Be an Active Health Care Consumer

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Contents

Tools, Surveys and Checklists

These tools are included to help individuals with disabilities get the most out of their visits to health care providers. These can also be used by people who assist individuals in planning for these visits.[1]

These tools use the term provider to refer to a broad group of people providing health care services. They include doctors, nurses, therapists, social workers, hospitals, x-ray technicians, and other health care professionals.

Health Care Self Advocacy Skill Survey	**Use this survey to identify advocacy skills that you would like to strengthen.**
Are You an Active or Passive Health Care Consumer?	**Use this checklist to learn how active or passive you are when working with your health care providers.**
Health Care Visit Strategies Quiz	**Take this quiz to see if you make the best use of very limited time during visits with your health providers.**
Accessibility Planning Checklist	**Use this checklist to identify specific assistance you will need to request before and during your health care visit.**
Effective Communication	**Sharpen your communication with providers through clearly expressing your questions and need.**
Chief Complaint / Reason for Visit	**Use this form to prepare for an appointment in which you must describe new symptoms (history, pain, location, frequency, possible causes, etc.)**
Test Results	**Use this form to help you and your other providers get copies of your test results.**

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[1] People who may serve in this role include but are not limited to peer mentors and counselors, patient educators, health care navigators, coaches, case managers, care coordinators, service coordinators, and social workers as well as health care providers.

Minutes count in these times of rushed, limited time health care appointments. It is critical, and of mutual benefit, to help people learn how to get the most out of their health care visits. Seventy-five percent of all office visits take place in under fifteen minutes. Many health care providers can help individuals maximize their visit time by reviewing effective visit strategies. It is common for health care professionals to think, “I barely have time to examine and treat patients, so how can I possibly have time to teach visit strategies?” These short selected pre-printed handouts can be used in teachable coaching moments, not only by doctors but by many others who support individuals in getting their health care needs met. Use these tools with other patient education handout materials. They can have significant positive impacts on patients receiving access accommodations and services, building partnership with providers, efficient and effective use of visit time, and increasing successful appointment and health outcomes.

Be an Active Health Care Consumer

Determining Your Priorities

Use the following **Health Care Self Advocacy Skills Survey** to identify personal health care practices, you would like to strengthen. You then can choose to read the entire article or just about the items you would like to strengthen.

Health Care Self Advocacy Skills Survey

Instructions:

1. When seeking health care circle how often you do this:

1= never, 2 = seldom, 3 = sometimes, 4 = often, 5 = almost always

2. Circle the check mark if you would like to strengthen this practice.

3. After rating each item, go back and choose for the top five practices you would like to improve your practice by circling the star

Sample Question

After tests, procedures, or surgeries, I ask for copies of summaries and reports to maintain my medical records.

Practice	[✓ 1]	2	3	4	5	[✓ ✓]	★

Before my health care visit

I trust my lived disability experience and my common sense, which helps me avoid feeling intimidated by health care providers.

Practice	**1**	**2**	**3**	**4**	**5**	✓	★

I plan for and request any help I will need before my visit and remind the staff when I arrive at the appointment [interpreter, a height-adjustable exam table, transfer assistance, etc. [See **Accessibility Planning Checklist**]

Practice	**1**	**2**	**3**	**4**	**5**	✓	★

When I have an urgent problem and get told my provider can’t see me for three weeks, I explain that this is not acceptable, and I state my need to be seen sooner.

Practice	**1**	**2**	**3**	**4**	**5**	✓	★

I learn as much as I can about my health conditions and disabilities, and every so often, look for updated information.

Practice	**1**	**2**	**3**	**4**	**5**	✓	★

I critically evaluate the quality of sources of the health information I get.

Practice	**1**	**2**	**3**	**4**	**5**	✓	★

I look for providers who will listen to me.

Practice	**1**	**2**	**3**	**4**	**5**	✓	★

When I can choose providers, I ask questions and evaluate information about them, which includes their qualifications, qualities, attitudes, and their ability to meet my accessibility needs.

Practice	**1**	**2**	**3**	**4**	**5**	✓	★

When I can I choose a health plan, I study the options and carefully choose the plan I feel is best for me.

Practice	**1**	**2**	**3**	**4**	**5**	✓	★

Before my visit, I create a list question list putting the most important items first.

