

# Advocating for Yourself in Healthcare Settings

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# Introduction

- My name is Nicole Noblet.
- I work for Eitas as a Peer Resource Specialist.
- I am involved with disability advocacy in Missouri and across the country.
- I have a dog named Pebble, who loves to run with me alongside my power wheelchair.
- I use Augmented and Alternative Communication (AAC).

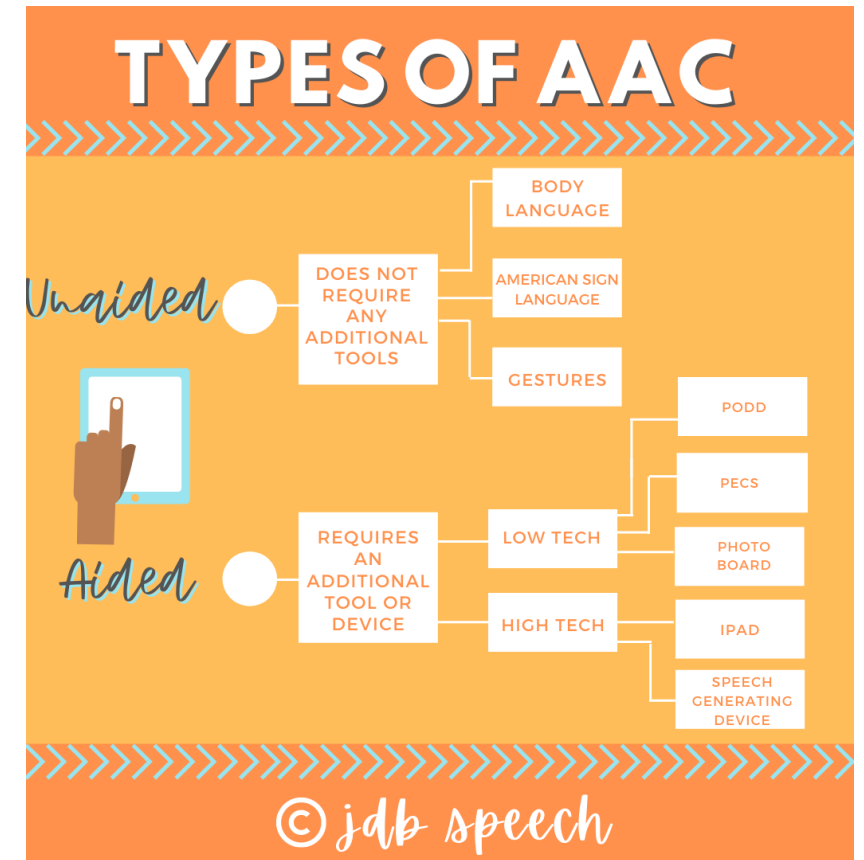


# What You Will Learn

- Communication strategies for AAC users and others with communication disabilities
- Getting your needs met
- Talking about your concerns
- Feeling listened to and respected
- Preparing for your appointment
- Using Charting the Life Course tools
- AASPIRE Toolkit
- Keeping track of your healthcare
- What to do if the provider is talking to your supporter and not yourself
- What to do if you are not satisfied with your care

