulsive disorder, eating disorders, post-traumatic stress disorder, or a personality disorder.

A person might also seek mental health therapy for help with changing unwanted behaviors, meeting goals, or finding strategies to improve life. Mental health therapists may be able to offer strategies, scripts (things you can memorize and say in specific social situations), or ideas for accommodations to help with communication, organization, or sensory sensitivities. Some mental health therapists assist with learning ways to understand and manage social situations. People may find therapy helpful in finding ways to understand and respond to negative emotions or to help prevent melt-downs. They may also use therapy to identify behaviors they wish to change and find ways to change them (for example, ways to stop smoking, change rituals that are interfering with life, or have more productive reactions in negative situations). Different mental health therapists may have different approaches to therapy, resources, or tools available to help address their clients’ specific needs. It’s important to find a mental health therapist whose ideas about therapy fit well with your own goals.

To find a mental health therapist in your area, ask your doctor or healthcare provider for a referral, or search the Internet for professionals in your area. Also, many of the tips in Finding a Healthcare Provider also apply to finding a mental health therapist.

4 Occupational Therapy

All people need skills for the ”job of living.” Occupational therapy (OT) helps people do things that they need and want to do. Occupational therapy is used to develop, recover, or maintain the daily living and work skills of individuals with physical, mental, or developmental conditions.[1] Occupational therapy also can help with adapting environments, modifying tasks, teaching new skills, and educating clients and their families.

People might seek occupational therapy if they are having difficulty with personal care tasks, motor movements, staying organized, or sensory processing. A person might also see an occupational therapist if they have difficulty with eating or drinking, balance and coordination, or with skills that are needed to do a job. Occupational therapists have a big-picture perspective and often focus on changing the environment to fit the client. Occupational therapists consider the client an important part of the therapy team.

Different occupational therapists will have various approaches, resources, and tools available to help address their clients' specific needs. It's important to find an occupational therapist whose ideas about therapy fit well with your own goals. Occupational therapy services often include:

- An individualized evaluation, during which the client and occupational therapist determine the client's goals,
- A customized plan to improve the client's ability to reach their goals,

- An outcomes evaluation to make sure the goals are being met and/or to make changes to the plan,
- Possible evaluations of the client's home and other environments (for example, the client's workplace),
- Recommendations for assistive technology and training in its use,
- Guidance and education for the client's family members and/or caregivers.

To find an occupational therapist in your area, ask your doctor or health care provider for a referral, or search the Internet for professionals in your area. Another resource is the America Occupational Therapy Association (AOTA). Also, many of the tips in Finding a Healthcare Provider may also apply to finding an occupational therapist.

5 Speech and Language Therapy

Most people find useful speech and language skills important for standing up for their rights and having a good life. Speech language pathologists (SLPs) can help autistic adults with a variety of speech and language related difficulties. Speech language therapy is used to develop, recover, or maintain speech and language and social communication skills. Speech language pathologists also work with people who have trouble swallowing.

An autistic person might seek speech and language therapy for speech difficulties and difficulties with using language in a social context. Speech production refers to the ability to make sounds, voice quality, and fluency. Some people have a hard time making specific sounds or combinations of sounds, difficulty modulating vocal quality or intonation (such as use of a ”monotone” voice), and stuttering.

Language refers to one's understanding and communication of thoughts, ideas, feelings, wants, and needs. Understanding and using words and grammar are part of language. Trouble with language can lead to communication breakdowns.

Language pragmatics refers to how language is used socially or in a social context. Issues with pragmatics are common in the autistic population. An individual with pragmatic difficulties might say atypical or unrelated things during conversations, or tell stories in a jumbled way, or take language very literally. Pragmatic disorders often coexist with other language-related issues, and they can interfere with social acceptance, as people might avoid conversation with someone who struggles with pragmatics.

Speech language therapy services often include:

- An individualized evaluation, during which the client and speech language pathologist determine the client's goals,
- A customized plan to improve the client's ability to reach his or her speech or language goals,
- An outcomes evaluation to make sure goals are being met and/or to make changes to the plan,
- Recommendations for assistive technology and training in its use,
- Guidance and education for family members and/or caregivers.

To find a speech language therapist in your area, ask your doctor or health care provider for a referral, or search the Internet for professionals in your area. The American Speech-Language Hearing Association (ASHA) provides many resources, as well a feature to help you find a qualified SLP in your area. Also, many of the tips in Finding a Healthcare Provider may also apply to finding an occupational therapist.

6 Assistive Technology for Communication

Everyone deserves access to communication that works for them. Alternative and Augmentative Communication (AAC) gives many people the ability to communicate in a way that works best for them. It involves communication methods that aid or replace speech and/or writing with other kinds of communication like pictures or sign language. AAC can be a temporary or a permanent feature in a person's life. Some individuals are full-time AAC users and others are part-time users. It is OK to only use AAC when you need it. Speech and Language Pathologists (SLPs) and Occupational Therapists are the kinds of therapists who usually help people get set up with AAC. Reasons why a person might seek AAC include challenges related to communicating with speech, either sometimes or all the time. There are a lot of different kinds of AAC. Which kind of AAC will work best for a person will have to do with his or her own personal strengths and motor, visual, cognitive, language, and communication styles. Some high-tech AAC solutions might include:

- Dedicated speech devices (for example, devices by Dynavox)
- Multi-purpose devices such as a laptop computer or an iPhone that has an AAC program installed (for example, Assistiveware's products)

Some low-tech or no-tech AAC solutions might include:

- American Sign Language (ASL), which is commonly used by Deaf people (Check your local community college or university for classes.)
- Communication boards or books with letters, words, phrases, and/or photos
- Notebooks or notepads

Some people will find a combination of AAC strategies useful. It is important for environments to support communication and foster interaction of AAC users. Activities might need to be adapted in order to be inclusive of people who use AAC. Non-AAC users might need help understanding how to accommodate an AAC user in business, conversations, entertainment, schooling, and other settings. To find out more about AAC, ask your doctor or health care provider for resources or referrals, or search the Internet for AAC devices that are sold either online or in your area. Speech language pathologists and occupational therapists are both trained to recommend, provide, and teach people with disabilities about AAC.

7 Other Types of Assistive Technology that May Be Useful

Assistive technology helps people to do things they could not do without the technology. Some assistive technology is so common that most people don't even think of it as special, like eyeglasses. Other kinds of assistive technology might be more rare or highly specialized, like a machine that translates typed text into Braille. There are a lot of reasons why people on the autism spectrum might find assistive technology helpful. Here are some ideas:

- To help with sensory issues
  - Headphones and music players, ear muffs
  - Sunglasses, tinted glasses, and hats with brims
  - Chewing gum or other chewable items
  - Stress balls or other ”fidgets”
- To help with motor skills
  - Mobility devices like wheel chairs or scooters
  - Computer keyboards or speech-to-text programs as alternatives to handwriting
  - Tools designed with large grips, often made for people who have arthritis

- To help with communication
  - Alternative and Augmentative Communication (AAC) strategies and devices (see Assistive Technology for Communication)
  - Speech to text programs for people who can express themselves with speech better than writing
  - Screen readers (text-to-speech) programs for people who have trouble reading
  - TTY (telecommunications device for the deaf) machines or relay services for telephone communication
- To help with organization and other learning disabilities
  - Smart phones, tablets, and computers with programs for organizing, managing calendars, setting reminders, and keeping instructions
  - Paper-based organizers, like day planners or visual schedules
  - Calculators
  - Egg timers, visual timers, programmable watches, and other kinds of clocks

Some assistive technology is easy to get, like day planners or sunglasses. For other equipment, a prescription from your doctor may be needed. For example, some mobility devices require a prescription. Talk to an occupational therapist, speech/language pathologist, disability services professional, other people on the autism spectrum who use assistive technology, or your healthcare provider for more information or ideas.

8 Service Animals

Some individuals on the autism spectrum find that service animals help them to be more independent, or live safer or happier lives. Though service animals do not replace human reasoning and judgment, they can be trained to help humans in many ways. Jim Sinclair, an autistic self-advocate, disability educator, rehabilitation counselor, and long-time private animal rescuer has worked with and written a lot about service animals, namely SSigDOGs (Sensory Signal Dogs or Social Signal Dogs). He notes many reasons[1] a person might want to use a service animal:

- Managing sensory and motor behavior; for example, a service dog can be trained to stop at all street corners, to lead its owner out of harm's way, or to pull its owner out of the path of obstructions.
- Orientation to social environments; for example, an office worker might have a good relationship with coworkers in the work environment, but might have trouble recognizing them outside of a work environment. A service dog can be trained to alert its owner to the presence of familiar people, or to people calling the owner's name.
- Help with routines and changes; for example, the dog's owner might struggle to remember necessary steps to get ready for work. A service dog can prompt the owner to dry off after a shower before getting dressed.

There are many types of service animals, including dogs, cats, birds, monkeys, and horses. The Americans with Disabilities Act (ADA) says that service animals must be allowed to accompany their owners in many settings, but it only recognizes specially trained dogs as service animals. So, for example, other animals may not necessarily be allowed in public buildings or at a job site. To find out more about service animals, ask your healthcare provider's staff or therapist for resources, or search the Internet for service animals near your area. For example you might search for ”certified service dogs Portland Oregon” if you lived near Portland, Oregon.

9 What qualities might I look for in a therapist?

If you are interested in therapy, it is highly recommended that you search for a therapist who has both a strong and positive history of working with autistic individuals. Not all therapists understand autism and the unique ways it can appear in individuals. Some therapists might have negative attitudes about autism, or might have been trained to communicate in ways that do not work well with autistic clients.

You may also want to think about the things in ”How do I know if a healthcare provider is a good choice?”

10 How might I pay for therapy?

10.1 If you have insurance:

Not all insurance will pay for all kinds of therapy. Before you go to your first therapy appointment, consider doing the following.

