

Making The Most of Your Doctor Visit: Advocating to a Doctor as a Caregiver

Presented by Salus University Occupational Therapy Institute

How to Talk With and Ask Questions of Your Doctor

When talking with your loved one's doctor, it is important to speak up regarding concerns and quality of care:

Suggested Tips:

- Ask for an interpreter ahead of time if there is a known language barrier
- Ask for alternative words/phrases if the doctor is using medical terminology that you or your loved one are not familiar with
 - Ask questions for clarity when you or your loved one are not familiar with the meaning of a word
- Ask for pictures/drawings/models to better visualize what the doctor is explaining about your loved one's condition
- Ask for instructions/information to be given slower/repeated
 - Especially if you or your loved one prefer to write down the information
- Ask for a printed summary of the visit at the end
- Find a different healthcare provider who is willing to listen and answer questions if you or your loved one don't feel comfortable

What Does It Mean to be There as a Support or Advocate for Someone?

- Being a second pair of eyes and a second mouth
- Help them prepare for the visit, talk through questions, do research ahead of time
- Encourage your loved one to ask questions and express concerns
- Respect your loved one's boundaries during exams
- Attending a doctor's appointment with your loved one isn't just about being in the exam room, but also offers the chance to provide logistical and emotional assistance

What Does It Mean to be a Caregiver for Someone?

- You may have the *essential* role of :
 - Taking care of household activities such as grocery shopping, preparing meals, cleaning and managing finances
 - Helping with activities of daily living such as bathing and dressing
 - Monitoring your loved one's health condition and scheduling appointments
- You *must* speak up
 - You have the important, daily and unfiltered knowledge and is important to share
 - You help make sure they are receiving the proper medical attention and care they deserve, and that their voice is being heard

Caregiver Stress

- Feeling pulled in so many directions often leaves caregivers feeling stressed and manifest in a variety of ways
 - Both physically and psychologically
- How to Manage Caregiver Stress

- Express your feelings to your loved one
- Take a break or plan time off
- Enlist backup
- Seek out for community resources
- Join a support group

Tips to a Successful Doctor's Visit: Before, During & After

3 Simple Steps to Remember

1. Before the Visit: **Be Prepared**
2. During the Visit: **Use Time Efficiently**
3. After the Visit: **Review & Organize**

Before the Doctor's Visit

Be Prepared: Important Conversations to Have as a Support

- Will my role stay as support? Or will I have to transition to the role of a caregiver?
- What are your expectations in comparison to my expectations?
- Do we need to discuss your healthcare documents in case of an life alternating emergency?
 - Healthcare documents
 - Medical power of attorney
 - Emergency information sheet

Be Prepared: Important Conversations to Have as a Caregiver

- Will my position be short-term or long-term?
- Do you have a plan for your end of life? For an expected or unexpected passing?
- What healthcare documents do we need to look over together and sign?
 - Healthcare documents
 - Advance directive
 - Living will
 - Durable power of attorney for healthcare (DPOAH)
 - Authorization to release healthcare information
 - Emergency information sheet

Be Prepared: Privacy Concerns & Awareness

- Ensure you can talk to your loved one's doctor after the visit by asking for the HIPAA forms at every healthcare provider's office that you visit and fill them out in accordance with your loved one's wishes
- **What is HIPAA?**
 - HIPAA stands for Health Insurance Portability and Accountability Act
 - HIPAA was passed to help protect your medical records and other personal health information

- Filling in a HIPAA release form allows doctors and nurses to share your loved one's medical status with you or another trusted person when your loved one is not in the room
- Print and bring two or three copies of the current medication list, medical history, list of questions for the doctor and HIPAA release forms
 - One copy is for your reference and notes
 - One copy is for you to give to the healthcare provider
 - One copy is for your loved one, if they would like

Make Scheduling an Appointment Easier:

- Asking your loved one's healthcare provider if they have a patient portal
- Setting up portal for your loved one if applicable or getting access to the portal they already have
 - Create account on the computer or via phone/tablets apps
- Check the portal
 - Access your test results
 - Request prescription refills
 - Communicate with your doctor
 - Manage your appointments
 - Setting up alerts for reminders of appointment time
 - Schedule your next appointment
 - View details of your past and upcoming appointments
 - Manage your account (update your phone/address, update insurance, view your statement, pay your bill)
- MyChart
 - Convenient app that allows you to have multiple portals in one place



What to do Days Before the Appointment?