Practice	**1**	**2**	**3**	**4**	**5**	✓	★

I use a support person system (individuals to assist me in remembering and communicating information, monitoring my care, supporting me emotionally, and advocating with me (during health care visits, tests, procedures or hospitalizations) [See **Take a Support Person with You].**

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Practice	**1**	**2**	**3**	**4**	**5**	✓	★

I line up my support people or advocates, anticipating as many possibilities as possible.

Practice	**1**	**2**	**3**	**4**	**5**	✓	★

I learn what I can about a test, procedure, or surgery in advance.

Practice	**1**	**2**	**3**	**4**	**5**	✓	★

During my health care visit

I sign forms only after I clearly understand what they mean.

Practice	**1**	**2**	**3**	**4**	**5**	✓	★

I ask, at the beginning of a visit, how much time is available for my visit and let my provider know that I have questions. I make the best use of very limited time.

Practice	**1**	**2**	**3**	**4**	**5**	✓	★

I communicate my health information briefly and concisely.

Practice	**1**	**2**	**3**	**4**	**5**	✓	★

When seeing new providers, I give a current and concise health history which details my conditions.

Practice	**1**	**2**	**3**	**4**	**5**	✓	★

I ask questions and express my concerns to providers.

Practice	**1**	**2**	**3**	**4**	**5**	✓	★

Even if I am not asked, I provide important information about my conditions/disabilities and how these may affect my care and the reason for my visit.

Practice	**1**	**2**	**3**	**4**	**5**	✓	★

I or my support person take notes and/or record discussions with providers.

Practice	**1**	**2**	**3**	**4**	**5**	✓	★

I let providers know when they are not communicating clearly.

Practice	**1**	**2**	**3**	**4**	**5**	✓	★

I ask providers to explain things in plain language, which may include asking them to draw pictures or use models so I can better understand the information.

Practice	**1**	**2**	**3**	**4**	**5**	✓	★

I take time to think about what I am told before making an important health care decision.

Practice	**1**	**2**	**3**	**4**	**5**	✓	★

At the end of a visit, I check my understanding by quickly repeating what I heard the provider say.

Practice	**1**	**2**	**3**	**4**	**5**	✓	★

After my health care visit

I obtain and keep copies of my medical records.

Practice	**1**	**2**	**3**	**4**	**5**	✓	★

I follow-up on the outcome of my procedures and tests by obtaining results.

Practice	**1**	**2**	**3**	**4**	**5**	✓	★

I get a second opinion if I think I need one.

Practice	**1**	**2**	**3**	**4**	**5**	✓	★

Being Active

Getting the most out of health care requires being active, not passive when dealing with health care providers. You are a customer who is purchasing services from your health care providers. You have a responsibility and right to be involved in the decisions that affect you.

Providers deserve respect, not worship! The old "doctor always knows best" attitude is outdated. You must speak up or you may not get important care. Being passive can be dangerous to your health.

Getting the health care that you need, when you live with reduced or no ability to walk, see, drive, read, hear, speak, understand, and remember, is not always easy. People with disabilities and others with access and functional needs often must deal with more barriers than other people. Therefore, being active in getting health care is even more important for you.

Being active in your health care and with your health care providers includes:

- Treating your health care providers as partner~~ships~~
- Making the best use of limited time
- Planning ahead when you need some specific assistance
- Clearly communicating your needs
- Understanding and remembering information (ask questions if you don't understand something)

    - Getting test results and making sure these results are shared with other health care providers active in your care.

Good health care helps you maintain and protect your health. Health care providers often do not understand the barriers and difficulties that people with disabilities have in getting health care. You can help your providers understand and better meet your needs by sharing and working with them.

Research tells us that people who play a more active role in their healthcare get better results medically and emotionally. They are physically healthier, recover faster, and are better able to deal with stress and pain.

Look for providers who:

- Welcome your active participation in health care decision making.
- Value open communication.
- Don’t feel threatened if you have a lot of knowledge about your health issue.

Passive health care consumers are processed instead of being partners in the process. Getting the most out of health care requires you to be active. You have the right and responsibility to be involved in the decisions that affect you. After all, your health and well-being are at stake. Don’t check your advocacy at the door; your lived disability experience is a vital contribution to helping you get good health care get what you need.

Being active and speaking up does not mean you have to battle with your provider. Be polite, but also truthful and assertive. These practices mean knowing what you need and knowing what to ask for, being firm, and when needed, being pushy. Bring your self-confidence, self-respect, and self-advocacy skills with you. They are all critical when you are a partner in your health care.

