

Accompanying an Individual to the Doctor*

TIPS FOR DIRECT SUPPORT PROFESSIONALS AND OTHER CAREGIVERS

What is the reason for today's visit?

Adults with intellectual or other developmental disabilities may have difficulties explaining their symptoms or expressing pain, so the health care provider may have trouble determining the presence of an illness or injury. Having a direct support professional who knows the patient, knows how the patient communicates, and knows some medical information about the patient can be vital to helping the primary care provider effectively treat the patient. If the patient is unable to do so, briefly explain why he or she is seeing the health care provider today:

- Yearly check-up
- Illness or issues
- Injury
- Chronic medical condition
- Behavior/mental health concerns

When illness is suspected

- What symptoms does the patient have?
- How long has the patient had these symptoms?
- How has the patient been eating and sleeping?
Any changes? Any changes in toileting habits? Any significant changes in the patient's life, such as a new roommate or loss of a parent or friend?
- If the patient has limited communication skills and is behaving differently than usual, what behaviors have created cause for concern?
- How long have these differences in behavior been evident?

When chronic conditions are present

- Alert the health care provider to the ongoing medical issues, (e.g. diabetes, seizure disorder, high blood pressure, high cholesterol).
- Bring any data that is maintained to monitor these conditions, preferably the past month's information.
- If this is a first visit to a new doctor, make sure the health care professionals are aware of the patient's developmental disability and the primary medical diagnosis, if known.



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What medications does the patient take?

- Bring a list with the name and dosage of all medications, over-the-counter drugs, vitamins, minerals and/or herbal supplements
- Reason for the medication
- Medication allergies
- Are refills needed?
- Any recent medication changes? (Starting or stopping a medication, changes in dosages)
- Any side effects?

Coordination of care

- If the patient sees other health care providers, have a list of these providers, their names, and the conditions for which they treat the patient.
- Make sure the patient has his/her insurance card.
- If possible, help the patient share his/her medical history and family medical history.

Communication is important

- Make sure you understand the doctor's instructions.
- Ask questions: What is this medication for? How soon should the patient see benefit from the medication/treatment? Are there possible side effects to watch for?

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* The IDD Electronic Toolkit and related resources were funded by a grant from the Special Hope Foundation, Palo Alto, CA.



VANDERBILT KENNEDY CENTER
FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES

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- Ensure good communication following the appointment between the direct support professional and the supervisor for the home or agency.
- Have a process to make sure that any health care instructions are shared with all support staff who work with the patient.
- Bringing back the paperwork from the physician's office is just the beginning of maintaining the person's health.

Vanderbilt Kennedy Center

The **Vanderbilt Kennedy Center** (VKC) works with and for people with disabilities and their family members, service providers and advocates, researchers and policy makers. It is among only a few centers nationwide to be a University Center for Excellence in Developmental Disabilities, a *Eunice Kennedy Shriver* Intellectual and Developmental Disabilities Research Center, and a Leadership Education in Neurodevelopmental and Related Disabilities Training Program.

IDD Toolkit www.iddtoolkit.org

The IDD Toolkit website offers health care information for primary care physicians and nurses to provide improved care to adults with intellectual and developmental disabilities. Checklists and disability-specific tables may help guide medical treatments and preventive care. Sections address informed consent and behavioral and mental health concerns, including crisis management and prevention. With funding from the Special Hope Foundation, Palo Alto, CA, the IDD Toolkit was adapted for U.S. use based on *Tools for the Primary Care of People with Developmental Disabilities* (Surrey Place, 2011).

Tennessee Disability Pathfinder

Tennessee Disability Pathfinder is a free statewide phone, web, and print referral service in English and Spanish. It connects the Tennessee disability community with service providers and resources. Its website database has 1,600 agencies searchable by Tennessee

county and service. Pathfinder is a project of the VKC and the Tennessee Council on Developmental Disabilities. Contact www.familypathfinder.org, (615) 322-8529, toll-free (800) 640-4636.

Other Resources

• Easy-to-read health materials

The Florida Center for Inclusive Communities offers a series of factsheets and materials that are aimed at helping patients with IDD understand their health care needs. <http://flfcic.fmhi.usf.edu/program-areas/health.html>

• Got Transition

The Got Transition website is dedicated to improving the supports for health care transition for young people with disabilities as they move into adult health care. www.gottransition.org

• Health Care Tool Kit

This 24-page booklet lets the individual introduce himself and his health care needs to a new health care provider. The booklet offers color-coded sheets for the patient, the family, the health care provider. www.wi-bpdd.org/publications/2010/Health%20Care%20Tool%20Kit%20Web.pdf

• Health & Wellness 101: The Basics

This site offers a checklist that young adults can use that addresses their changing role in the health care process. www.ct.gov/dph/lib/dph/family_health/children_and_youth/pdf/hrtw-transitions-role_for_youth.pdf

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