

TechOWL



Technology for Our Whole Lives



Communication First in Collaboration with ACES: **Accessing Better Communication for Deciding Together (ABCD)**



Institute on Disabilities



ACES: Talking with Doctors

Strategies for Communicating with Doctors

October 27, 2020



Institute on Disabilities

Housekeeping

- Have mic turned off when not speaking
- Questions and comments can be typed in the chat
- There will be time at the end for more questions
- If you use your device, you will want to turn up your volume so all can hear

Thing to Keep in Mind

- Respect the privacy of other participants
- Things that are shared here, stay here
- This is a safe and collaborative space
- You do NOT need to share if you are not comfortable
- You do NOT need to have your video on
- All communication is valued here (devices, mouthwords, typing, etc.) → use what you are comfortable with!



Using Patient Portals

- How do you access the internet?
- Can you send a message directly to your doctor/nurse?
- Is the website clear, direct, and organized in a way you can understand?
- Communicating the need for additional accessibility to your doctor's practice

Familiar Communication Partners

- Who? → family, friend, legal guardian, supports person, etc.
- What role can they play to help you?
- Co-constructed messages v. fully independent message construction

**Poll: I use a communication partner
during my appointments.**

Yes

No

Sometimes



Written Narratives

- More detailed accounts of your medical history
- Answers to commonly asked questions
- What you want to accomplish at that particular visit



Advocating for Yourself

- Use direct, firm language
- Be polite (when you can), but assertive
 - Being polite does not mean you can't say "NO"
 - Its ok to NOT be polite

Do you agree or disagree with this list? Is it effective for you?

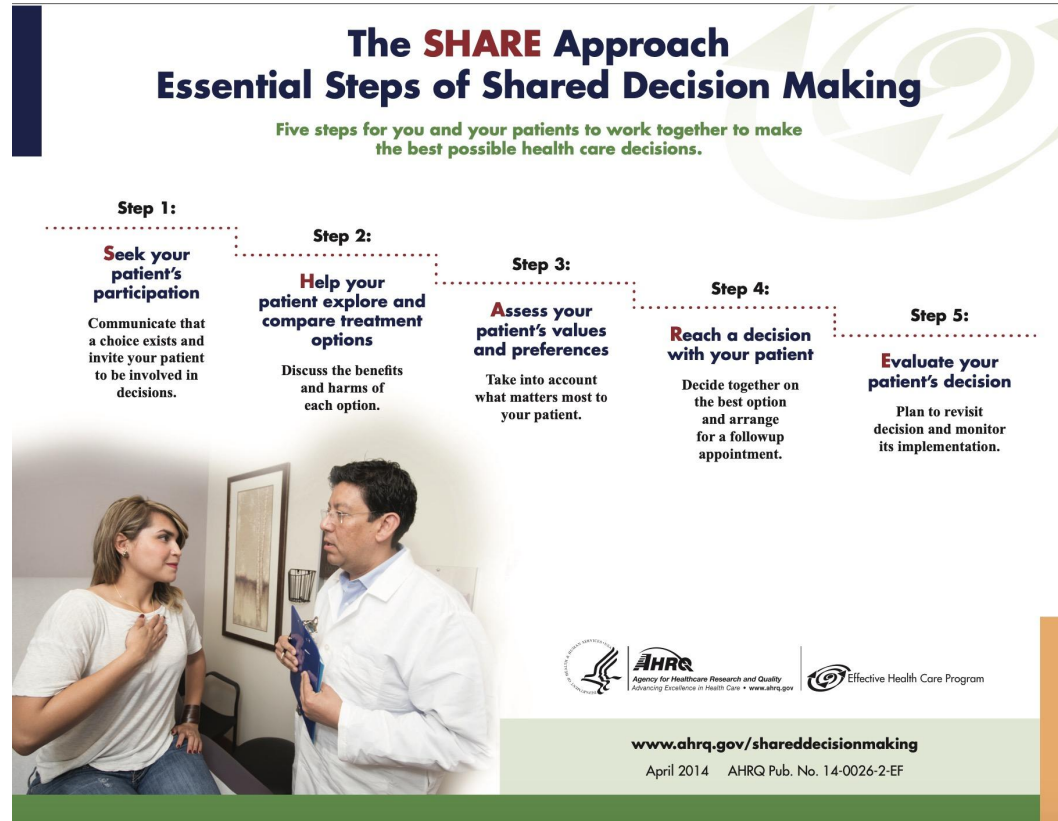
- Participant video:

<https://www.youtube.com/watch?v=ozGwNfVIK6k>

Personal Websites for Advocacy and Information

- Caitlin's blog on being a good communication partner: <https://www.caitlyn-connelly.com/blog>
- Donnie's blog: <https://donnie.lgbt>

The SHARE Approach One-Pager



<https://www.ahrq.gov/sites/default/files/publications/files/shareposter.pdf>

SHARE Approach Messages

- This is how I communicate and I understand:
 - Everything you say
 - Best with the following accommodations:
Visual/Auditory/Written/Video
 - What's important to me & What I hope to achieve
- I make the decisions about my care
- Direct your information to me, not my caregiver
- What are the risks of this treatment?
- What are the risks of not following this treatment?

Messages on The AAC Device

- What to pre-program
- What to do spontaneously
- Short messages to direct the conversation
 - To direct responses back to the AAC user
 - To express that you understand information
 - To say that you need more information to help you decide
- Should you need to mention your academic credentials?
- Combating ableist assumptions

Healthcare Messaging for Trans, Non-binary, Bi-gendered Folks

- Healthcare needs are human needs and generally no different
- Messaging for exploring HRT
- Messaging for exploring further transition procedures
- Messaging for combating the combination of ableist and homophobic bias

Poll: I get the time I need to articulate my ideas and thoughts during an appointment.

Always

Often

Sometimes

Occasionally

Never

N/A



Need to Know Document

- Include information about:
 - Health conditions/disabilities
 - Assistive tools
 - Accommodations
 - Lifestyle
- Free printable from TechOWL:
<https://techowlpa.org/news/need-to-know/>



Healthcare Passports

- Similar to the Need to Know document, but can be more detailed
- Include information about:
 - Communication methods
 - Medical history
 - Current medications (how /when I take my meds)
 - Allergies
 - How I show pain
 - How someone can help when I'm upset
 - How I cope with medical procedures
 - Mobility needs
 - Personal care/hygiene needs
 - Eating/drinking needs
 - Sensitivities
 - How to make future/follow-up appointments easier for me

Free Healthcare Passports

- University of South Florida:
http://flfcic.fmhi.usf.edu/docs/FCIC_Health_Passport_Form_Typeable_English.pdf
- NHS Foundation Trust:
<https://www.england.nhs.uk/6cs/wp-content/uploads/sites/25/2015/03/healthcare-passport.pdf>
- Communication Wallet Card:
<https://www.cdacanada.com/wp-content/uploads/2013/10/Communication-Instruction-Card-Sample-for-a-Hospital-Stay.pdf>

Communication in Emergencies

- How can we plan if we don't know when an emergency will happen?
- Have a Go Bag
- Need to Know document
- Copies of scripts & medicine for 3 days
- Light Tech device backup
- Emergency Communication 4 All Core Board
 - <http://bit.ly/Emergency4All>
 - Has pain scale and body picture to point to
- More Information:
<https://aaccommunity.net/2018/09/emergency-preparation-for-a-ac/>
- AAC in the Cloud: <http://bit.ly/AACemergencies>
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Creating Videos for SHAREing with Your Doctor

- Include:
 - Introduction statement
 - Who I am
 - How I communicate
 - How I best understand
 - Values/preferences
 - Additional instructions/requests for the doctor
- Include information about the Need to Know document or other documents you have with you

Poll: I want my video to live on....

AAC device

A Shareable Link

My Smartphone

Caregiver's Smartphone

Multiple places

Questions for Roundtable 3

- Which mode would you use most effectively in your video?
 - Written
 - Spoken
 - Visual
 - Speech-generating device
- Do you want to be seen, or just your communication device?
- What information will you want to share with your doctor?
- How can you use the SHARE approach to create authentic messages that you can use?
- How do we get healthcare providers to better value AAC?

Contact Information

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Thank You: Please Complete This Survey!

Presenters: ACES

Topic: ACES Talking with Doctors Webinar 3

[BIT.LY/PIAT_T1](https://bit.ly/piat_t1)