- Caregivers can assist in making a checklist
 - A list of all the medications that your loved one is currently taking
 - A list of all the healthcare providers your loved one sees and why they see them
 - A list of the symptoms they are having and note which ones bother them the most
 - Write down when each symptom started and what has been done (if anything) to make them better
 - Write down directions or disease management aspects that are going well and those not going well



Checklist: To-Do the Night Before the Doctor's Visit

- Put out comfortable clothes you and your loved one don't mind getting dirty at the doctor's
- Schedule travel time in your calendar so you and your loved one can get to the appointment on time regardless of traffic/unforeseen delays
 - If taking public transit: plan bus, train, etc. route
- Have the doctor's contact information written down in case of a delay/last minute cancellation
- Reflect on questions and update any questions already written down
- Write a to-do list for the appointment
- Do some research
 - Use trusted websites like cdc.gov, nih.gov or mayoclinic.org to find general information about your known conditions
 - For specific questions about conditions, use trusted foundation or established organization websites such as: MS Foundation, Arthritis Foundation, American Diabetes Association, or the American Heart Association
 - Avoid symptom checkers and other sources with questionable information
 - Notes:



Checklist: To Bring to Your Doctor's Visit

- A form of ID to verify your loved one's identity & insurance card
- A pen or pencil
- Notebook/paper to write on
- Your symptom tracker
- Food diary information
- Information on medication, vitamins, supplements, insurance card, medical history, etc.
- Folder with all medication pamphlets, names and phone numbers of the doctors your loved one sees and medical history
- A family member or friend (if applicable)
- Eyeglasses (if applicable)
- Hearing aids (if applicable)
- Other items: _____
- Other items: _____
- Other items: _____
- List of questions/concerns you and your loved one would like to discuss with the doctor**

- Questions:

Helpful Suggestions for Organizing Questions:

- Encourage your loved one to prepare a list of questions/concerns they would like to discuss with their doctor
 - Leave a sheet of paper on the fridge in your loved one's home or a running list in a notes app on both of your phones
- Separating questions into main categories to make sure you hit all the talking points
 - Generalized information about the condition or management
 - What does this mean for me?
 - What is this condition?
 - Questions about next steps: future medical tests, stages/progression of conditions, how to manage the condition
 - Will they call me? Or do I need to call?
 - Do I need to change my diet or exercise routine?
 - What are the steps in diagnosing or managing this condition?
 - Cost/Insurance of treatment
 - Specific concerns
 - Questions about secondary conditions and their impact on new medications, supplements, treatments or tests
 - Affect on your lifestyle, independence or function
 - Do I have to stop eating certain foods?
 - Will the medications affect my ability to participate in social gatherings?
 - Is it okay to drink alcohol?
 - Other specialist recommendations
 - Who should I follow up with?
 - Do you have any specialists you recommend?
 - Other options

During the Doctor's Visit

Communicate Effectively by Asking Your Doctor Questions:

- You don't want the doctor to make assumptions about you or your loved one's thoughts or feelings
- The doctor does not know what either of you are concerned about, only you two do
 - **Be direct**, tell the doctor you and your loved one have a list of things you both want to discuss
 - Bring up family history, especially if it concerns you or your loved one
 - Remind the doctor of other specialists your loved one sees, especially if they are in a different hospital system, or a private office
- If you or your loved one don't ask questions, they may assume you already know the answer, you don't want more information, or that it is not important
 - Don't wait for the doctor to raise a specific question or subject; they may not know it's important
 - If you or your loved one start to feel overwhelmed ask "What does that mean?"

