



AASPIRE

# Healthcare Toolkit

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## Healthcare: Preparing for a Visit

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# Healthcare: Preparing for a Visit

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Last Updated September 29, 2015

## **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 para-transit), 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](https://www.disability.gov). Checklists and worksheets:

- [Symptoms Worksheet](#)
- [What to Bring to a Visit checklist](#)