- Find out if your insurance company will cover the kind of therapy you want.
- If the therapy is covered, find out if you need a referral to a therapist from your primary care provider, and try to get one if needed.
- Find out how much of the appointment will be covered by the insurance and how much you will need to pay ”out of pocket” or ”co-pay.” Make sure you can afford this.
- Find out if there is any additional paperwork, communications, or forms that the insurance company needs in order to agree to pay for the therapy.

10.2 If you do not have insurance or insurance won’t cover the type of therapy you want:

You still might be able to get the therapy you want even if you don’t have insurance, or if the insurance won’t cover the therapy. Some options to ask about:

- Ask the therapist or their office staff if they will see uninsured or self-pay patients.
- Ask the therapist or their office staff if they have a sliding scale or other low-cost option for self-pay patients.
- Find out how much it would cost for you to see the therapist, and consider if you can afford it.
- If there is a university in your area that trains therapists, find out if you can see a therapist in their program for a lower cost.

11 Consent and Self-Advocacy in Therapy

All people are worthy of inclusion and respect, regardless of what a person’s support needs may be. Autistic individuals deserve helpful and respectful therapy. Self-advocacy is important in therapy. Many autistic people are concerned about scientifically unproven treatments. Others are concerned about therapists who care more about making an autistic person look ”normal” than they do about that person’s self worth and quality of life. Meaningful therapy works with an autistic person’s natural way of being instead of trying to ”intervene” against, change, or wipe out who they are. Respectful therapy plans do not make autistic people feel bad, guilty, or inferior. It is important that you know your rights and how to advocate for them. There are some situations where your rights may be limited. For example, if you have a conservator or guardian, that person may make decisions about your therapy that you do not always agree with. Or if a professional is concerned that you might be suicidal or dangerous to others, he or she may have the right to take actions that you don't agree with to ensure your safety. However, in most circumstances, you should not be forced into a therapeutic situation without your permission. If you are uncomfortable with a healthcare provider, therapist, or mental health professional, then you have the right to say no to their services and to seek therapy from someone else. If a professional makes you feel uncomfortable or does something you feel is wrong, bring it up to him or her. Make it known that you are uncomfortable and that you would appreciate if they would respect your boundaries and concerns. Your therapist should always be able to explain to you why they are doing something and how it relates to what you want out of therapy. If your therapist cannot respect your wishes, you do not have to continue seeing them and you can look for another therapist. If you feel you have been treated wrongly by a therapist, three places to try asking for help are:

- your state's Protection and Advocacy (P and A) program.
- the therapist's professional licensing board in your state; for example, search for terms like ”speech language pathology licensing board Arizona” or ”occupational therapy licensing board Oregon”.
- a primary care provider (a ”regular doctor”) who you trust, if you have one. Tell him or her what happened, and ask for advice.

12 Links and Resources

- American Occupational Therapy Association
- American Speech-Language-Hearing Association
- Augmentative and Alternative Communication Institute
- Autistic Self Advocacy Network (Scroll down to Therapies and Health Care.)

- State assistive technology programs

13 References

[1] Sinclair, Jim. ”What Is A SSIG (Autism) Service Dog? by Jim Sinclair.” *Http://www.inspire.com*. N.p., n.d. Web. 23 May 2013.

AASPIRE **Healthcare Toolkit**

Autism Information: Disability Rights Laws

Contents

- What is this topic about?
- Are people on the autism spectrum protected by disability rights laws?
- What laws protect the rights of people with disabilities in the U.S.?
- Where can I get more information about these laws?
- Links

Autism Information: Disability Rights Laws

www.aaspire.org
Last Updated September 29, 2015

1 What is this topic about?

There are laws in the United States that help prevent discrimination against people with disabilities. A person with a disability is discriminated against if they are treated unfairly just because they have a disability. People on the autism spectrum may be protected by these laws. This topic gives a brief summary of the major laws that protect the civil rights of people with disabilities in the U.S. For more information about these laws, please see the section ”Where can I get more information about these laws?”. These laws include civil rights protection in:

- Employment
- Public and private services and buildings
- Public Transportation
- Telecommunications (like telephones and pagers)
- Housing
- Air travel
- Voting
- Institutionalized settings

- Education

How these laws may apply specifically in healthcare is covered in more detail under Your Rights in Healthcare. These laws are a good start in helping to prevent discrimination. Unfortunately, in practice these laws are not always followed very well. Understanding your rights is just one part of a continuing fight for equal access to education, employment, and the community.

2 Are people on the autism spectrum protected by disability rights laws?

The U.S. government uses the following definition of disability for all of the laws listed here except IDEA. The IDEA definition of disability can be found on the IDEA web site. ”An individual is considered to have a ’disability’ if s/he

- has a physical or mental impairment that substantially limits one or more major life activities,
- has a record of such an impairment,
- or is regarded as having such an impairment.

Persons discriminated against because they have a known association or relationship with an individual with a disability also are protected.” (Source: Americans with Disabilities Act Questions and Answers). This means that if

1. a person has an autism spectrum diagnosis, and
2. being on the autism spectrum makes it hard for that person to do things like hold a job, use the telephone, or have relationships with others, or
3. others consider that person to be on the autism spectrum,

then that person would likely be protected by these laws. A person does not need to call themselves ”disabled” to meet this definition. The definition covers the perception by others of disability.

3 What laws protect the rights of people with disabilities in the U.S.?

This is a summary of the more detailed list that can be found at A Guide to Disability Rights Laws published by the U.S. Department of Justice (DOJ). The detailed list can be found at www.ada.gov/cguide.htm.

3.1 Americans with Disabilities Act (ADA)

The ADA is a broad law that makes sure people with disabilities are not discriminated against and have equal access to

- employment,
- state and local government services, information, and buildings,
- public transportation,
- privately operated facilities that are open to the public (for example, restaurants, retail stores, hotels and movie theaters, to doctors' offices, homeless shelters, and recreation facilities),
- telephone service, including the requirement that telephone companies provide relay service.

For more detailed information, see the Americans with Disabilities Act on the DOJ site.

More information and resources can also be found on the ADA Regulations and Technical Assistance Materials page, as well as on the ADA home page www.ada.gov

3.2 Telecommunications Act

This law requires equipment like telephones, cell phones, and pagers to be accessible and usable by people with disabilities. The law also requires that telephone services like operator services, emergency calls, and directory assistance are accessible to and usable by persons with disabilities.

For more detailed information see the Telecommunication Act on the DOJ site.

3.3 Fair Housing Act

This law says people can not be discriminated against in housing based on their disability (as well as other things like race). This law covers both buying and renting homes. This law also requires that owners of housing facilities make changes to their policies to give people with disabilities equal access. For example, a landlord with a ”no pets” policy may be required to let someone who has a service animal rent from them.

For more detailed information, see the Fair Housing Act on the DOJ site.

3.4 Air Carrier Access Act

This law says people with disabilities can not be discriminated against in air travel. It requires airlines to provide accommodations, such as early boarding, assisted boarding, or wheelchair access, to people with disabilities.

For more detailed information, see the Air Carrier Access Act on the DOJ site.

3.5 Voting Accessibility for the Elderly and Handicapped Act

This law requires polling places to be accessible to people with disabilities for federal elections. If it is not possible to make polling places accessible, then a different way for people to cast their votes needs to be offered. This law also requires voter registration and information about voting to be accessible.

For more detailed information, see the Voting Accessibility for the Elderly and Handicapped Act on the DOJ site.

3.6 National Voter Registration Act

This law requires that all state-funded programs that provide services to persons with disabilities give the people they serve voter registration forms. It also requires the programs to offer assistance with registering to vote.

For more detailed information, see the National Voter Registration Act on the DOJ site.

3.7 The Civil Rights of Institutionalized Persons Act (CRIPA)

This law says the U.S. Attorney General can look into the conditions of institutions of confinement, such as jails, nursing homes, or institutions for people with developmental disabilities. Its purpose is to allow the Attorney General to find and correct problems that may harm the health and safety of residents.

For more detailed information, see the CRIPA section of the DOJ site.

3.8 Individuals with Disabilities Education Act (IDEA)

This law requires public schools to educate individuals with disabilities through age 21. This includes providing accommodations and services that meet the individual needs of each student.

Note: Colleges are covered under the ADA.

For more detailed information, see the IDEA section of the DOJ site.

3.9 Rehabilitation Act

This law says people with disabilities can not be discriminated against in any program that gets money from the government. This includes state-run colleges and higher education. It also protects people with disabilities who are government employees. Some of the things in this law are also covered by the Americans with Disabilities Act. Section 508 of the Rehabilitation act requires the government to have accessible technology, including accessible web sites.

For more detailed information, see the Rehabilitation Act on the DOJ site.

3.10 Architectural Barriers Act

This law requires that all new or re-built government buildings are made to be accessible to people with disabilities.

For more detailed information, see the Architectural Barriers Act on the DOJ site.

This is a summary of the more detailed list that can be found at A Guide to Disability Rights Laws published by the U.S. Department of Justice (DOJ). The detailed list can be found at www.ada.gov/cguide.htm.

4 Where can I get more information about these laws?

Online:

- Department of Justice summary of laws http://www.ada.gov/cguide.htm
- ADA Centers http://adata.org

Offline request for information:

- 800 - 514 - 0301 (voice)
- 800 - 514 - 0383 (TTY)
- U.S. Department of Justice

Civil Rights Division

950 Pennsylvania Avenue, N.W.

Disability Rights Section - NYAV

Washington, D.C. 20530

5 Links

- http://www.ada.gov/cguide.htm
- ADA Regulations and Technical Assistance Materials
- Telecommunication Act
- Fair Housing Act
- Air Carrier Access Act
- Voting Accessibility for the Elderly and Handicapped Act
- National Voter Registration Act
- CRIPA
- IDEA
- Rehabilitation Act
- Architectural Barriers Act

Autism Information:
Meeting Others on the Spectrum

Contents

- What is this topic about?
- Autistic Culture
- Meeting autistic people in person
- Meeting autistic people online or learning about the self-advocacy movement online
- Finding autistic people you like
- Reflections from autistic people
- Summary
- Links and Resources

Autism Information: Meeting Others On the Spectrum

www.aaspire.org
Last Updated September 29, 2015

1 What is this topic about?

This topic is about Autistic culture, and how to find other people on the autism spectrum both in person and on the Internet. Meeting other people who are like you can be rewarding.