- To doctors diagnosing can sometimes be like a guessing a game so they need the knowledge you share about yourself to assist them in making informed decisions on your loved one's individualized care
- Confirm with your loved one's doctor if test results, medication information, etc. can be accessed through the patient portal
- Use the portal when you and your loved one have several questions that can't wait
 - Especially if questions relate to an upcoming procedure or test
- Arrive early, you and your loved one might need to fill in forms before meeting with the doctor
 - Arrive 15 to 20 minutes early for your appointment
- **Include Your Loved One**
 - Encourage the doctor to speak to your loved one, not to you, regardless if you are there for support, there to advocate, or a caregiver
 - Try not to speak for your loved one, but do remind them if they forget to bring up something they wanted to discuss
- **Take Notes**
 - Record any diagnosis the doctor gives your loved one
 - Record the name and phone number of any other doctor that your loved one should see about their medical problem
 - Take notes on what the doctor tells you and your loved one and ask questions if you or your loved one do not understand a medical term, the reason for the doctor's recommendations, or the instructions for taking medication
 - Give your doctor "The run down"
 - Even if you or your loved one think you understand - repeat the steps, instructions or important points discussed during your visit to ensure you, your loved one and the doctor are on the same page
- **Communicate Your Loved One's Wishes**
 - Medical teams can better act in accordance with a patient's wishes if a clear discussion has been had or is well documented ahead of time
- **Medication Management**
 - Compare your version of your loved one's medication list with the one in the electronic medical record utilized at the doctor's office and make corrections if necessary
 - If the doctor prescribes medicine for your loved one, learn what those new pills do and how your loved one should use them
 - Remember that the pharmacist may also be able to go over this information with you and your loved one and help determine a schedule
 - **Tip:** If you or your loved one need assistance with medication management, reach out to us at OTI@salus.edu or call us at (215) 276-3646 to schedule a screening today!

Communicate Openly and Honestly:

- **Speak Up**
 - If you feel the encounter with the physician isn't going well, express those concerns
- **Don't Speak Over**
 - Let your loved one speak fully and don't jump in until they ask you to
- **Help Answer Questions**
 - If you know the answer to a question is critical and your loved one can't remember, don't be afraid to assist
- **Be Fully Honest in Your Answers**
 - You and your loved one should not feel embarrassed or ashamed to talk about anything with the doctor
 - Leaving out details or lying to the doctor can be bad for your loved one's health because it affects their care, so tell the doctor everything
- **Allowing Your Doctor Adequate Time to Answer Questions**
 - You and your loved one may want to give the doctor time to answer your questions properly - let them know if it is a question you are willing them to call you or email you the next day with an more thought out response
- **Listening to the Doctor When They Are Speaking**
 - Be sure to ask questions for clarity
 - Ask the doctor to speak slower, louder or to repeat anything you missed
- **Before You and Your Loved One Leave**
 - Ask the doctor for handouts or brochures that you and your family members can review at home
 - Make sure your loved one is satisfied before the doctor leaves
- **If You or Your Loved One Become Overwhelmed During the Visit**
 - Simply tell the doctor you or your loved one don't understand, do not know what to do, or do not know what this means
 - This will tell your doctor that you or your loved one may need more guidance

After the Doctor's Visit

Review

- Review any material the doctor gave and/or the notes you took
 - If you or your loved one cannot understand something, write down a list of questions before calling the office to speak to the doctor
- Follow the doctor's instructions and keep them informed
 - Follow up with the doctor on test results, adverse reactions to medication, or any complications or worsening of your loved one's condition
- Use the patient portal to access information or communicate with the doctor

Organize

- Record the date and time for any scheduled blood tests, x-rays, or other medical tests ordered by the doctor

- Include the test, testing facility name and phone number
- Write down how the results will get back to the doctor
- Make note of how to prepare for the test (e.g., don't eat anything before the blood is drawn, or wear loose fitting clothing, etc.)
- Follow Up
 - Pick up prescriptions and arrange for pill boxes to be filled by you, your loved one, a family member, or a licensed home healthcare agency
 - Update medication lists
 - Consider use of pre-packaged medication options
 - Perform any other follow-up tasks
 - If your loved one is supposed to be contacted within a timeframe, verify that the communication took place
 - If not, take appropriate actions
 - Record the date and time of your next doctor's visit
 - Portal will have it and automatically send reminders

For more information about getting ready to visit the doctor:

National Institute on Aging: www.nia.nih.gov

Centers for Medicare & Medicaid Services: www.cms.gov or www.medicare.gov

MedlinePlus National Library of Medicine: www.medlineplus.gov

Agency for Healthcare Research and Quality: www.ahrq.gov