# Communication Strategies

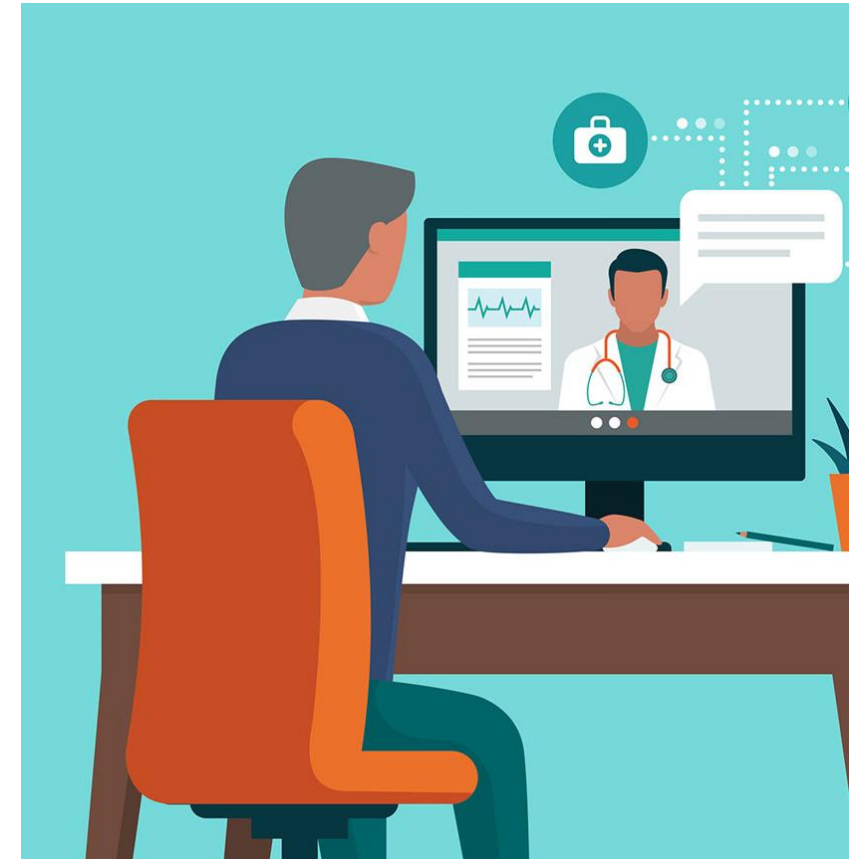
- If possible, schedule a longer appointment.
- Tell your provider how you communicate and how they can best communicate with you.
- Keep your Speech Generating Device charged and with you.
- Have access to age appropriate AAC, that uses accurate names for body parts.
- Add to your patient chart that you use AAC or have a communication disability.
- Doctors make assumptions about what they don't know.
- To save time, I add things to my device: full name, Date of Birth, height, weight, medications.



# Getting Your Needs Met

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- Find a provider that is knowledgeable about your health conditions.
- Write down what you want to talk to your provider about.
- Bring a support person who knows your medical history, if needed.
- When able, ask for Tele-Health (video or phone call) visits, if this is helpful.
- If you don't understand something, tell your provider and have them explain it in a way you can understand.
- Have the provider write down instructions step by step, in a way you can understand.
- Ask for accommodations if needed.



# Talking About Your Concerns

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- Make a list of things you need to talk to your provider about.
- When scheduling the appointment, a lot of times they will ask why you are making the appointment.
- When the nurse is checking your vitals and going over your medications, tell them what you need to talk to your provider about.
- If your provider doesn't address all the things you needed to talk about, speak up.
- If you need to see a specialist, ask your Primary Care Provider for a referral.





# Feeling Listened to and Respected



- Correct assumptions providers may make about you or your disability.
- Find a provider that makes you feel comfortable and safe - one who cares about you as a person, not just a number.
- Example: I saw a doctor who told me they don't treat patients with cognitive delays - this was not a good doctor for me.
- Find a doctor who listens and takes your seriously, no matter how small your concerns are.

# Preparing for Your Appointment

- Check-in online if you have a patient portal (saves time).
- Write down what you need to talk about.
- Bring a support person, if needed.
- Know what medications you take. Write this down if needed.
- Know what type of provider you are seeing.
- Keep track of your appointments.



**8 TIPS FOR A BETTER DOCTOR APPOINTMENT**

**BRING A LIST OF QUESTIONS**

It's so common — we head for a doctor appointment intending to discuss certain topics, yet we leave the office having forgotten to do so! Write down a list and bring it along to jog your memory.

**INVITE A RELATIVE OR FRIEND**

Unless you prefer that your appointment be totally private, bring a companion to help you remember questions you wanted to ask, and to take notes and remind you later about what the doctor said.

