

# Self Advocacy in a Medical Setting

ATSU-KCOM Medical  
Students

# Bad Example of a Doctor's Visit

# Good Example of a Doctor's Visit

# Important Questions to Ask Your Doctor!

# Questions to Ask at the Hospital or Clinic Visit:

1. “I would like to check that I understand ...”
  - a. And repeat back to the Doctor what you think is happening.
2. “I don’t quite understand, could you explain again?”
3. “Can I have a copy of any letters or documents about my health?”

You can write things down or ask the doctor or family member to write things down that you don’t understand so you can look them up later!

# Questions to Ask About Tests Being Done:

1. What are the tests for?
2. What do the results mean? Who will explain them to me?
3. How do I get the results?
4. What should I do if I don't receive results?

# Questions to Ask About Treatments/Medication:

1. Can you explain how this is going to help me?
2. Are there any side effects?
  - a. What should I do if I feel any side effects?
3. How do I know if the treatment is working?
4. Are there any alternative treatment options available?
  - a. Is there anything else I can be doing to improve my health?

# Questions to Ask About What To Do Next:

1. When should I come back and see you again?
2. Who should I talk to if things get worse or don't get better?
3. Where can I get more information about my illness or treatment?
4. Can I check that I understood what you said?
5. Who should I ask if I have any other questions or problems?

# Your Rights as a Patient

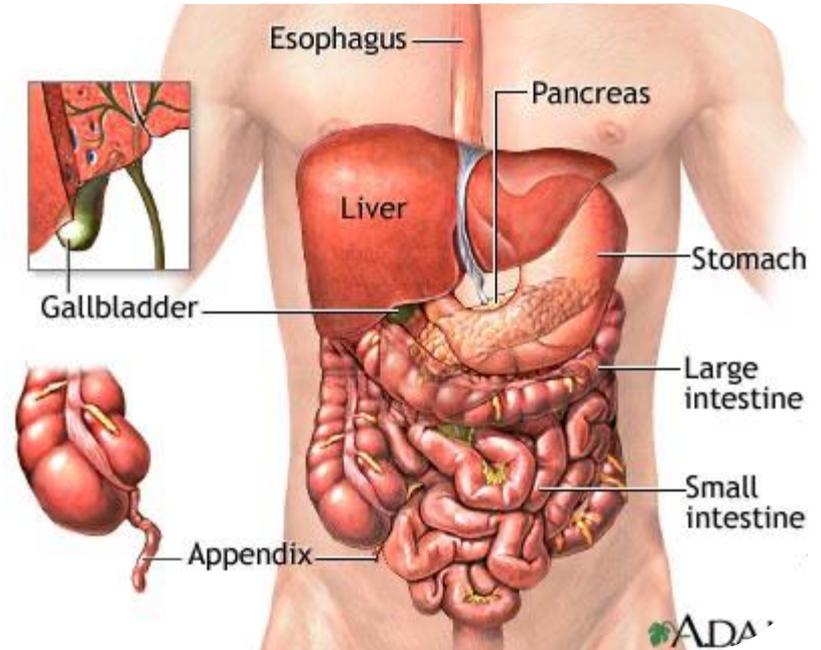
1. You have the right to a copy of your medical records
2. You have the right to refuse any treatment or procedure that you are not comfortable with
3. You have the right to ask questions
4. You have the right to feel respected, important, and cared for
5. You have the right to a Doctor that cares for you and puts your best interests first

# Different Medical Symptoms

# Abdominal/Belly Pain

What might cause our belly/abdomen to hurt?

- How can we explain how it hurts?
  - Sharp - like a pencil poking you
  - Aching - like someone is pinching you
  - Dull - like someone is squeezing you
  - Burning
- Where does it hurt?
  - High, Low, Left, Right
  - Does the pain stay in one spot or does it spread out?
- When did it start?
  - Did the pain just start or has it been there for a long time?
  - Is it there all the time or does it come and go?
- Does anything make it better or worse?