2 Autistic Culture

Culture brings people together to share everything from common beliefs and principles, to goals, identity, customs, and arts, to literature, history, shared experiences and communal achievements. Most people end up sharing their family's culture. For example, children of Latino parents often adopt a Latino culture. This is not always the case, though. Individuals from heterosexual families can adopt a LGBT culture; deaf people from hearing families can adopt the culture of the Deaf community, and autistic individuals from non-autistic families can adopt an Autistic culture. For cultures that are not always passed through family lines, culture and information are passed from established members to newer members in a cycle that continues to build on and create tradition. Examples of Autistic cultural events include Autreat, Autistic Pride Day, Autism Acceptance Day, and Autistics Speaking Day. There is an

Autistic community that many Autistic people enjoy being a part of. The Autistic community is similar to the Deaf community though it is much newer (the Deaf community has been around since the 1800s) and more often considers autism to be a disability. Like other minority communities, the Autistic community has its own support systems, leaders, values, social spaces, traditional events, and organizations. There is much to gain by meeting and befriending other autistic people. Interacting with autistic people can positively impact an autistic person's social life and well being. We have much to learn from each other and our individual experiences. The Autistic community generally champions neurodiversity, including appropriate services and support[1].

3 Meeing autistic people in person

If you are interested in in-person social gatherings, advocacy groups, and support groups, here are some ideas for finding groups in your area:

- Check Meetup.com for local autism-focused groups in your area. Some groups will likely be for parents of autistic children, but others may be for autistic teens and/or adults. If your area has groups for teens and adults, you might find advocacy-focused groups, social groups such as gaming groups, or support groups.
- If you are a student, check out the student-run groups at your university to see if they have any established chapters for autistic students. If not, you might consider if you have the time to start a group at your university.
- Check out your favorite autism or disability rights organizations to see if they have chapters in your area. For example, you could check with Autism Society of America (ASA), Autistic Self Advocacy Network (ASAN), Self Advocates Becoming Empowered (SABE), or ADAPT.
- Do an Internet search for groups with your city or town name included. For example, google ”adult autistic social group Portland”.

Groups may have different goals and areas of focus. When you come across a group that interests you, find out about their mission and goals to see if it fits what you're looking for. You might need to try a few groups before you find one that fits your needs.

If you're interested in self-advocacy, look for an advocacy-focused group where you can get involved with other autistic people who are interested in changing legislation (laws) that affects autistic people. Advocacy groups also educate the public about autism and work to combat fear, pity, and negative stereotypes.

4 Meeting autistic people online or learning about the self-advocacy movement online

If you're interested in meeting other autistic people, but you feel more comfortable doing it online, there are many listserves, forums, and web sites that you can visit. To find local groups and listserves, go to Google Groups and browse for autism-focused groups in your city or state.

The sites below can help you get started. They will have links and resources that might be of interest to you:

- Association for Autistic Community (AAC)
- Autistics.org: The Real Voice of Autism
- Making Sense of Autism
- Shift Journal of Alternatives: Neurodiversity and social change
- The Autism Acceptance Project (TAAP)
- The Autistic Self Advocacy Network
- The Autism Society of America (ASA)

- The Thinking Person's Guide to Autism
- WrongPlanet.net
- Jim Sinclair's archive via the Way Back Machine
- Autism Women's Network (AWN)

5 Finding autistic people you like

It's important to remember that autistic people are as unique, varied, and shaped by personal life experiences as anyone else in the world. If you run across an autistic person who does not treat you well (either online or in person), try not to take it personally. Just like everyone else, autistic people range in personality and interests. Keep on looking and exploring, and eventually you'll probably find an autistic person who shares some of your interests and views.

6 Reflections from autistic people

"I recently met a lot of autistic people at an advocacy group I attended last night. For the first time in my life, I felt like I could be myself and that people would understand me and not judge me for being autistic. I was in good company!" Ernie "Autistic people should reach out to each other for friendship and support. You never know who you will meet that you might end up having a lot in common with." Alice "I've been around autistic people all of my life. But I did not realize that I was autistic too until I was diagnosed in adulthood (shortly after my son received a diagnosis). I had always known there was something different about me, as I always felt that I was from another planet. I had joined an autism-focused listserve shortly before my diagnosis. And that is where I met one of my friends. Like me, she is autistic. Over the years we have had many deep conversations about autism and about being autistic, from what it was like growing up to defining ourselves in the here and now. It brings happy tears to my eyes to admit that it is my autistic friend who helped me to find myself and who helped me to explore and understand myself, my needs, and my relationship to the world." Jemma "Autistic people ROCK!" Kramer

7 Summary

- Autistic culture has common beliefs, goals, customs, arts, literature, history, and community achievements.
- Some ways to meet autistic people in person are through meetup.com, through student-run groups, and through autism or disability rights organizations.
- There are many web sites, listserves, and forums for meeting autistic people online, or for learning more about the self-advocacy movement.
- Many autistic people enjoy meeting others like them and participating in Autistic culture. Just like any people though, not everyone will get along. When you do find people you do get along with it can be rewarding.

8 Links and Resources

General Autism Groups

- ¡a href="http://autisticcommunity.org/"¿Association for Autistic Community (AAC)
- The Autism Society of America (ASA)
- Autism Women's Network (AWN)

- The Autism Acceptance Project (TAAP)
- WrongPlanet.net

Disability Rights and Advocacy Focused Groups

- The Autistic Self Advocacy Network
- Self Advocates Becoming Empowered (SABE)
- ADAPT

Other Information and Resources

- Autism Now
- Autistics.org: The Real Voice of Autism
- Making Sense of Autism
- Shift Journal of Alternatives: Neurodiversity and social change
- The Thinking Person's Guide to Autism
- Jim Sinclair's archive via the Way Back Machine

9 References

[1] Kapp, S. K., Gillespie-Lynch, K., Sherman, L. E., & Hutman, T. (2012, April 30). Deficit, Difference, or Both? Autism and Neurodiversity. Developmental Psychology. Advance online publication. doi: 10.1037/a0028353

AASPIRE **Healthcare Toolkit**

Your Rights in Healthcare

Information and resources about disclosing an autism diagnosis, getting equal access to healthcare, understanding privacy and decision-making authority in healthcare.

Contents

- Disclosure
- Equal Access
- Privacy
- Decision Making Authority

AASPIRE **Healthcare Toolkit**

Your Rights in Healthcare: Disclosure

Contents

- What is this topic about?
- Confidentiality - who can know about my ASD diagnosis?
- Should I disclose my ASD diagnosis to my healthcare providers?
- Can I be denied employment if I disclose my ASD diagnosis to my healthcare provider?
- Can I be denied or loose my health insurance if I disclose my ASD diagnosis?
- Summary

Your Rights in Healthcare: Disclosure

www.aaspire.org
Last Updated September 29, 2015

1 What is this topic about?

This topic is about the potential benefits or drawbacks of disclosing your autism spectrum disorder diagnosis to your doctor, your doctor's staff, or your health insurance provider.

2 Confidentiality - who can know about my ASD diagnosis?

In most cases, only people you choose can know about your ASD diagnosis. Your health information, including your ASD diagnosis, is confidential and protected under the Health Insurance Portability and Accountability Act, or HIPAA. That means your health information is kept secret by healthcare providers, healthcare staff, and insurance companies except in certain situations.

- If you choose to, you can give healthcare providers permission share your information with other people who you name.
- If you have a guardian or conservator, your healthcare providers can share your health information with them without your permission.

- In rare cases, your information can be shared legally with others without your permission (for example, if you are in danger of hurting yourself or someone else).
- In rare cases, your information can be gotten illegally (for example, by thieves or computer hackers).

Note that HIPAA privacy protection does not apply to most people outside of a medical setting. So if you tell someone like a classmate or co-worker, they do not have to keep your diagnosis secret, and they might tell other people.

3 Should I disclose my ASD diagnosis to my healthcare providers?

Whether to tell your provider about your ASD diagnosis is your choice. In most cases, the benefits of disclosing a diagnosis far outweigh the risks, but you need to weigh the risks and benefits for yourself to know what is right for you.

3.1 Possible Benefits of Disclosing an ASD Diagnosis

- Understanding - Knowing your diagnosis may help the healthcare provider to understand you better and to provide better healthcare.
- Communication - Knowing your diagnosis may help the healthcare provider not to misinterpret the things you say and do. This can help them to communicate with you better.
- Avoiding Misdiagnosis - Knowing your real diagnosis may help the healthcare provider not to misdiagnose you with something you don’t have (for example, psychosis, anxiety, depression, malingering)
- Accommodations - If you disclose, you can ask for specific accommodations or strategies to help you get better access to quality healthcare. You

may also need a note from your healthcare provider to get accommodations in employment or other areas of your life.

- Referral for Formal ASD Diagnosis - If you don't already have a formal ASD diagnosis, your healthcare provider can possibly help you get one. More information can be found in the section on Adult ASD Diagnosis.

3.2 Possible Risks of Disclosing an ASD Diagnosis

- Misunderstanding - The healthcare provider may not know very much about autism and may misunderstand what it is (but you can educate them).
- Misjudging Abilities - The healthcare provider may underestimate your abilities (for example, think you don't understand things that you do) or overestimate your abilities (for example, think that because you can speak you can communicate well in speech). They might misjudge you based on their lack of understanding about autism (though, again you can educate them).
- Disbelief - Some providers may not believe your diagnosis if you do not fit their limited understanding of what people on the autism spectrum are like. Providers may also have negative opinions about people who self-diagnose autism.
- Confidentiality - While healthcare providers are not allowed to tell other people about your diagnosis in most circumstances (see the section on HIPAA), there is a very small chance of loss of confidentiality (chance that your diagnosis won't be kept secret).