**BRING A LIST OF YOUR MEDICATIONS**

Keep your list up to date so you can share it with each of your healthcare providers. The list should include prescription and over-the-counter drugs, as well as supplements. This can help avoid drug side effects and interactions.

**BE HONEST AND OPEN**

Your doctor can measure your blood pressure, cholesterol and so forth. But some information — your exercise level, smoking, alcohol consumption, memory problems, depression or if you've suffered falls — can only come from you.

**REQUEST MORE INFO**

If you are confused about the doctor's instructions, diagnosis or recommended treatment, ask the doctor to explain again. Ask for written instructions, a brochure or a link to online information.

**BRING YOUR GLASSES OR HEARING AIDS**

Inform staff about your vision or hearing loss. Speak up if you're having trouble hearing or seeing. And if you need an interpreter, let the doctor's office know ahead of time.

**FOLLOW UP LATER**

Doctor appointments today can seem rushed. And often it's not until the appointment is over that we think of questions we wish we would have asked! Phone or email your provider with additional questions, or if something isn't clear.

**BRING YOUR PROFESSIONAL CAREGIVER**

Families who use in-home care should know that home care doesn't only happen at home! Your caregiver can provide transportation to healthcare appointments, and can accompany you during the appointment.

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# Using Charting the Life Course Tools

**Healthy Living | My Health Care Support Needs**

My Name: \_\_\_\_\_ Date: \_\_\_\_\_  
Supporter's Name (if needed): \_\_\_\_\_

**MY HEALTH CARE SUPPORT NEEDS**

**Understand Medical Information**

☐ I do not need help with understanding medical information.

**I would like help to:**

☐ Understand what my health care workers tell me or what they recommend.  
☐ Learn about all my options or choices.  
☐ Understand the pros and cons of each option to help me make an informed decision.  
☐ Other: \_\_\_\_\_

**How health care workers can best support me:**

☐ Use photos or pictures to explain procedures or directions.  
☐ Use simple language.  
☐ Provide extra time.  
☐ Other: \_\_\_\_\_

**Communicate with Health Care Workers**

☐ I do not need help communicating with health care workers.

**I would like help to:**

☐ Share my current situation.  
☐ Communicate my decisions or choices.  
☐ Ask the health care worker questions.  
☐ Respond to the health care worker's questions.  
☐ Other: \_\_\_\_\_

**How health care workers can best support me:**

☐ Repeat my answers back to me.  
☐ Ask me to "teach back" instructions.  
☐ Ask me questions.  
☐ Other: \_\_\_\_\_

**Follow Through with Next Steps**

☐ I do not need help following through with next steps.

**I would like help to:**

☐ Follow through with my medical decisions or choices.  
☐ Set up my medications.  
☐ Share a summary of my visit with: \_\_\_\_\_

**How health care workers can best support me:**

☐ Write down instructions for next steps.  
☐ Update and organize my information such as my medication list or health care visit summary.  
☐ Give reminders of upcoming appointments.  
☐ Check in with me to see how it is going.  
☐ Other: \_\_\_\_\_

**Healthy Living | My Health Care Support Team**

My Name: \_\_\_\_\_ Date: \_\_\_\_\_  
Supporter's Name (if needed): \_\_\_\_\_

**MY HEALTH CARE SUPPORT TEAM**

**Personal Support**

Name: \_\_\_\_\_ Relationship: ☐ Family ☐ Friend ☐ Other: \_\_\_\_\_

Role At Visit:

☐ Understand medical information  
☐ Follow through with next steps  
☐ Communicate with health care workers  
☐ Other: \_\_\_\_\_

Name: \_\_\_\_\_ Relationship: ☐ Family ☐ Friend ☐ Other: \_\_\_\_\_

Role At Visit:

☐ Understand medical information  
☐ Follow through with next steps  
☐ Communicate with health care workers  
☐ Other: \_\_\_\_\_