Here’s an example: Fred is a wheelchair user, who, with help, can stand and walk a few steps. The first-time Fred had a physical exam with a new doctor; the doctor never had him get out of his wheelchair and onto the exam table. He assumed that Fred couldn’t get up, and Fred was too shy to suggest that the doctor do the exam differently. If Fred had explained that he could get out of his chair and with some assistance to get on the exam table, he could have:

- avoided getting a poorer quality of care
- received a more complete physical exam, and
- gotten the same quality and standard of care that people without disabilities get.

Trust Your Life Experience and Your Common Sense

Remember you are the expert on your body. You live in and with your body all the time. A provider only sees you once in a while, sometimes only once a year or less. No one knows as much about your body’s functioning as you. Use this knowledge and understanding to boost your confidence sharing important information and speaking up for what you need.

Being prepared and trusting your life experience and your common sense will help you feel more confident knowing that you are a partner in your health care can help you feel comfortable about speaking up. Don’t be intimidated by credentials and degrees! You don’t have to be a rocket scientist to be a partner in your health care. Your personal experience and knowledge are what count.

Don’t be passive. When working with providers, try to avoid:

- Wanting providers to take charge of your health
- Relying totally on providers’ advice
- Failing to ask questions
- Offering information only when asked
- Adopting a “what will be will be” attitude
- Thinking and asking about other options that are not presented to you.
- Feeling helpless and lost in the health care system
- Worrying that your health care will be negatively affected if you ask questions or disagree with a provider
- Being processed instead of being a partner in the process

> “Nobody can make you feel inferior without your consent.”
> --Eleanor Roosevelt

Take the **ARE YOU AN ACTIVE OR PASSIVE HEALTH CARE CONSUMER?** quiz to learn if you are more of an active or passive health care consumer. Then take the **HEALTH CARE VISIT STRATEGY QUIZ** to find out how well you use your health care visit time.

ARE YOU AN ACTIVE OR PASSIVE HEALTH CARE CONSUMER?

Answer Yes, Sometimes, or No to these questions to find out if you are more of an active or passive health care consumer.

Yes	**Sometimes**	**No**	
			1. I will seek another provider if I am not satisfied with my provider.
			2. I rely totally rely on the provider’s advice.
			3. I avoid asking providers questions.
			4. I try to learn as much as possible about my health conditions.
			5. I periodically seek updated information about my health conditions.
			6. I offer information only when asked.
			7. I ask questions and express concerns to my providers.
			8. I feel helpless in the health care system.
			9. I treat relationships with providers as partnerships.
			I share in decision making and responsibility for:
			• 10. *choosing* health care options and alternatives.
			• 11. *developing* my treatment plans.
			• 12. *understanding my* condition(s).
			• 13. preventing or decreasing complications and poor results.
			• 14. *learning* what my health plan covers.
			• 15. *using* community services and resources.
			16. I worry that my health care will be negatively affected if I question, challenge, or disagree with a provider.
			17. I feel I’m being “processed” instead of being a partner in the health care process.

If you answered YES to questions 1,4,5,7,9 – 15, Congratulations! You have active health care consumer skills.

If you answered YES to *all* or *some* of questions 2,3,6,8, and 17 you may be a less active health care consumer. The good news is that you can change. Begin by practicing the skills in questions 1,4,5,7,9 - 15.

The more active you are in your health care, the greater the chance that you will receive the health care services you need.

HEALTH CARE VISIT STRATEGY QUIZ

Take this quiz to see if you make the best use of very limited time during your visits with a health provider.

Yes	Sometimes	No	
			Before my visit:
			1. I ask for specific assistance I will need to have successful visits with health providers (interpreters, height-adjustable exam table, transfer assistance, consent forms and instructions in a version that I can use and understand (large print, audio, digital, Braille, pictures).
			2. I ask how much time is available for my visit.
			3. I ask for an appointment when a provider is less likely to be rushed (such as the first appointment of the day or right after lunch).
			4. I send a copy of my questions and concerns or give a copy to the receptionist, to give to my provider before or when I arrive.
			5. When possible, I send a current and short health history to a new provider before my visit and ask if the provider has read it.
			6. I ask that needed forms be sent to me before my appointment, so I can carefully, and thoughtfully give the answers.
			During my visit:
			7. I let your provider know that I have questions.
			8. I state my major concerns and what I want to discuss.
			9. I create a “questions and concerns list,” putting the most important items first.