# Chest Pain

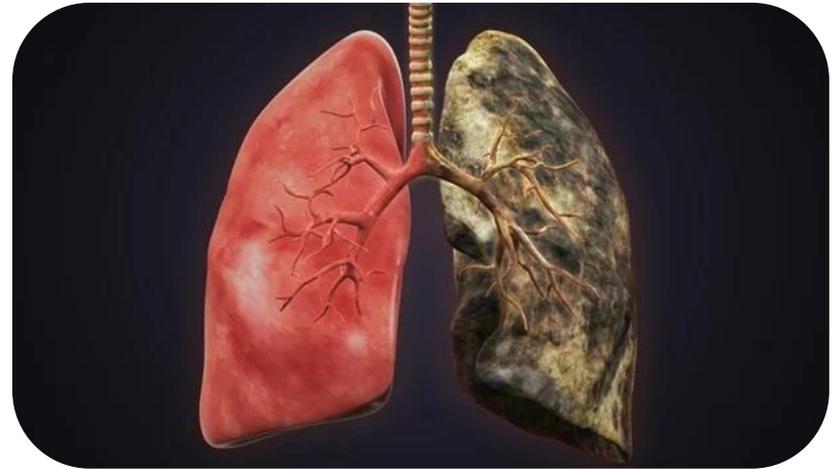
What might cause our chests to hurt?

- How can we explain how it hurts?
  - Crushing - like an elephant sitting on you
  - Sharp - like a pencil poking you
  - Burning
  - Constant? Or all the time?
- Where does it hurt?
  - Just in your chest? In your arm, jaw, or belly?
  - Do you feel like you might faint?
  - Is it hard to breathe?
- Does anything make it better or worse?
  - Does it get worse with exercise?
  - Does it hurt when someone presses on it?
  - Does it occur when you eat food?



# Trouble Breathing

- Are there times when you have trouble breathing? What does it feel like?
- When is it happening?
  - All the time or when you do certain things?
- Medical conditions that cause breathing problems (shortness of breath):
  - Asthma
  - Pneumonia (Infection)
  - Anxiety or panic attacks
  - Smoking cigarettes/vaping



# Head/Face Pain

What might cause our heads to hurt?

How can we explain the pain?

- Lightheadedness - Do you feel like you're going to fall over or pass out
- Headache - is it sharp, dull
- Location of the pain
  - One spot – can you point to it?
  - Band of pain
- When does the pain happen? All the time or when you do certain things?



# Mouth & Throat Pain

What might cause our mouth and throat to hurt?

Cavities, Infection

- Does it hurt when I chew on something?
- Does it hurt when something cold is in my mouth?
- Does it hurt when I swallow?



# Mental Health

- What is mental health?
- Ways our bodies manifest mental health issues?
  - Stomach pain
  - Rapid breathing & pounding heart
  - Racing thoughts & feeling overwhelmed
  - Feeling sad & tired



What should you do if you feel these ways?

TALK TO YOUR DOCTOR. TALK TO YOUR FRIENDS. GET  
EXERCISE. EXPRESS YOURSELF.

Medical Diagnostic Techniques:  
What we use to help us figure  
out what is wrong with our  
patients!

# Stethoscope

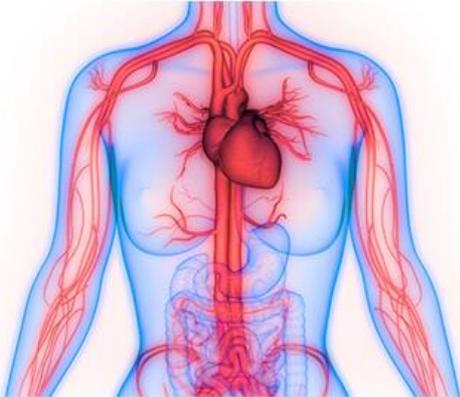
Helps the doctor listen to different parts of the body!

- Heart
- Lungs
- Stomach
- Blood vessels



# Blood Pressure Cuff

Helps the doctor see how healthy our blood vessels are!



# Ophthalmoscope

So we can look into our patients eyes!

- Doctor has to get close to the patient's face for some exams so it may be a little uncomfortable.



# Reflex Hammer

Allows us to check different reflexes on our patients!

Some places the doctor may hit are your elbow, wrist, knee and ankle.



# Otoscope

Allow us to see inside of our patient's ears!