Name: \_\_\_\_\_ Relationship: ☐ Family ☐ Friend ☐ Other: \_\_\_\_\_

Role At Visit:

☐ Understand medical information  
☐ Follow through with next steps  
☐ Communicate with health care workers  
☐ Other: \_\_\_\_\_

**Formal Support**

Name: \_\_\_\_\_

Relationship: ☐ Paid Staff (PCA, RSH) ☐ Residential/Provider Agency Staff ☐ Other: \_\_\_\_\_

Role At Visit:

☐ Understand medical information  
☐ Follow through with next steps  
☐ Communicate with health care workers  
☐ Other (e.g., transportation, safety): \_\_\_\_\_

Name: \_\_\_\_\_

Relationship: ☐ Paid Staff (PCA, RSH) ☐ Residential/Provider Agency Staff ☐ Other: \_\_\_\_\_

Role At Visit:

☐ Understand medical information  
☐ Follow through with next steps  
☐ Communicate with health care workers  
☐ Other (e.g., transportation, safety): \_\_\_\_\_

Name: \_\_\_\_\_

Relationship: ☐ Paid Staff (PCA, RSH) ☐ Residential/Provider Agency Staff ☐ Other: \_\_\_\_\_

Role At Visit:

☐ Understand medical information  
☐ Follow through with next steps  
☐ Communicate with health care workers  
☐ Other (e.g., transportation, safety): \_\_\_\_\_

**Healthy Living | Medical Provider List**

This Medical Provider List belongs to: \_\_\_\_\_

|  Type of Medical Provider |  Name of Provider/Practice |  Phone Number |  Email |  (Why Do I See Them?) |
|--|---|--|---|--|
| Ex: Specialist<br>Cardiologist   | Ex: Dr. Smith   | Ex: 555 - 555 - 5555   | Ex: smiths@abc.com  | Ex: Takes care of my heart   |
| Primary Doctor   |   |  |   |  |
| Primary Doctor   |   |  |   |  |
| Specialist<br>Type   |   |  |   |  |
| Specialist<br>Type   |   |  |   |  |
| Specialist<br>Type   |   |  |   |  |
| Specialist<br>Type   |   |  |   |  |
| Hospital   |   |  |   |  |
| Urgent Care  |   |  |   |  |
| Pharmacy   |   |  |   |  |