Yes	Sometimes	No	
			10. I leave space between each question and concern to take notes.
			11. I communicate information briefly and clearly.
			12. I work with a support person, if helpful. (See:” Take a Support Person with You”)
			13. I present a current and short health history that explains my condition(s) (when seeing new providers).
			14. I provide essential information about my condition/disability, even if I am not asked.
			15. I give providers relevant information about how my disability affects my health care.
			16. I share useful written information about my disability or condition with a provider.
			17. I take notes and/or record my discussion with providers.
			18. I ask providers to add to their descriptions by using pictures and models when needed.
			19. I make sure to get the appropriate routine screenings. List examples here
			20. I take time to think about my options before making an important decision. If needed, I get back to my provider with my answer or ask for a second appointment.
			21. I ask for sources of additional information: books, articles, web sites, videos, or support groups.
			22. At the end of a visit, I check my understanding by briefly repeating what I heard the provider say.

Yes	**Sometimes**	**No**	
			23. I establish a friendly relationship with the provider’s staff so they will remember me, especially when I call to ask for something.
			After my visit:
			24. I follow-up to get my test results.
			25. I update my copies medical records.
			26. I get an opinion from another provider if you think you need one.
	Your Answers Unless you answered YES to all these questions, you still have room to improve. Begin by working on ways to adopt these practices in your future visits to health care providers. improve on the items for which you checked “NO.”		

Adapted from: Kailes, J. I. (2005). *Be a Savvy Health Care Consumer, Your Life May Depend on It!* KAILES Publications. jik@pacbell.net.

Accessibility Planning

Plan Ahead

- No one likes surprises when it comes to healthcare.
- Planning can help you get the supports and services that you need during your appointment.
- Your planning and requesting this help before you arrive for your appointment will help providers better prepare to provide the accommodations you need.

Ask for any specific assistance in advance to make your visit more successful. Even if you have seen a health care provider before, it is helpful to remind them about your specific needs.

Complete the **ACCESSIBILITY PLANNING CHECKLIST**. Use this information to let providers know what your needs are before and again when you get to your appointment.

Starred items (★) are things you should ask for in advance when you schedule your appointment. For example:

- For an interpreter for a non-emergency appointment, providers need to have notice (sometimes several weeks) to have one available.
- For assistance transferring to an exam table or other medical equipment, your provider may need time to arrange for people to help you.

ACCESSIBILITY PLANNING CHECKLIST	
Use this list to plan for items that would be helpful or critical for you to request from health care providers.	
✓	**Check all items that apply to you:**
	I use a service dog, so please alert anyone who may be allergic to or frightened of dogs. ★
	I am hard of hearing:
	I read lips, and I need people to face me when speaking. Therefore:
	• People should keep their hands away from their mouth when speaking.
	• People should use their normal tone of voice when talking with me.
	• People should raise their voice so I can hear what they are saying to me.
	• I need to an assistive listening device ★
	• I need Communication Access Real-Time Translation (CART) ★
	I am deaf and need to use an interpreter:
	• American Sign Language (ASL) ★
	• Signed English★
	• Oral interpreter
	• I will use a family member or friend.
	• The speaker should speak directly to me and not the interpreter.
	• Other:

	I need to have consent forms and instructions read to me. ★
	I need consent forms and instructions provided in this format: ★
	• Braille
	• Large print
	• Digital
	• Audio
	I need assistance in filling out forms. ★
	I want the forms I must complete sent to me before my appointment. I will read them, complete them, and bring them with me to the appointment. ★
	My speech is slow and/or difficult to understand.
	• Allow extra time so that I can ask questions. ★
	• Avoid acting as if you understand me unless you do.
	• If what I say is not understood, ask me to repeat it, even three or four times, if needed.
	If what I say is still not understood, ask me to:
	• Use paper and pen.
	• Spell the words.
	• Other:
	I use a communication device or a communication board.
	• Do not interrupt or finish my sentences.
	• It is OK to interrupt or finish my sentences.
	• Allow for extra time, so I can ask questions.
	• Other:

	I need to know if the building, office, exam rooms, scales, and equipment are wheelchair accessible. ★
	• I need a height-adjustable (high/low) exam table★ and/or
	• I need help getting onto an exam table. ★
	I need to use a wheelchair-accessible restroom. ★
	I need to take a bus and need to use an accessible route from the bus stop to the office.
	I need an accessible parking space and route (including an elevator if not on entry level) into the health provider’s office. ★
	When referred to another provider (such as a specialist) for consultations, procedures, or tests, I need to be sure that the facilities and equipment are accessible, and staff can assist with:
	• Transfers
	• Positioning
	• Other:
	I have ____life-threatening or ____ health-threatening reactions to: ★
	• Latex
	• Pesticides
	• Roofing sealant
	• Paint
	• Scented personal care products
	• Other:
	• I will need to reschedule my appointment if I will be exposed to the above products.