4 Can I be denied employment if I disclose my ASD diagnosis to my healthcare provider?

Your healthcare provider is not allowed to disclose your protected health information, including your ASD diagnosis, to anyone outside of the healthcare system except in very special circumstances. Your healthcare provider is not allowed to tell your employer about your ASD diagnosis without your permission. See the information on HIPAA and Privacy for more information on who your provider is allowed to share your health information with. You do NOT have to tell your employer about your ASD diagnosis, or about any other medical diagnosis you may have. However, if you want to get accommodations in employment under the Americans with Disabilities Act (ADA), employers require you to disclose, and sometimes also require a note from your healthcare provider confirming your diagnosis. In that case, you might ask your healthcare provider to talk to your employer about your ASD diagnosis. The ADA protects people with disabilities from discrimination in the workplace. It is supposed to give people with disabilities an equal opportunity at employment. However, there is an exception within the ADA for employees who pose what is called a ”direct threat.” This means that the you may not be hired, or can be fired, if your mental or physical health would make the job unsafe for you or for co-workers. Who decides what is a ”direct threat” is left vague. Whether or not a direct threat exists is determined on a case by case basis, so it depends on the particular job and the particular applicant or employee. Because of this, it is difficult to say how disclosing your ASD diagnosis to your employer would affect current or potential employment. If this is a concern of yours, seek legal advice in your area.

5 Can I be denied or loose my health insurance if I disclose my ASD diagnosis?

While it was once possible that you could be denied or lose your coverage because of an ASD diagnosis, it is no longer the case.

ASD is considered a pre-existing condition. A pre-existing condition is a medical condition that existed before someone applies for or enrolls in a new health insurance policy.

On January 1st, 2014, a part of the Patient Protection and Affordable Care Act (PPACA; also known as Obamacare) started. This part of the PPACA changed the way insurance treats people who have pre-existing conditions. Insurance companies are no longer allowed to drop patients, raise rates, and offer poor coverage for patients with conditions they consider high risk because of a pre-existing condition. As long as a person pays their insurance bills, the insurance must cover them the same as everyone else.

6 Summary

Only people you choose can know about your ASD diagnosis. Your health information is protected by a law called (HIPPA). In very rare cases your information may be shared for emergency medical reasons or due to your medical records being stolen.

It's your choice if you want to tell your new healthcare provider, their staff, or your insurance company about your ASD diagnosis. Telling your provider may help them better understand you and make working with you easier (but some providers may also need some education). It may also be necessary if you want to get accommodations for work.

Your healthcare provider is not allowed to share your ASD diagnosis with your employer unless you give your permission. The ADA protects people with disabilities from being discriminated against at work. However it also says someone can be fired or not hired because of their disability if it would be unsafe for the person or their co-workers. Seek legal advice if you are concerned about this.

Currently, it is unlikely that you will lose or be denied health insurance coverage because of your ASD diagnosis, but it is possible. However, on January 1, 2014, a part of the Patient Protection and Affordable Care Act (PPACA; also known as Obamacare) will start. It will prevent insurance companies from denying coverage or dropping patients because of pre-existing conditions, including ASD. Then it won't be possible anymore to be denied insurance or dropped from coverage because an ASD diagnosis.

AASPIRE **Healthcare Toolkit**

Your Rights in Healthcare: Equal Access

Contents

- What is this topic about?
- What is the ADA?
- What are "reasonable accommodations"?
- How does the ADA apply to healthcare?
- How do I request ADA accommodations for my healthcare?
- What if my healthcare provider does not immediately give me the ADA accommodations I asked for?
- How do I make sure other healthcare providers know about my ADA accommodations?
- Do I have to tell my healthcare provider about my ASD diagnosis to get accommodations?
- Where can I find more information and advice on the ADA?
- Summary and Tips

Your Rights in Healthcare: Equal Access

www.aaspire.org
Last Updated September 29, 2015

1 What is this topic about?

This topic is about getting equal access to healthcare. Equal access means having the same opportunity to get quality healthcare as people who are not on the autism spectrum.

The Americans with Disabilities Act (ADA) is the main law that requires equal access to healthcare for people with disabilities, including people on the autism spectrum. This section talks about how the ADA applies to healthcare, how to get accommodations for equal access, and where to find more information about the ADA in healthcare settings.

2 What is the ADA?

The Americans with Disabilities Act (ADA) is a broad law that makes sure people with disabilities are not discriminated against and have equal access to

- employment,
- state and local government services, information, and buildings,

- public transportation,
- privately operated facilities that are open to the public (for example, restaurants, retail stores, hotels and movie theaters, doctors’ offices, homeless shelters, and recreation facilities),
- telephone service, including the requirement that telephone companies provide relay service and assistive telecommunications devices for the deaf and hard of hearing.

3 What are ”reasonable accommodations”?

Healthcare settings are covered under state and local government services, information and buildings, and under privately operated facilities that are open to the public.

Making healthcare accessible is typically done by providing ”reasonable accommodations”.

An *accommodation* is a modification or adjustment to something that enable a person with a disability to do something they would not otherwise be able to do.

A *reasonable* accommodation is an accommodation that can be made without causing ”undue hardship”. Undue hardship is considered ”significant difficulty or expense”.

Accommodations are not defined in the ADA. It is expected that accommodations will be negotiated on a case-by-case basis. What is ”reasonable” is also not defined in the ADA beyond saying it is ”feasible” and ”plausible” and would not cause ”undue hardship.” Part of the reason for this vagueness is because what is ”reasonable” could change depending on the situation.

An example of an *accommodation* for someone who has a hard time hearing or following quick real-time speech might be hiring someone to provide closed captions.

That accommodation might be *reasonable* if it's requested at a large government-sponsored conference.

But the same accommodation might cause *undue hardship* for a small conference where the cost of hiring someone to provide closed captions would be larger than the entire conference budget.

4 How does the ADA apply to healthcare?

The ADA does not give specific recommendations for how to give people equal access to healthcare. This is because different people have different needs. What helps one person might not help another. Instead the law just requires that facilities and services are accessible, as long as it does not cause ”undo hardship.” What will cause ”undue hardship” will be different depending on where you get your healthcare. For example, a clinic that's part of a large city hospital might have a greater ability to accommodate some needs, for example providing an American Sign Language (ASL) interpreter, than a small, rural practice. A small, rural practice may have a greater ability to accommodate other needs, for example, they may be more able to offer house calls. Healthcare providers may not know about the ADA or understand that it applies to them. Each provider is different, but in general, it is easiest to educate providers about the ADA while discussing your own personal needs for accommodations. Here are some examples of ways that accommodations under the ADA can happen in healthcare. These are just meant to be examples. You might not need these things. Your clinic may also not be able to provide all of them.

4.1 Accessible Buildings / Facilities

The ADA requires that certain buildings (such as state and local government buildings) follow accessibility standards to ensure people with disabilities can fully access them and the services that happen within them. Most healthcare facilities and buildings are covered under this law. Examples of ways buildings or facilities can be made accessible to people on the autism spectrum are by:

- providing sensory-friendly waiting or examination areas,
- providing maps or assistance navigating buildings,
- making sure mobility devices can access buildings.

4.2 Accessible Communication / Services

The ADA requires healthcare facilities to provide patients and their supporters with services to ensure effective communication between patients and healthcare providers. This includes things like:

- qualified interpreters
- note takers
- real-time computer-aided transcription services or real-time captioning
- written materials
- exchange of written notes
- braille materials
- screen readers
- large print materials

Other examples of ways communication and healthcare services can be made accessible to individuals on the autism spectrum are:

- allowing a service animal or trusted person to be present,
- allowing extra time for communication,

- preparing a schedule of the visit in advance and being communicative of changes,
- requesting healthcare providers use direct, specific language.

The examples given here are just that: examples. If there is something you need in order to make healthcare facilities or communication with healthcare providers accessible to you, discuss it with your healthcare provider. The ADA is open-ended so that lots of different kinds of needs can be met.

5 How do I request ADA accommodations for my healthcare?

If you need accommodations to access healthcare, talk to your healthcare provider or their office staff about your needs.

No one can say for sure how a particular provider will respond to a particular patient's requests for accommodations. However, the following are a few tips that may make your request for accommodations more effective:

- Do not make the request seem like a demand.
- Explain the way(s) that your disability makes it difficult to get good healthcare. Give concrete examples.
- Say that you would like to discuss possible accommodations that could help make visits go more smoothly. (Or that could help you make it to your appointments, or that could help you better follow the providers recommendations, etc.)
- Give some ideas of possible accommodations. Ask if they would be possible or if the provider has other ideas of accommodations that would work well in their clinic or practice.

Sometimes, you may be able to ask for some accommodations before you go to an appointment. Here is an example of a way to request an accommodation from office staff before your visit.

> *"I am on the autism spectrum and I have a very hard time waiting in busy waiting areas. I get so overstimulated and confused that by the time I go see the doctor, I can no longer pay attention to what he is saying or answer his questions. I would love your help to think about possible accommodations. One idea would be to let me wait in a quiet room until it is my turn. Another would be to let me wait in my car and then call or text my cellphone when it is my turn. Would either of these things work? Do you have any other ideas? I really appreciate your help."*

However, more complex discussions of accommodations take time. It is best to schedule an appointment with your provider to talk about a good long-term plan.