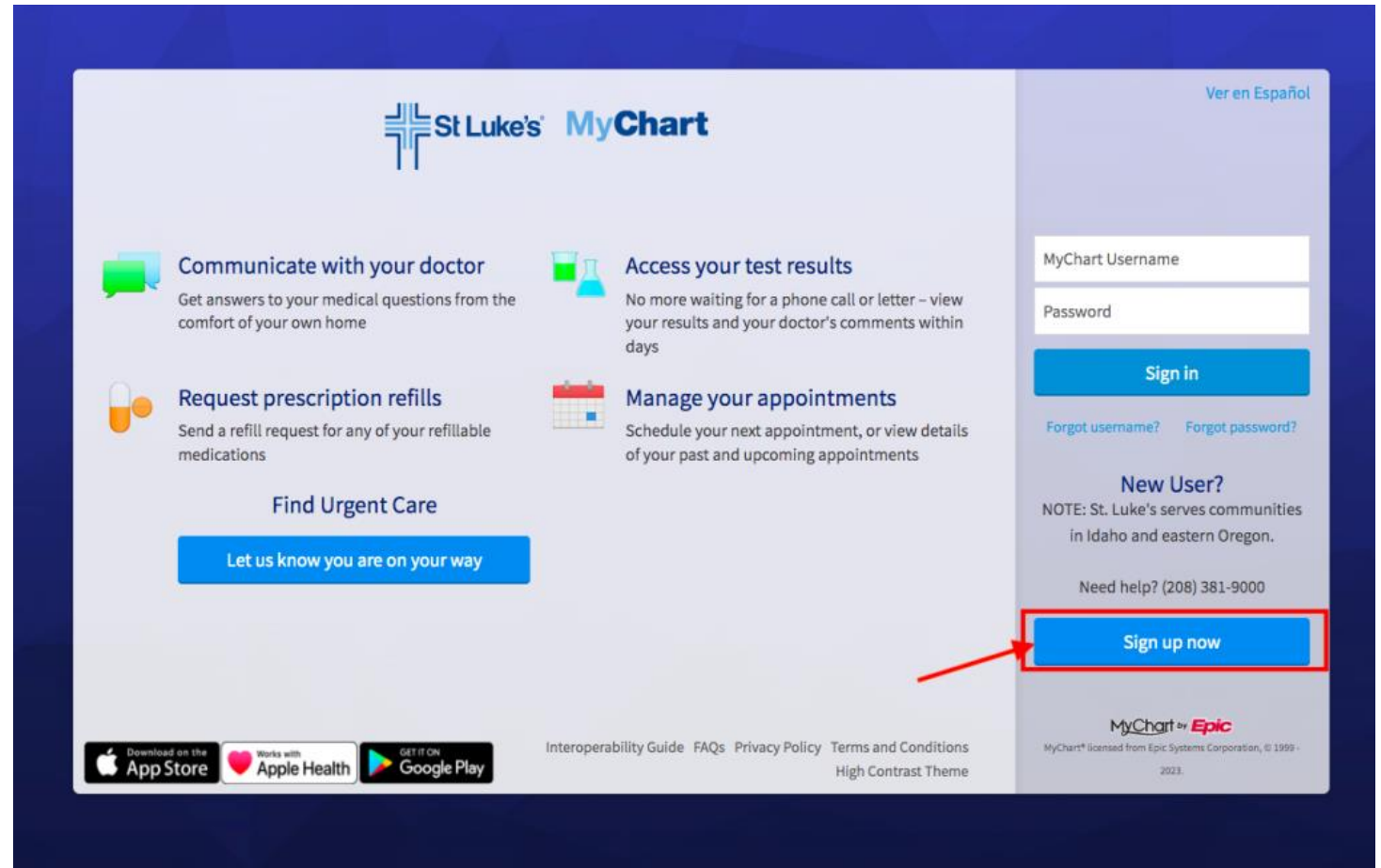
 Charting the Life Course  
Research Center  
Charting the Life Course and Tools: community resources developed by the LifeCourse team  
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|   |                                       |  |  |
|---|---------------------------------------|--|--|
| <b>Healthy Living   Today's Health Care Visit</b>   |                                       |  |  |
| FILL OUT THIS PAGE BEFORE GOING TO THE VISIT  |                                       |  |  |
| My Name: _____  |                                       |  |  |
| Supporter if needed: _____  |                                       |  |  |
| <b>ABOUT MY APPOINTMENT:</b>  |                                       |  |  |
| Date of Appointment _____   | Who is with me today? _____           |  |  |
| Appointment Type (check one) _____ Family Doctor _____ Specialist (specify what kind) _____   |                                       |  |  |
| For _____ Dental _____ (Check my therapy bill) _____ Walk-in Clinic _____ Urgent Care _____ Hospital/TR Visit _____   |                                       |  |  |
| <b>THINGS TO BRING WITH ME:</b>   |                                       |  |  |
| My ID _____ Medication List _____ Health Insurance Card _____ Medicaid/Medicaid Card _____ Way of Payment _____   |                                       |  |  |
| Other _____ Other _____ Other _____   |                                       |  |  |
| <b>REASON FOR MY VISIT:</b>   |                                       |  |  |
| Why am I at the doctor or health care provider today?<br>_____ Scheduling Test _____ Injury/Accident _____ Regular Checkup/Physician _____ Medication Refill/Change |                                       |  |  |
| Have any of these things been bothering me in the last week or longer? (check if yes)   |                                       |  |  |
| <input type="checkbox"/> Pain   | <input type="checkbox"/> Head         | <input type="checkbox"/> Throat            | <input type="checkbox"/> Skin          |
| <input type="checkbox"/> Nausea/Dizziness   | <input type="checkbox"/> Eyes         | <input type="checkbox"/> Heart             | <input type="checkbox"/> Arms/Hands    |
| <input type="checkbox"/> Sleeping   | <input type="checkbox"/> Ears         | <input type="checkbox"/> Breathing         | <input type="checkbox"/> Leg/Foot      |
| <input type="checkbox"/> No Energy/Tired  | <input type="checkbox"/> Nose         | <input type="checkbox"/> Stomach           | <input type="checkbox"/> Irritation    |
| <input type="checkbox"/> Frequent/Feeling   | <input type="checkbox"/> Mouth/Throat | <input type="checkbox"/> Going to Bathroom | <input type="checkbox"/> Sexual Health |
| Describe what is going on:<br><br><br>  |                                       |  |  |
| How I have used for this reason before? Yes <input type="checkbox"/> No <input type="checkbox"/>  |                                       |  |  |
| <b>QUESTIONS I WANT TO ASK TODAY:</b>   |                                       |  |  |
| <br><br><br><br><br><br>  |                                       |  |  |