	- My provider should consider developing a scent-free workplace policy.
	Ask providers to use "every day” clear and understandable plain language and to pause often, to be sure that I am following and understand what they are saying.
	Ask providers to use pictures or models. Sometimes I need them to demonstrate how to do something or what they want me to understand.
	I need to ask questions that are important to me, and I need providers to be patient when I am trying to understand new information.
	A slow response or lack of response does not necessarily mean I am not aware of what is said. Providers should allow extra time for me to respond.
Sources: Kailes, J. (2002). Preferred Practices to Keep in Mind as You Meet People with Disabilities, Available at www.jik.com/resource.html or from jik@pacbell.net. MCARE, The National Clearinghouse on Long-Term Supports and Services for Individuals with Disabilities and Their Families Institute on Disability, University of New Hampshire (Draft, 199). *Taking Charge of My Health: Tools for Individuals with Disabilities who want more say in their Health Care Services*.	

Adapted from: Kailes, J. I. (2005). *Be a Savvy Health Care Consumer, Your Life May Depend on It!* KAILES Publications. jik@pacbell.net.

Effectively Communicating with Health Care Providers

Expressing your needs, letting providers know what you want, and asking questions will help you get the right health care services. This is true for anyone, but it may be truer for people with disabilities because providers may make assumptions about you and your health. For example, some providers incorrectly assume that people with disabilities cannot be healthy. Sometimes providers think that all people with disabilities are the same. These attitudes and assumptions are wrong and should be corrected.
For example, you might say, “you think I get no exercise, but I go to the fitness center at least three times a week to exercise.

When talking with health care providers:

- *Be active and assertive.* Ask for what you want or need. Bring up questions or issues of concern. Active, assertive communication will help you stay in control.
- *Avoid being passive.* Don’t wait for information or for results to happen. Passive communication gives your power away.
- *Be specific.* Give enough detail for the provider to act on your request. Non-specific communication is fuzzy and unclear.
- *Be results-oriented, not problem-oriented.* Effective communication is solution-specific and results-oriented. Stating problems only gives away your power and leaves it to the other person to figure out the solution. It is passive and removes you from responsibility

for the outcome. If your communication style is results-oriented, health care providers will know what you think the solution is. They can then use that information to make decisions with you.

- *Don't stop or give up.* Be respectful, but firm, in asking for what you need.

The DES Script: A Tool for Improving Communication

People who communicate their health care needs clearly can achieve better results. The DES Script described below can help you sharpen your communication skills. This tool reminds you to think and speak in ways that will help you:

- Feel more confident as you express your needs.
- Help lessen other people’s feelings that you are attacking them.
- Make sure you state what you want to get out of a situation.

Here are some examples of helpful and not helpful communication:

TYPES OF HELPFUL AND NOT HELPFUL COMMUNICATION

Helpful	***Not* Helpful**
Active Communication “I believe I need to have my blood pressure, cholesterol, and weight checked. I also need a flu shot.”	**Passive Communication** “Well, I thought I might need some tests and some shots, but I guess if you don’t see anything that needs to be looked at…I mean, you’re the doctor.”
Specific Communication “I need a referral to a mammogram center that can work with people like me who are unable to stand.”	**Non-Specific (Fuzzy) Communication** “I need to get a breast checkup.”
Results-Oriented Communication “I would like to have my physical while on the exam table. I need assistance getting on the exam table.”	**Problem-Oriented Communication** “I don’t want to have my physical while seated in my scooter.”
Persistent Communication “I know you have other patients waiting, but I feel that this is important. I think I’m overweight and I smoke too much. Could you take a few minutes to discuss these issues with me?”	**Non-Persistent Communication** “OK. I think I’m overweight and I smoke too much, but I understand that you’re running short on time.”

THE DES SCRIPT

The DES Script breaks down statements into three pieces:

D - Describe the situation as you see it.