Here is an example of a possible way to request accommodations during a visit with a provider:

> *"I am on the autism spectrum and I sometimes have a hard time with office visits. I often get so anxious or confused that I can't answer questions well or understand recommendations. Could we talk a little about possible accommodations that would make it easier for me to make it through an office visit?" (wait for response.) There are a few things that may help. First, I get really anxious and confused if I don't know what to expect. One thing that might help is to write down a list of things to expect during the visit and then point to each step as we get to it. Is that something that would be possible? Do you have other ideas to help me better understand what to expect during a visit?" (wait for response and discuss ideas)*

> *”Another problem is that I sometimes can’t process information quickly. That means that I may not be able to understand what you are saying, think about it, and make a decision as fast as other patients. One idea is to tell me your recommendations, write down the key points, go see another patient, and then come back and let me tell you what I would like to do. Another idea would be to write down the key points, let me think about it at home, and then let me tell you my decision via your secure messaging system. Would either of these ideas work? Do you have other ideas that may help give me extra time to process information?” (wait for response and discuss ideas)*

6 What if my healthcare provider does not immediately give me the ADA accommodations I asked for?

Most providers really do want to offer effective healthcare. There may be a number of reasons that a provider does not immediately comply with a request for ADA accommodations:

- They may not understand how your disability affects your healthcare. Try to give very practical examples of how your disability gets in the way of your healthcare. For example, instead of just saying *”I don’t like fluorescent lights,”* say, *”I am really sensitive to fluorescent lights. The buzzing and flickering makes it hard for me to focus on what you are saying.”*
- They may have perceived your request as an accusation that they did something wrong. Then they may have gotten defensive. It can help if you start your conversation with one of the following sentences to try to set them at back ease:
  - *”I know you are trying to help me.”*
  - *”I appreciate your time and your patience with me.”*
  - *”I appreciate that you are very busy.”*

  - *"Sometimes I am very direct, but I would really like to work with you to make visits go more smoothly."*
  - *"I appreciate _______"* (where you fill in the blank with something you honestly do appreciate about your healthcare provider).

- They may not know how to actually give you accommodations. Give them practical examples of what may help.
- They may not be able to do exactly what you ask, and may think that it's the only option. Make it clear that these are just ideas and you are open to other things that may work better in their practice.
- They may be stressed about time and feel like they don't have the time to deal with your request for accommodations. Try to make it clear that you respect how busy they are. Work with them to find a better time to talk about your request. Tell them you would like to work with them to find accommodations that can fit into a busy clinic schedule.
- They may get overwhelmed if you make too many requests at once. It is best to highlight just a few accommodations. Focus on the ones you think are going to be more useful.
- They may not be thinking of your requests as ADA accommodations. Many providers think of the ADA as it applies to things like the need for wheelchair ramps, but they may not have ever thought about the ADA as is applies to their own patient care. They may be confusing your requests as "preferences" instead of actual ADA accommodations. Using the word "accommodations" and specifically linking the requests to your disability may help. If not, it may help to educate them about the ADA. But it is best to do so in a non-threatening way. For example, instead of saying, *"The law says you have to give me accommodations,"* you may say, *"The ADA protects my right to have reasonable accommodations in healthcare, and I want to work with you to figure out what would be reasonable in your practice."*

Getting the right accommodations is likely going to take time. It may take more than one visit to set up the accommodations you need and to find ways to actually make them work. Your accommodations are also likely to change over time. If a provider seems to be open to working with you, have patience and keep trying to figure out what works best. If a provider does not seem willing to work with you, you have the right to go to a different provider. Some providers are never going to work well with some patients. Try to find someone who will.

7 How do I make sure other healthcare providers know about my ADA accommodations?

Encourage your healthcare provider to keep a written list of your accommodations with your records so they and their staff will know your accommodations the next time you need healthcare. You might want to make an Autism Healthcare Accommodations Report for your healthcare provider. Keep a copy of your accommodations report so that you can show it to other providers.

During emergency situations, you might not be interacting with your regular doctor, or you might not be able to communicate your needs. Write down the most important accommodations you need and keep the note in your wallet, bag, purse or something that you are likely to have with you. That way emergency personnel can find it. A PDF form you can download and fill out is available at www.my-healthkey.com.

You may also want to consider getting a medical ID that notes important information about accommodations you need in medical situations. You can get medical IDs online from many places such as www.americanmedical-id.com and http://www.medicalert.org/. You can search for ”medical id jewelry”. Some jewelry stores will also make them. Ask your local jewelry stores.

8 Do I have to tell my healthcare provider about my ASD diagnosis to get accommodations?

If you want to get accommodations under the ADA, you need to disclose your diagnosis to your healthcare provider. This is because the ADA only requires people to make accommodations for individuals who have a documented disability. For more information on how the ADA defines disability see ”Are people on the autism spectrum protected by disability rights laws?”

It is sometimes possible to get informal accommodations without disclosing that you have ASD. For example, you might just say, ”I have a disability that makes it hard for me to talk on the phone, can we come up with a different way for me to communicate with your office?” Others may be willing to accommodate your needs, and not question why you need them. However, people will not be required to accommodate your needs if you do not share that you have a documented disability. They can refuse and you will not be able to do anything about it legally.

For more information on disclosure see the Disclosure section.

9 Where can I find more information and advice on the ADA?

You can get more information about the ADA, as well as information about other laws that protect the rights of people with disabilities in the section Disability Rights Laws.

Also, here is a comprehensive list of links to resources related to the ADA.

Main ADA page - http://www.ada.gov

For more information on the ADA and healthcare - http://www.pacer.org/publications/ada
For more a very in-depth legal analysis of the ADA in healthcare, see http://www.ncbi.nlm
(note: this article is written in a very academic style)

ADA Centers see http://adata.org/Static/Home.html

For a useful questions an answers article on the ADA and healthcare from the Pacer Center: http://www.pacer.org/publications/adaqa/health.asp

ADAdata.org has a frequently asked questions page where you can learn more about the ADA. http://adata.org/faq-page

Here are direct links to the ADA Centers for each region in the U.S.:

- New England ADA Center - Maine, New Hampshire, Vermont, Massachusetts, Connecticut, and Rhode Island www.NewEnglandADA.org
- Northeast ADA Center - New Jersey, New York, Puerto Rico and the U.S. Virgin Islands www.dbtacnortheast.org
- Mid-Atlantic ADA Center - Delaware, District of Columbia, Maryland, Pennsylvania, Virginia and West Virginia www.adainfo.org
- Southeast ADA Center - Alabama, Florida, Georgia, Kentucky, Mississippi, North Carolina, South Carolina and Tennessee www.sedbtac.org
- Great Lakes ADA Center - Illinois, Indiana, Michigan, Minnesota, Ohio and Wisconsin www.adagreatlakes.org
- Southwest ADA Center - Arkansas, Louisiana, New Mexico, Oklahoma and Texas www.dlrp.org
- Great Plains ADA Center - Iowa, Kansas, Missouri and Nebraska www.gpadacenter.
- Rocky Mountain ADA Center - Colorado, Montana, North Dakota, South Dakota, Utah and Wyoming www.adainformation.org
- Pacific ADA Center - Arizona, California, Hawaii, Nevada and the Pacific Basin www.adapacific.org
- Northwest ADA Center - Alaska, Idaho, Oregon and Washington www.dbtacnorthwe

10 Summary and Tips

The Americans with Disabilities Act (ADA) is the main law that requires healthcare settings to be accessible to people with disabilities.

The ADA does not specify how to make healthcare settings accessible but requires that

- Healthcare buildings and facilities are physically accessible.
- Communication with healthcare providers and healthcare services is accessible.
- Modifications to make healthcare accessible do not cause significant difficulty or expense to implement.

Figuring out how to make facilities and communication accessible in a way that works well for everyone is done in a conversation with the healthcare provider or their office staff.

If you need an accommodation for regular healthcare visits, request it from your healthcare provider or their office. For accommodations and communication during emergency situations, carry a note or use a medical ID that has the most important accommodations listed on it.

If you want accommodations under the ADA, you need to tell your healthcare provider about your ASD diagnosis. You may also request accommodations without disclosing your diagnosis, but your healthcare provider or their office may legally refuse your request.

AASPIRE **Healthcare Toolkit**

Your Rights in Healthcare: Privacy

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Your Rights in Healthcare: Privacy

www.aaspire.org
Last Updated September 29, 2015

1 What is this topic about?

You have privacy rights under a federal law that protects your health information. These rights are important for you to know. You can exercise these rights, ask questions about them, and file a complaint if you think your rights are being denied or your health information isn't being protected. This section is about that federal law, called the Health Insurance Portability and Accountability Act, or HIPAA. It includes what kind of information is protected by HIPAA and under what conditions your private health information can be shared.

Most of the information in this section was created by the Department of Health and Human Services. It is available in the pamphlet ”Your Health Information Privacy Rights”.

2 What is HIPAA?

The Health Insurance Portability and Accountability Act is a federal law that gives national standards for keeping health information private. It is commonly referred to by its acronym, HIPAA.

HIPAA prevents healthcare providers, most health insurance plans, and other healthcare agencies from to disclosing your personal health information without your written permission. Health information protected by HIPPA is:

- Anything in your medical record
- Conversations your medical providers have about your care or treatment (for example, conversations your doctor may have with his nurse about your care)
- Information about you in your health insurer's computer system
- Your medical billing information
- Most other health information about you held by anyone involved in the healthcare system

3 Who must follow HIPAA?

- Most doctors, nurses, pharmacies, hospitals, clinics, nursing homes, and many other health care providers
- Health insurance companies, HMOs, most employer group health plans
- Certain government programs that pay for health care, such as Medicare and Medicaid

4 How can I receive a notice about my privacy under HIPAA?

You can learn how your health information is used and shared by your provider or health insurer. They must give you a notice that tells you how they may use and share your health information and how you can exercise your rights. In most cases, you should get this notice on your first visit to a provider or in the mail from your health insurer, and you can ask for a copy at any time.

You may have other health information rights under your state's laws. When these laws affect how your health information can be used or shared, that should be made clear in the notice you receive.

5 Can I see my health records?

You can ask to see and get a copy of your medical record and other health information. You may not be able to get all of your information in a few special cases. For example, if your doctor decides something in your file might endanger you or someone else, the doctor may not have to give this information to you. In most cases, your copies must be given to you within 30 days, but this can be extended for another 30 days if you are given a reason. You may have to pay for the cost of copying and mailing if you request copies and mailing.

6 Can I have corrections made to my health records?

You can ask to change any wrong information in your file or add information to your file if it is incomplete. For example, if you and your hospital agree that your file has the wrong result for a test, the hospital must change it. Even if the hospital believes the test result is correct, you still have the right to have your disagreement noted in your file. In most cases the file should be changed within 60 days, but the hospital can take an extra 30 days if you are given a reason. Your healthcare providers and their staff can share your health information with each other, as well as with insurance companies and others involved in healthcare billing. In general, your health information cannot be given to your employer, used or shared for things like sales calls or advertising, or used or shared for many other purposes unless you give your permission by signing an authorization form. This authorization form must tell you who will get your information and what your information will be used for.