# Patient Portal

- Quick access to providers
- Access on your Smart Phone or tablet



## What Is a Patient-Centered Medical Home (PCMH)?

**It's not a place... It's a partnership with your primary care provider.**



PCMH puts **you** at the center of your care, working with your health care **team** to create a **personalized plan** for reaching your goals.

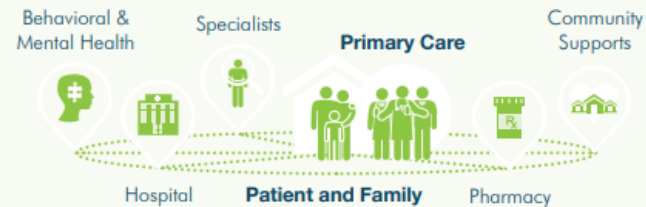


Your **primary care team** is focused on getting to know you and earning your trust. They care about you while caring for you.



Technology makes it easy to get health care when and how you need it. You can reach your doctor through **email**, **video chat**, or after-hour **phone calls**. **Mobile apps** and **electronic resources** help you stay on top of your health and medical history.

**As you pursue your health care journey, you may make stops at different places:**



Wherever your journey takes you, your **primary care team** will help guide the way and coordinate your care.

**Studies show that PCMH:**



Provides better **support** and **communication**



Creates **stronger relationships** with your providers



Saves you **time**



To learn more about the PCMH, visit [www.pcpcc.org](http://www.pcpcc.org)