E - Express how you feel about it, using “I” statements, such as “I feel . . .” or “I believe . . .”

S - Specify what you want to see done, changed, accomplished.

The key to using this tool effectively is practice. Below are additional examples.

Situation The doctor is rushing through your appointment because she is running late, and there are many more patients waiting.	
Response	
D	It seems like you’re in a hurry and I have several concerns we haven’t discussed.
E	I feel like my needs are not being met, and I’m not OK with that.
S	What can we do to make sure we get the chance to discuss my questions before I leave today?

Situation	
The doctor begins to give you your annual physical while you are still seated in your wheelchair. You want the exam to be done on the exam table.	
Response	
D	I have concerns about not getting a complete physical while seated in my wheelchair.
E	I feel like I’m not getting the best treatment possible.
S	I would like to have my physical while on the exam table.

Situation	
You feel that you’re gaining weight, and you’ve been unsuccessful in stopping smoking, but the doctor never discusses these concerns.	
Response	
D	We never discuss my diet, eating, and smoking habits.
E	I’m concerned about my weight and my smoking.
S	I need to discuss these concerns with you.

Situation	
You know you’re at risk of osteoporosis because of your size, family history, and because you’ve had a spinal cord injury. You’re only 30 years old, but you’re concerned about the future.	
Response	
D	Because of my walking limitations, I don’t do a lot of walking or standing.
E	I’m only 30, but I feel worried about my bone density.
S	I want you to help me get a bone-density test to see if I have a problem.

Situation You’re having your annual checkup. You use a walker, but you don’t have the balance needed to step up onto the scale and stand on it. The nurse says, “Since we can’t weigh you, tell me what you think your weight is.”	
Response	
D	I want to be weighed like everyone else.
E	Don’t you base the dosage of my medication on my height and weight?
S	Can you get an accessible scale that I can use?

Situation On your last doctor visit, you found that you weren’t able to get onto the exam table. The staff was not prepared to assist you with transferring safely, and there were no options. When you schedule your next appointment, you call ahead to plan.	
Response	
D	On my last visit, I found that your high exam table doesn’t work for me.
E	I would be able to safely get on to a height-adjustable table that lowers to 18-20 inches.
S	Can you get one? Here’s a list of some of the available tables. Or can you have staff available who can assist me in transferring safely on and off the exam table?

Situation Because of your disability, you have trouble maintaining the position needed for a mammogram. As a result, the images aren't always clear. You feel you also need screening using ultrasound. The imaging center's staff says that that's not possible because of their policies.	
Response	
D	I have a history of unclear mammography films because it's hard for me to stay in the position needed.
E	I would like an ultrasound in addition to the mammogram.
S	I need your help to make this happen.

Now you practice thinking and planning. Think of a situation that might come up for you at a provider visit. What response could you give for this situation?

- How would you "**Describe**" this?
- What words might best "**Express**" how you would feel?
- How can you "**Specify**" what you want to be done?

D	
E	
S	

Now that you've got the hang of it, practice with a few more situations.

D	
E	
S	

D	
E	
S	

Use this CHIEF COMPLAINT / REASON FOR VISIT form to prepare for an appointment in which you must describe some new symptoms (history, pain, location, frequency, possible causes, etc.)

Date ___/___/_____	**Chief Complaint / Reason for Visit**
Symptoms I have been experiencing	
Date Started (Onset):	
Location of the symptoms. (stomach, right leg, etc.)	
Do symptoms occur more frequently at certain times of the day, week, month, or year (patterns - all the time, periodic, intermittent)?	

Describe pain: (dull, sharp, shooting, stabbing, piercing, throbbing, gnawing, pounding, etc.)	
How intense -- (on a scale of 1 - 10, 1 = very slight pain, 10 = absolutely terrible pain	
What bothers me most?	
Does positioning, posture, diet, medication make a difference?	
Is there a change when you feel tired?	
Have you started using a new product, exercising, eating a new food; taking new medication or	

vitamins that may cause a reaction?	
Is there a change in your life (stress - the death of friend or family member, loss of a job, divorce, etc.)?	
Have you had the problem before? If yes, when and what did you do? Previous treatment for the condition and results: drugs, tests, and improvements.	
Other related or unrelated symptoms:	
What do you think is causing the condition	
Referral (Who sent you?)	