7 Who gets to know about my health information?

Your healthcare providers and their staff can share your health information with each other, as well as with insurance companies and others involved in healthcare billing. In general, your health information cannot be given to your employer, used or shared for things like sales calls or advertising, or used or shared for many other purposes unless you give your permission by signing an authorization form. This authorization form must tell you who will get your information and what your information will be used for.

8 What if I want to share my health information with someone?

HIPAA only prevents unauthorized sharing of your health information. You can give your permission in writing that some or all of your health information can be shared with someone else, usually called a third party. Ask your healthcare provider give you a form to do this. This document authorizes your medical provider to share your medical information with a third party of your choosing. 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 does the following:

- Says how much will be shared - You can share your complete record, just one section or information related to a specific medical problem.
- How often can the information 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 will it 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.

9 Is there a way to know how my health information has been shared?

Under the law, your health information may be used and shared for particular reasons, like making sure doctors give good care, making sure nursing homes are clean and safe, reporting when the flu is in your area, or making required reports to the police, such as reporting gunshot wounds. In many cases, you can ask for and get a list of who your health information has been shared with for these reasons. You can get this report for free once a year. In most cases you should get the report within 60 days, but it can take an extra 30 days if you are given a reason.

10 How else can my private health information be protected?

10.1 Ask to be reached somewhere other than home

You can make reasonable requests to be contacted at different places or in a different way. For example, you can have the nurse call you at your office instead of your home, or send mail to you in an envelope instead of on a postcard. If sending information to you at home might put you in danger, your health insurer must talk, call, or write to you where you ask and in the way you ask, if the request is reasonable.

10.2 Ask that your information not be shared

You can ask your provider or health insurer not to share your health information with certain people, groups, or companies. For example, if you go to a clinic, you could ask the doctor not to share your medical record with other doctors or nurses in the clinic. However, they do not have to agree to do what you ask.

11 How do I file a complaint if I think my privacy has been violated?

If you believe your information was used or shared in a way that is not allowed under the privacy law, or if you were not able to exercise your rights, you can file a complaint with your provider or health insurer. The privacy notice you receive from them will tell you who to talk to and how to file a complaint. You can also file a complaint with U.S. Government. More information on filing a complaint can be found on the Department of Health and Human Services (DHHS) web site, emailing DHHS at OCRMail@hhs.gov or by contacting the regional office closest to you.

Region 1 (CT, ME, MA, NH, RI, VT)
Voice phone (800) 368-1019
FAX (617) 565-3809
TDD (800) 537-7697

Region 2 (NY, NJ, PR, VI)
Voice Phone (800) 368-1019
FAX (212) 264-3039
TDD (800) 537-7697

Region 3 (DE, Washington DC, MD, PA, VA, WV)
Voice Phone (800) 368-1019
FAX (215) 861-4431
TDD (800) 537-7697

Region 4 (AL, FL, GA, KY, MS, NC, SC, TN)
Voice Phone (800) 368-1019
FAX (404) 562-7881
TDD (800) 537-7697

Region 5 (IL, IN, MI, MN, OH, WI)
Voice Phone (800) 368-1019
FAX (312) 886-1807
TDD (800) 537-7697

Region 6 (AR, LA, NM, OK, TX)
Voice Phone (800) 368-1019
FAX (214) 767-0432
TDD (800) 537-7697

Region 7 (IW, KA, MO, NB)
Voice Phone (800) 368-1019
FAX (816) 426-3686
TDD (800) 537-7697

Region 8 (CO, MT, ND, SD, UT, WY)
Voice Phone (800) 368-1019
FAX (303) 844-2025
TDD (800) 537-7697

Region 9 (AS, AZ, CA, GU, HI, NV)
Voice Phone (800) 368-1019
FAX (415) 437-8329
TDD (800) 537-7697

Region 10 (AK, ID, OR, WA)
Voice Phone (800) 368-1019
FAX (206) 615-2297
TDD (800) 537-76

12 How do I get more information about HIPAA?

This is a brief summary of your rights and protections under the federal health information privacy law. You can ask your provider or health insurer questions about how your health information is used or shared and about your rights. You also can learn more, including how to file a complaint with the U.S. Government, at the website at ¡a href=”http://www.hhs.gov/ocr/hipaa/” target=”HHS”¿www.hhs.gov/ocr/hipaa/¡/a¿.

13 If I disclose ASD to my healthcare providers, is it covered by HIPPA?

Yes. Your healthcare provider can only share your medical information, including your autism spectrum disorder diagnosis, with other health-related people or agencies for billing, insurance, and treatment purposes. Otherwise, your medical records and information, including your ASD diagnosis, must be kept private.

14 Summary

- The Health Insurance Portability and Accountability Act (HIPAA) is a federal law that provides national standards for the privacy of health information.
- Because of HIPAA, healthcare providers, their staff, most insurance companies, and healthcare-related government programs can not share your health information without your written permission. They are allowed to share it with other healthcare providers involved in your care, for example a doctor can tell her nurse.
- You have a right to request your own medical records and ask for corrections to them. You also have a right to receive a notice explaining how

HIPAA affects you. You can request this information from your healthcare provider.

- If you want to share your healthcare information with someone other than your provider (a third party) you can do so by giving written permission. Ask your provider for a release form.
- If you think a healthcare provider has violated your privacy under HIPAA, you can file a formal complaint. The HIPAA web site gives information about how to do this.
- Your ASD diagnosis is protected by HIPAA, just like all your other protected health information.

15 Links and Resources

To see the flyer most of this information was taken from download HIPAA's consumer rights PDF.

For more information on HIPPAA see:

- http://www.hipaa.com/
- http://www.hhs.gov/ocr/privacy/hipaa/understanding/consumers/index.html
- http://www.cms.gov/HIPAAGenInfo/Downloads/HIPAALaw.pdf
- http://www.privacyrights.org/fs/fs8-med.htm

Your Rights in Healthcare: Decision Making Authority

www.aaspire.org
Last Updated September 29, 2015

1 What is this topic about?

This topic is about what legal rights you have to make medical decisions. It covers healthcare-related legal documents, state laws about medical decision making, what to do if you disagree with a healthcare decision, and where you can go for help relating to medical decision making.

2 Consent and Self-advocacy in Healthcare

All people are worthy of inclusion and respect. Respectful healthcare does not make people feel bad, guilty, or inferior. It is important that you know your rights and how to advocate for them. There are some situations where your rights may be limited. For example, if you have a conservator or guardian, that person may make decisions about your medical care that you do not always agree with. Or if a professional is concerned that you might be suicidal or dangerous to others, he or she may have the right to take actions you don't agree with in order to ensure your safety. However, in most circumstances, you should not be forced into a healthcare situation without your permission. If you are uncomfortable with a healthcare provider, then you have the right to say ”no” to their services and to seek healthcare from someone else. If a professional makes you feel uncomfortable, or does something you feel is wrong, bring it up to him or her. Make it known that you are uncomfortable and that you would appreciate if they would respect your boundaries and concerns. Your healthcare provider should always be able to explain to you why they are doing something and how it relates to your healthcare. If your healthcare provider cannot respect your wishes, you do not have to continue seeing them and you can look for another provider if it's a bad fit. If you feel you have been treated wrongly by a healthcare provider, two places to try asking for help are:

- Contact your state's Protection and Advocacy (P&A) program
- Contact the healthcare provider's professional licensing board in your state; for example, search for terms like ”osteopath licensing board Arizona” or ”family practice licensing board Oregon”.

3 What state laws exist about medical decision making?

The laws differ from state to state but most states assume adults can make medical decisions on their own. In some states, having a developmental disability may put into question someone's decision-making capacity. The American Bar Association has a chart describing each state's default medical decision making law. This chart lists the priority order of decision makers for each state. It also describes the procedure for determing the decision maker if there is a disagreement. The chart also describes the procedure for when there is a disagreement on who is the decision maker. (Note: this chart was last updated in 2009, so some information may be out of date.)

4 Can healthcare providers determine my ability to make a healthcare decision?

Healthcare providers often use an interview and their clinical judgment to determine if someone is able to make a particular healthcare decision for himself or herself. A person may have the ability to make a simple decision, but may not be able to make a more complex decision. Their ability to make a decision may also change at different times. For example, a person who is very ill may be confused one day, but may be thinking clearly another day. Healthcare providers cannot determine if someone needs a guardian. Decisions about guardianship have to be made in the legal system.

5 What happens if I'm unable to make medical decisions and I don't have a legal medical decision maker?

You can name the person you would like to have as a legal medical decision maker using an advance directive. This person would be able to make medical decisions for you if you became incapacitated (unable to make decisions for yourself). For example, they might make decisions if you were in a coma. If you don't have an advance directive and become incapacitated, hospitals follow state laws about who can make healthcare decisions for you. Many states rank possible decision makers (called surrogate decision makers) and mandate that hospitals follow this priority order. The ranking for each state is listed in this American Bar Association chart (Note: this chart was last updated in 2009, so some information may be out of date.)

5.1 What about domestic partners or close friends?

In most states, domestic partners or close friends are last on the list of potential proxies. In some states, domestic partners and close friends are not on the list at all. Family members generally have higher priority than friends. If you want to allow your domestic partner or a close friend to make medical decisions for you when you can not make decisions for yourself, you need to name them on an advance directive.

5.2 What about emergency situations?

In emergencies, most states allow medical providers to act without the consent of the patient or surrogate decision maker.

6 What are advance directives and how do they relate to decision making?

Advance healthcare directives are legal documents. They have instructions telling healthcare providers what actions to take or not take when an individual is no longer able to make healthcare decisions for himself or herself. This is usually due to illness or incapacitation. The purpose of these documents is to make sure the patient's medical wishes will be followed even when he or she isn't able to communicate them.

Advance directives are also known as living wills, personal directives, or advance decisions.