**A Patient-Centered Medical Home is the right care at the right time. It offers:**



**Personalized care plans** you help design that address your health concerns.



**Medication review** to help you understand and monitor the prescriptions you're taking.



**Coaching and advice** to help you follow your care plan and meet your goals.



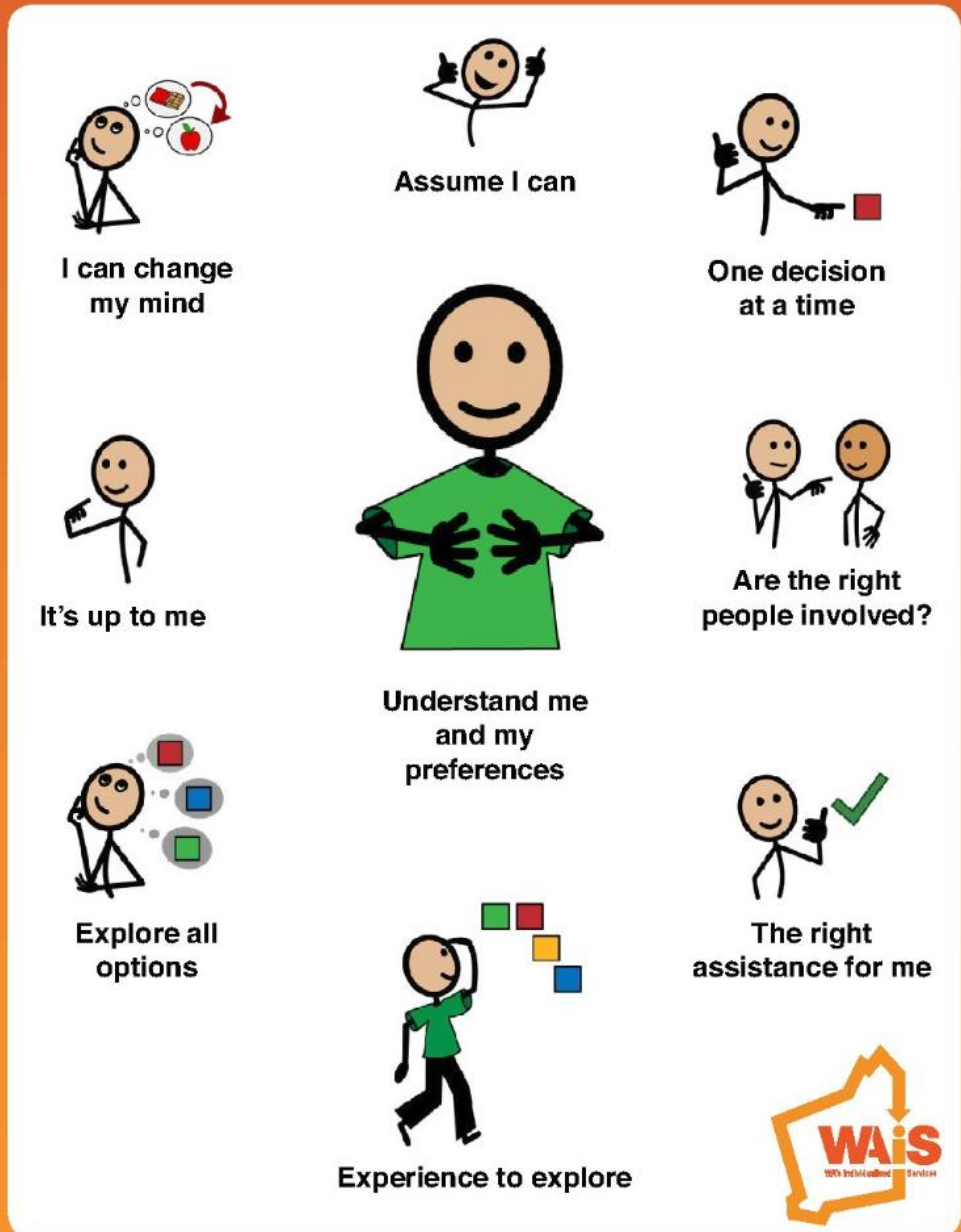
**Connection to support and encouragement** from peers in your community who share similar health issues and experiences.

# Medical Home

- Patient Centered
- Comprehensive
- Coordinated
- Accessible
- Committed to Quality and Safety
- Culturally Competent Care

# Supported Decision Making for Healthcare

- Getting help making healthcare decisions.
- Having someone you trust help you understand what your provider is saying.
- Make a Supported Decision-Making agreement.
- Make an Advanced Directive.
- Durable/Power of Attorney.
- If you are told that you cannot bring a support person with you to your appointment, you can. You just might have to fight for your right to do so. This will benefit more than just yourself.





# Talk to Me, I'm the Patient

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- Remind the provider to talk to you, not the support person.
- "I am capable of answering your questions. Please direct your questions towards me".
- You are the expert on your body. Don't let someone else decide what is best for you.



# Not Satisfied with Your Care

- You can choose a different provider. This can be challenging because of insurance coverage, but it is an option you have.
- Talk with your provider, or the clinic/hospital's case manager or patient advocate.
- If you believe that you have been discriminated against, you can file a case with the Missouri Commission on Human Rights.
  - I just resolved my case of discrimination.



Questions