Understanding and Remembering Information From Visits With Health Care Providers

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Sometimes you may not be able to remember or explain what your provider told you at your appointment. Your friends and family may ask what your health care provider said, but you are not sure, or you cannot remember. People may ask you questions that you wish you had asked during your visit. You are not alone. Below are ways to help you understand and remember what happens at your appointments.

Take a Support Person with You

To make the most of your appointment, think about taking a support person with you. A support person can be a friend or family member who you trust. A support person is someone who listens, takes notes, ask questions, and can record the discussion for you. A support person can also help you remember what the doctor says. Remember, it’s your right to bring one support person into your appointment with you, but you are never required to bring someone if you don’t want to.

When choosing a support person, make sure the person is:

- Someone you trust.
- Someone who will not take control of the visit.
- Someone you can rely on for support.
- Someone who can listen carefully and take good notes and/or record the visit so that you can review the information later.

After choosing a support person, work together to get the most from your appointment. Use the checklist below to improve the chances that your appointment goes smoothly.

Effectively working with Your Support Person

- **Before your appointment, tell your support person what you need. For example, you may want some private time with your provider. If so, tell your support person about this need.**
- **Introduce your doctor to your support person. Make sure your doctor talks both to you and your support person.**
- **Make sure that you and your support person take notes. If you cannot take notes, sit close to your support person. This will allow you to refer to your support person's notes if you need to.**
- **After your appointment, compare notes with your support person. Make sure you understand what the provider said.**

Take Notes

"The faintest ink is more accurate than the strongest memory." On average, people forget half of what they hear in a few minutes.
At the end of your appointment, review the information with your provider. Tell your provider what you thought her main points were. If your provider corrects you, change your notes.

Record Your Appointments

Sometimes you may not want or be able to take notes. You may not be able to find a support person. You can record your appointment using the recording function on your smartphone, mobile device by using an inexpensive recorder. Recording the visit helps you focus on what your provider says without being distracted by note taking.

Before you record an appointment, tell your provider why you want to record what she says. You might say, "Do you mind if I record our appointment?   I do not want to miss anything you say by taking notes. I want to remember everything I hear, and recording helps me."

When you get long and/or complicated information or instructions, you can ask that this information be read into your recorder or voice mail (if available to you).

Ask for Pictures

If you do not understand something your provider says, ask her to show you on a model or draw a picture. Ask for a copy of the picture. Or take a picture with your phone.

Get Your Test Results

Never assume things are OK when you don't hear from your doctor about your test results. Studies show most providers do not always follow up on test results. Be assertive and follow up if you don't get your test results. The results are more important to you than to anyone else. Tell your provider you want a call about the results, whether they are positive or negative, as soon as possible. Also, request a copy of them for your records. Don’t consider the test complete until you get the results.

Be sure that your test and routine screening results are shared with your other health care providers active in your care. Having these results:

- Helps everyone stay current and informed about your health
- Prevents time delays when information is needed to make treatment decisions
- Avoids tests from being repeated unnecessarily
- Reminds the provider that other people are involved in your care that they may need to consult

Use the **Test Result Communication Form** to help ensure that you and your providers get copies of your test results. Give a copy of this form to the provider who orders or does the test.

TEST RESULT COMMUNICATION FORM

Please send my test results to:

Patient*:		
Address		
City	**State**	**Zip**
Phone:	**Fax:**	
Primary Care Provider:		
Name		
Address		
City	**State**	**Zip**
Phone:	**Fax:**	
Provider:		
Name		
Address		
City	**State**	**Zip**
Phone:	**Fax:**	
Provider:		
Name		
Address		
City	**State**	**Zip**
Phone:	**Fax:**	
Provider:		
Name		
Address		
City	**State**	**Zip**
Phone:	**Fax:**	

Provider:			
Name			
Address			
City		**State**	**Zip**
Phone:	**Fax:**		
Provider:			
Name			
Address			
City		**State**	**Zip**
Phone:	**Fax:**		
Comments:			
• Always include yourself on the lists of individuals who are to receive your test results.			
Adapted from: Kailes, J. I. (2005). *Be a Savvy Health Care Consumer, Your Life May Depend on It!* KAILES Publications jik@pacbell.net.			

Important Ideas to Remember:

- The most successful relationships with health care providers are those you treat as partnerships.
- I can get better health care results when I am active rather than passive.
- Good communication can lead to better health care.
- If I plan and ask for help specific to my disability, I can get better care and services.
- Consider taking a support person with me to my appointments.