The two most common types of advance directives for healthcare are living wills and durable power of attorney for healthcare (or healthcare proxy). Advance directives will only be used if you are unable to make medical decisions for yourself. An individual may have more than one kind of advance directive. You can create these documents with a lawyer. Information about how to get help seeing a lawyer is in the section ”Where can I get legal help related to decision making?” Many doctors' offices and hospitals also have forms ready that you can fill out without a lawyer. You can ask your doctor or the clinic or hospital staff for help filling out advance directive forms.

6.1 Living Wills

Living wills outline what types of medical treatments should or shouldn't be performed. These may include (but are not limited to) drug administration, hydration, feeding, or resuscitation and life support decisions. A living will doesn't let you select someone to make decisions for you, only what kind of treatments to give you. For that you need to name someone as having durable power of attorney or guardianship.

6.2 Durable Power Of Attorney for Healthcare (also known as a healthcare proxy)

When you give someone written permission to represent you or act on your behalf in legal matters, it is called giving that person power of attorney. Durable power of attorney for healthcare lets you name someone to make healthcare decisions for you, if you were to become unable to make your own decisions. The person you name as a healthcare proxy can make any healthcare decision that you could make, but only if you were unable to make your own decisions.

6.3 What happens if I don't have an advance directive?

If you do not have an advance directive, hospitals follow state laws about who can make healthcare decisions for you. Many states rank potential decision makers in order of priority. States differ on who they will consider. For example, in most states, spouses and blood relatives rank first while a domestic partner or close friend may be last on the list of potential proxies. In some states, domestic partners and close friends are not on the list at all. The ranking for each state is listed in this American Bar Association chart. (Note: this chart was last updated in 2009, so some information may be out of date.) If you want to be sure that the people you name can make medical decisions for you if you become unable to make them for yourself, you need an advance directive.

7 What are Physician Orders for Life Sustaining Treatments (POLST)?

A Physician Orders for Life Sustaining Treatments (POLST) documents a patient's preferences for end-of-life treatments. POLST forms are often used when a person is chronically ill or near the end of life. POLST forms are physician orders that can tell other professionals what to do or not do in the case of an emergency. The POLST document can communicate to a first responder that the patient does not want cardiopulmonary resuscitation (CPR), or to be transported the hospital if they had stopped breathing. If a POLST were not in place, the first responder would be obligated by law to do these things. POLST forms are not only used to limit treatment. They can also document life-sustaining treatments a person wants. POLST isn't available in every state but a growing number of states are adopting them. For information about POLST in your state, see polst.org POLST orders are also known as medical orders on life-sustaining treatment (MOLST), medical orders on scope of treatment (MOST), or physician's orders on scope of treatment (POST).

8 What is the Difference between Advanced Directives and Physician Orders for Life Sustaining Treatments (POLST)?

Advance directives indicate what a person would want IF they were to become too incapacitated to make their own decisions. They are filled out while the person can make his or her own decisions. They only come into use in the future when the person becomes incapacitated. POLST forms are active orders that are in place now. They can be filled out by the person themself or by their power of attorney for healthcare. For example, someone may say on an advance directive that if he were ever in a persistent vegetative state (”brain death”), he would not want to be kept alive on a breathing machine. But if that person is at home and suddenly stops breathing, paramedics can’t use the advance directive to decide whether or not to put him on a breathing machine. A person with a terminal cancer may not want paramedics to resuscitate him, even if he is not in a persistent vegetative state. That person may wish to fill out a POLST form indicating that he does not wish to have cardiopulmonary resuscitation (CPR) or be put on a breathing machine. Paramedics can see a POLST form, read the person’s wishes, and not start CPR.

9 What should I know about guardians or conservators?

9.1 What is a guardian or conservator?

A guardian or conservator is someone who can act as the legal authority for another person. A guardian is usually appointed by a court. Guardians are appointed for a number of reasons. If the ward is a minor without parents, guardians are assigned by the courts until the ward reaches the age of 18. Guardians can be appointed for adults as well. This is only done if the ward is incapacitated or someone has decided that their disability makes them unable to care for themselves. Because establishing a guardianship may remove considerable rights from an individual, it should only be considered after all other alternatives to guardianship have proven ineffective or are unavailable.

9.2 Is there a difference between a guardian and a conservator?

This depends greatly on what state you reside in. In some states there are few differences but in other states there are many differences. In some states one term or the other isn’t used at all. See your state resources for more information about guardianship in your state.

9.3 What role does guardianship play in healthcare?

Guardians or conservators are allowed to make healthcare decisions for another person. A guardian may be appointed by the courts if the patient's illness or disability makes him or her unable to make their own decisions.

9.4 What are alternatives to guardianship?

Because having a guardian or conservator takes away a great deal of power from the ward, people often seek alternatives to guardianship. Some alternatives to guardianship might be:

- Representatives or substitute payees
- Case/care management
- Durable powers of attorney for health care
- Living wills
- Financial powers of attorneys
- Personal advocates or supporters

9.5 How can I have guardianship or conservatorship removed?

Guardianship can be removed through a legal process at the court that made the determination.

10 What should I do if I disagree with a healthcare decision a guardian has made for me?

A guardian has a legal duty to act in the best interests of the ward, but there are times when the ward and guardian may disagree about medical treatment.

Disagreements about healthcare can be difficult because in most states the guardianship laws consider the ward unable to make informed healthcare decisions. If you disagree with your guardian about treatment, and the treatment could have a big impact on you, then the courts may need to get involved. The court usually acts as the final decision maker when the ward and guardian can't agree.

10.1 If I have a guardian, is my consent needed for medical care?

No. A guardian is authorized to consent on the ward's behalf. The guardian should take into account the ward's preferences for healthcare providers, treatments, and other healthcare services,. It is appropriate for a guardian to communicate with and seek the ward's involvement and agreement whenever possible. This is called getting the "assent" of the ward."

10.2 Are there any treatments that cannot be forced on me?

There are certain treatments that a guardian cannot force on a ward without a court's consent. For example, treatments that have substantial side effects such as psychotropic medications often require consent from a court. Another example would be major or experimental surgeries.

10.3 How do I petition the court about a medical disagreement?

A petition asking the court to review the guardianship can be filed with the court that issued the guardianship. The court may have a form that you can fill out. The petition can be filed by the you (the ward), your attorney, a family member, a friend, or a supporter. The petition should simply say why you are requesting a hearing. It is strongly recommended that you speak to a lawyer before submitting the form to make sure everything is in order. See the section on ”Where can I get legal help related to decision making?” for more information.

10.4 Are there other alternatives to court proceedings?

Full court proceedings can be costly. Many states have options such as ombudsman programs, or medical or legal advocates that help resolve the disagreement. See the section on ”Where can I get legal help related to decision making?” for who to contact.

10.5 What if my guardian and my healthcare proxy don’t agree?

When a ward has both a healthcare proxy from an advance directive and a guardian, there is sometimes confusion over who has the authority to make health care decisions on the ward’s behalf. Unfortunately there is no easy answer here. It varies by state. See the section on ”Where can I get legal help related to decision making?” for more information.

11 Where can I get legal help related to decision making?

The US Administration on Intellectual and Developmental Disabilities (AIDD) is a government agency that works to support programs that help people with intellectual and developmental disabilities fully participate and contribute to their communities. The AIDD is a good place to start if you are looking for help understanding legal decision making. The AIDD oversees the State Protection and Advocacy Systems (P&As). The P&As work at the state level to help individuals with intellectual and developmental disabilities advocate for themselves. The P&As are another good resource if you are looking for help. Because they work on the state and local level they are more likely to know of services local to you. Some of the services they provide include:

- Information and referral
- The protection and advocacy of legal and human rights.
- Investigation of into the violation of rights of individuals with developmental disabilities.
- Help to resolve complaints through mediation, alternative dispute resolution and litigation.

Some areas also have legal aid clinics that offer low-cost or free legal help. Law school clinics also sometimes offer free legal advice. There are also some organizations and individual lawyers that do pro bono work (work for free). You can contact your local university or search the Internet to look for these types of services. Note: This information is provided in hopes that it will be helpful. We cannot say whether or not these resources will be able to address your legal questions or issues. We cannot say whether or not you will be able to get the legal outcome you would like. We cannot say whether or not you will receive good legal advice from these sources.

12 Summary

In most situations, you have the right to have a say in your own medical decisions. The situations when you may not have a say are:

- If you become unable to make your own decisions due to illness or injury.
- If a healthcare provider is concerned that you may harm yourself or others.
- If you have a legal guardian or conservator.

If you become incapacitated and unable to make your own decisions due to illness or injury, each state has its own list of who gets to make decisions for you.

- If you would like someone you name to make decisions for you, you will need a legal document called a durable power of attorney for healthcare, which is a kind of advance directive.
- Other kinds of advance directives include living wills, which name the kinds of treatments you would or would not like done if you become incapacitated.
- You can create an advance directive with the help of a lawyer. Many healthcare offices and hospitals can also help you fill out advance directives.

Physician Orders for Life Sustaining Treatments (POLST) give directions to emergency personnel and other healthcare providers about what life-sustaining treatments you do or do not want. If you have a guardian or conservator, they are allowed to make healthcare decisions for you without your consent.

- A guardian may be appointed if you are incapacitated and do not have an advance directive.
- A guardian may be appointed if some process has determined you are unable to make medical decisions for yourself.
- If you have a guardian and disagree with medical decisions they are making for you, you may need the help of a lawyer.
- Some treatments may require a court approval before they can be given to you, even if the guardian wants them done.

The State Protection and Advocacy Systems (P&As) may be a good place to start if you want more information about how to get legal help or better understand laws about medical decision making.

13 Links

13.1 Advance Directives

- Family Doctor.org
- The Patient's Rights Council
- American Bar Association links to every state's advance directive forms (PDF)
- Caring Connections is an organization that helps individuals access information about advance care planning and care at the end of life. This site has helpful information on Advance Directives and access to Advance Directive forms for all 50 U.S. states.
- Many states have laws that allow Advanced Directives for mental health. The National Alliance On Mental Illness (NAMI) has information on Advance Directives relating to mental illness.