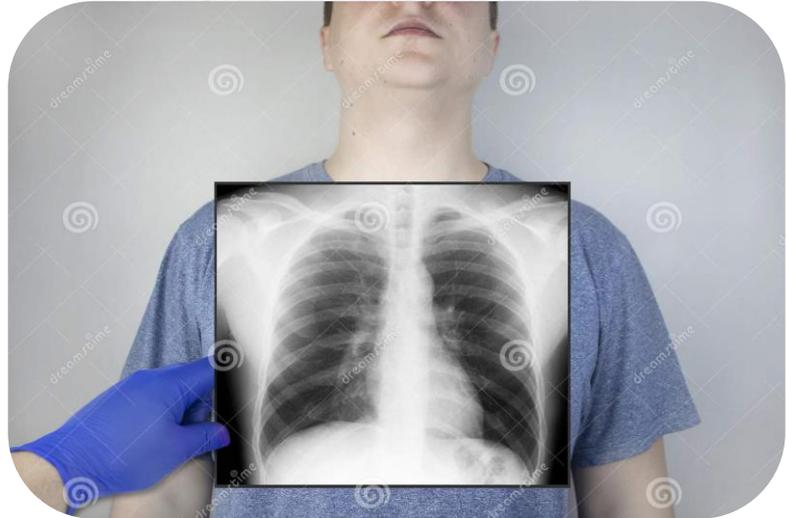
Can help to diagnose hearing problems and pain in the ear such as an infection.



# Scans that Doctors May Order

Sometimes your doctor may want to order imaging to get a better picture of what is going on. Some examples include:

- Ultrasound
- X-Ray
- MRI
- CT Scan



# Labs that Doctors may Order

- Complete blood count (CBC)
  - To make sure our cells are healthy
- Complete Metabolic Panel (CMP)
  - To make sure we have the right amount of electrolytes
- Heart/Cardiac Enzymes
  - To make sure our heart is healthy
- Thyroid Panel
- Liver function tests (LFTs)
- Tests for Type II Diabetes Mellitus (can present earlier in this community)
  - HgA1c, Fasting Blood Glucose, or Random Blood Glucose

# Roles of Direct Support Professionals (DSPs)

# DSPs

DSPs can have a great impact on activities of daily living (ADLs) and quality of life (QoL).

Help create a plan for upcoming clinical encounter or create medical history reference with patient.

Role is patient dependent - necessary for good communication between individual with I/DD, DSP, and health care provider.

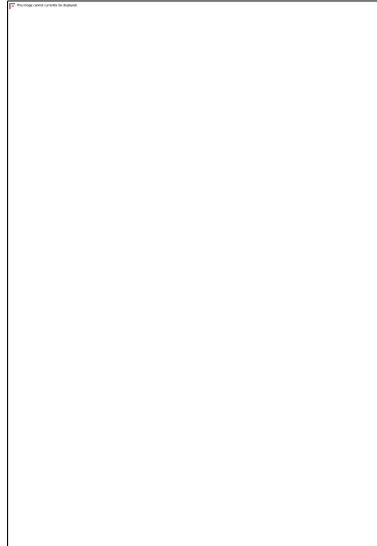
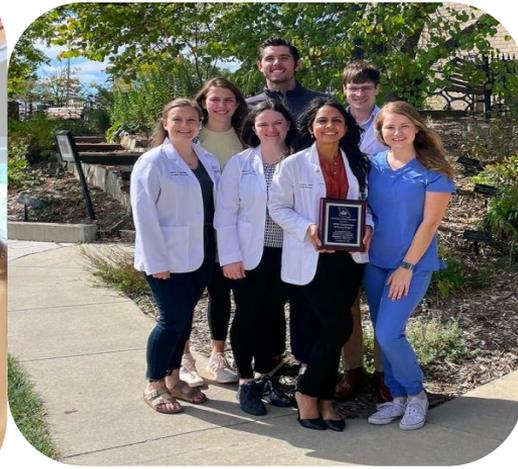
May need to re-direct provider to address patient instead of self, clarify medical history, and/or provide additional information regarding medical complaint

Make sure the patient gets there questions answered by the provider

# ATSU's Community Mentors Project

# Mentor Program

- Medical students are paired with an IDD community member. The student will serve as the mentee and will learn from/assist their mentor with specific goals/projects created by the mentor to achieve throughout the year. The purpose of instilling these roles is to promote self-advocacy for the IDD individuals and to give them the opportunity to educate students on various aspects of their daily life.
- Mentors keep items that are purchased as it contributes to longevity of their goals and they are goal/mentor specific



# References

Health Check: Comprehensive Health Assessment of Adults with Intellectual and Developmental Disabilities. Casson, I., Gemmill, M., Green, L., Grier, E., Hung, A., Ladouceur, J., Lepp, A., Niel, U., Ross, M., Sullivan, W.; Developmental Disabilities Primary Care Program of Surrey Place, Toronto, 2019.

My Health Care Visit: Understanding Today's Visit and Follow-up. Malhas, M., Hermans, H., Orr, E., Salonia, C., Zaretsky, L., & Lunsy, Y., Developmental Disabilities Primary Care Program of Surrey Place, Toronto, 2019