13.2 Physician Orders for Life Sustaining Treatments

- www.polst.org has nation-wide information about POLST.

13.3 Decision Making Laws and Priorities

- American Bar Association's priorities-by-state table
- Information about domestic partners and healthcare decision making from Unmarried Equality

13.4 State Protection and Advocacy Systems and Other Legal Help

- The US Administration on Intellectual and Developmental Disabilities (AIDD)
- The State Protection and Advocacy Systems (P&As)

13.5 Guardians / Conservators

- General information about guardians / conservators.
- Table of guardian / conservator laws by state

AASPIRE Healthcare Toolkit

Computer and Internet Access

Contents

- What is this topic about?
- Where can I access a computer with Internet service for free or for a small fee?
- I already own a computer. Where can I access Internet service for free or a small fee?
- Summary

Computer and Internet Access: Computer and Internet Access

www.aaspire.org
Last Updated September 29, 2015

1 What is this topic about?

The AASPIRE Healthcare Toolkit includes tips on using the Internet to search for healthcare providers and online links to other information about health, healthcare, and your community. In addition, the Autism Healthcare Accommodations Report can only be used online. This topic is about how to access a computer and Internet service when you don't have a computer or Internet service. We hope some of the tips in this section will be helpful to people who want to use these resources but do not have good Internet access of their own. This information talks about using a computer to access the Internet. Smart phones, tablets, and other devices will work just as well as a computer.

2 Where can I access a computer with Internet service for free or for a small fee?

- **Share a computer** with family, friends, or neighbors. Others might share their computer and Internet service in exchange for something like babysitting, house sitting, yard work, walking their dog, or taking out their trash. Be careful about doing banking or shopping online when you're sharing Internet service. Make sure you fully trust the person or people you're sharing with.

- **Libraries** often provide computers and free access to the Internet as part of their mission to meet the information needs of their communities. Computers and free Internet access are available in many libraries.
- **High school and university computer labs** are usually available to students. If you're a student, you can probably access a computer and the Internet for free at school. If you're not a student, ask your local community college if they offer computer lab hours to the public. Be sure to ask if there's a fee.
- **Parks and recreation centers** may require you to have a recreation pass to use any of the facilities, including computer labs, if they are offered. Fees for center passes vary depending on whether you live in or outside the zone the center serves.
- **Community centers** are similar to parks and recreation centers. Many community centers will charge a small fee for in-district visitors.
- **Senior centers** often offer computer labs and classes. Some don't require you to be a senior, and others might have a small annual charge for use of the computers. Check with the senior center in your community to see if it has computers for public use and to find out if you can use them.
- **Career centers**, if your community has one, might have computers, printers, Internet access, telephones, and fax machines at no cost. These centers are usually meant to be used for job banks, resume design, and employment research.
- **Non-profit and government agencies** might have additional resources. If you receive services from a local nonprofit or government agency, ask if there are computers available for use as part of the program.

3 I already own a computer. Where can I access Internet service for free or for a small fee?

- **Free Internet Service Providers (ISPs)**; for example, NetZero offers up to 10 hours a month for free. AOL offers new customers free access for one month. The Free Site has a list of free Internet access providers.
- **Share an ISP** with family, friends, or neighbors. Others might share their Internet service in exchange for something like babysitting, house sitting, yard work, walking their dog, or taking out their trash. Be careful about doing banking or shopping online when you're sharing Internet service: make sure you fully trust the person or people you're sharing with.
- **Free Wi-Fi** is offered by many cafes, bookstores, and coffee houses. Make a purchase, such as a small cup of coffee, and then ask the salesperson or associate if a password is needed to access the Internet. In some places, you may be able to get Wi-Fi without making a purchase. For example, some shopping malls, community centers, or libraries have free Wi-Fi.
- **Airports and hotels** sometimes offer free Internet service to customers. This is handy when you're traveling. Some hotels and airports charge a fee for Wi-Fi privileges.

4 Summary

Some places to access free or low-cost computers with internet access are:

- Libraries
- School computer labs
- Parks, recreation centers, and community centers

- Senior centers
- Career centers
- Non-profit and government agencies

Some ways to get fee or low-cost Internet access if you already have a computer are:

- Free Internet Service Providers
- Sharing an ISP with others
- Using free Wi-Fi offered by a business
- Using Wi-Fi in airports and hotels while traveling

Medical Information: Medical Information

www.aaspire.org
Last Updated September 29, 2015

1 Medical Information

Here are links to reliable medical information, as well as to other tools that may be helpful.

These sites were not created by, and are not maintained by AASPIRE. Most materials on these sites are free; a few may cost money.

1.1 General Medical Information

- WebMD
- Medline Plus
- The Mayo Clinic
- Family Doctor
- Health Finder
- Florida Center for Inclusive Communities

1.2 Other Checklists, Worksheets, and Tips

- Healthy Transitions (primarily for transitioning from pediatric to adult care though some parts could be useful for adults who have already transitioned as well)
- University of San Francisco Office of Developmental Primary Care
- The Health Passport for use in emergency situations or with individuals not familiar with providing care to people with developmental disabilities, available in English and Spanish.

1.3 Online Symptom Trackers

- from the Mayo Clinic
- from WebMD

1.4 Other Tools:

- Healthcare communication tools for purchase - Giving Greetings
- Healthcare toolkit for kids on the spectrum - Hands In Autism

Forms and Worksheets

- **Making an Appointment Worksheet** - 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.

- **What to Bring to a Healthcare Visit Checklist** - This is a checklist you can use when putting together the things you need to bring to a healthcare visit. It has second page with extra things to bring to a first visit, or if you haven't seen your healthcare provider in a long time.

- **Symptoms Worksheet** - This worksheet covers the information healthcare providers usually want to know about symptoms. Not all questions apply to all symptoms. But thinking through some of these questions may help you better describe your symptoms or answer your provider's questions.

- **After the Visit 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:
  - Make a follow-up appointment with your healthcare provider
  - See a specialist or make an appointment with a different healthcare provider
  - Get a lab, x-ray, or other test
  - Take a medication
  - Do something to manage your health condition at home

Making an Appointment Worksheet

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: ______________________________________

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:

   ____

   ____

   ____

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 _________________________________

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:

   ____

   ____

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?

   ____
   ____
   ____

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:

____

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.

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:

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, of 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.

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)

AASPIRE

SYMPTOMS WORKSHEET

Describing Your Symptoms

This worksheet covers the information healthcare providers (like physicians, physician assistants, and nurse practioners) 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.

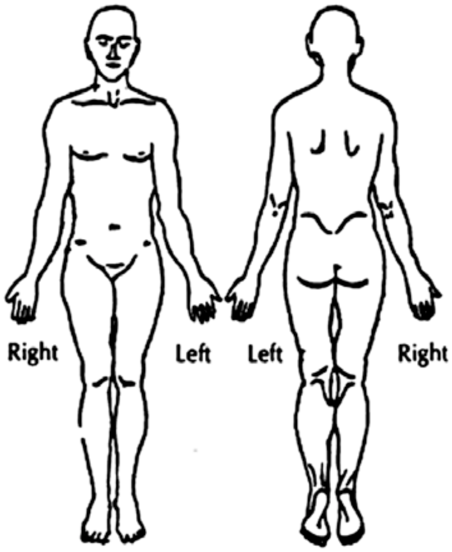
Use this worksheet for your own reference. Healthcare providers may become overwhelmed if you ask them to read it. For more information and examples see [reference and link to tookit]

What Is the Symptom (or set of symptoms)? Describe them:

____
____
____
____

Location – What areas of your body are affected?

____
____
____
____

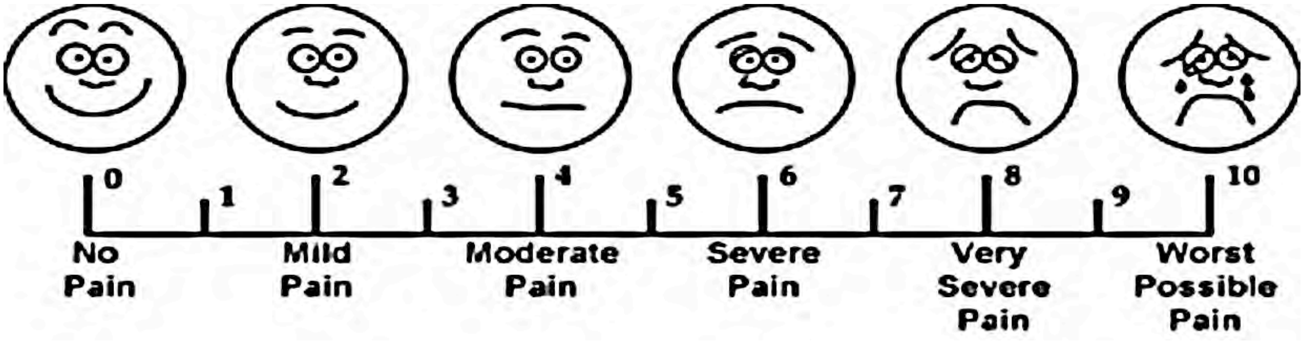


Optional: Put an X or shade in the areas of your body where the symptoms are.

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

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

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?

SYMPTOMS WORKSHEET

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

____

____

____

____

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

____

____

____

____

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

____

____

____

____

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

____

____

____

____

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

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

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

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

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?

____

____

____

____

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

____

____

____

____

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

____

____

____

____

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 many 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? ____________

____

How should I contact them? ____

____

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?

____

____

____

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

____

____

____

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 Test

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? _________________

Managing Health Condition(s) at Home

Your healthcare provider may have asked you to do things at home to manage your health condition or conditions. For example, you may have been asked to keep a pain diary, to eat a special diet (for example, a diabetic diet, or a low-salt diet), or to use some kind of medical equipment.

Before you leave the office, make sure you have instructions that you understand for what to do at home. The instructions might be given to you by a nurse or other health professional.

Use this space to write any instructions for managing your health at home.