

Self-directed Health Care Kit



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As a community nurse who works in and around Madison, Wisconsin, I direct a program called Wellness Inclusion Nursing (WIN) - a Waisman Center outreach program. I assist and advocate for the proper care for individuals who have intellectual and developmental disabilities (I/DD) along with challenging health issues. This includes attending doctors' appointments with people or helping them to prepare for doctors' appointments and also helping as they try to follow instructions and doctor's orders. As a result of my extensive knowledge and experience, I have been collaborating with the Wisconsin Board for People with Developmental Disabilities (BPDD) on their projects.

Regular medical appointments and care are important for people who have intellectual and developmental disabilities (I/DD). In addition to the standard tests and assessments, individuals with certain types of disabilities may be at higher risk for some chronic illnesses that should be monitored more closely. Proactive health care can prevent chronic illness and treat other conditions before they worsen into a health crisis and/or hospitalization.

Individuals who have I/DD may not attend appointments regularly if it is difficult because of mobility obstacles, behavioral challenges, transportation issues and/or difficulty arranging for a support person to attend the appointment. Sometimes, too, lab tests and other screening tests are not considered necessary by health professionals when a person has I/DD. Additionally, doctors may not thoroughly assess a person who is unable to get on the exam table without use of a Hoyer lift. Advocacy to remove these barriers to care is essential to ensure each individual with I/DD has quality health care.

Individuals and their families or other caregivers often are stressed and are unsure of what to share at an appointment. High turnover of caregivers can also add to this complicated matter, causing lack of and/or improper documentation. Doctors may miss diagnosing a problem because of unclear, missing or limited information. Medical professionals may also assume that a person with I/DD whom they see is always nonverbal or unable to walk because of his or her disability rather than probing to see if these limitations are indications of an illness.

This Self-directed Health Care Kit is a practical way to help you and your supports set up and prepare for appointments by gathering the needed information ahead of time. It gives you the necessary tools to be prepared and to receive the quality care you deserve at every medical appointment or hospital visit. We hope this kit is useful to you and becomes a part of your health and wellness routine.

Where and when possible, there should be an agreement to the support person's role during the visit. This may include completing the **TODAY'S VISIT** and **SUMMARY OF VISIT (both Light Blue)** forms.



PURPOSE

This Self-directed Health Care Kit is designed to help individuals with developmental and intellectual disabilities (I/DD) advocate for their own health care and support clear communication between the individual and their health care practitioners. The kit includes a set of forms for tracking health care concerns and interventions. It has also been designed to help the person in a supportive role to help advocate for the individual and enhance the interaction between the individual and the health care practitioner.

EXPECTATIONS OF SUPPORT PERSON

This process is built on the presumption that a support person would help prepare the individual for a medical appointment to which the individual would go alone or be accompanied by the support person who assisted.

The preparation begins with the support person reviewing the kit with the individual and completing the medical history form. This would include the individual's health concerns and current medication. A completed National Task Group-Early Detection Screen for Dementia (NTG-EDSD) form may also be helpful for the visit and should be completed by someone who is familiar with the individual for at least 6 months.

**See the NTG-EDSD form for more information*

Where and when possible, there should be an agreement to the support person's role during the visit. This may include completing the **TODAY'S VISIT** and **SUMMARY OF VISIT (both Light Blue)** forms.

This kit provides VALUE:

- **For the individual** – he or she will go into a health care visit prepared and more confident that they will be listened to and that their concerns will be addressed.
- **For the support person** – he or she will have a better sense of the individual's concerns and a plan for presenting those concerns. Time taken in preparation will save time and stress during the visit.
- **For the health care practitioner** – he or she will have a better understanding of the individual's current concerns, abilities and disabilities. The supportive person's role will be defined for them and they will have information they need in writing. Putting their instructions on the form should provide more assurance to them that those instructions will be carried out.
- **Overall** – Keeping the forms in the individual's file will build an ongoing medical history for people supporting the individual in the future. It will be a beginning point for preparing for future health care visits. Successive use will foster better communication and interaction between patients and providers.

What is included in the Self-directed Health Care Kit?

LEFT SIDE OF PACKET

(WHITE PAPER):

- **Introduction**
- **Helpful Tips and Suggested Questions** – This is additional information that may help you be better informed about your health.
- **Setting up Your Health Care Appointment** – This is a helpful tool to help you prepare and advocate for an appointment that is best for you.
- **Health History** – Completing this form and keeping it in the packet will help establish a medical history and help you prepare for future health care visits. As a completed form in the kit, it can be helpful as a reference for completing the TODAY'S VISIT form. This information will be useful for support people and health care practitioners in your life.
- **The National Task Group – Early Detection Screen for Dementia (NTG-EDSD)** – This form should be completed every 6 months, after the age of 40, by a person who has known the individual for at least 6 months. It should be updated as needed and brought to the person's physician appointments.
*See the NTG-EDSD form for more information

RIGHT SIDE OF PACKET

(THIS INFORMATION MAY BE GIVEN TO HEALTH CARE PRACTITIONER VERBALLY INSTEAD OF PROVIDING FORM):

- **TODAY'S VISIT (Light Blue)** – Complete this form and take to the health care practitioner.
- **SUMMARY OF TODAY'S VISIT (Light Blue)** – This form is to be completed by the health care practitioner, if possible, at the visit. Once completed, it should be filed into the Self-directed Health Care Kit.
- **ABOUT ME (Yellow)** – This form can be an additional aid for information about you. This form would be especially helpful for a first time visit with a health care practitioner. As a completed form filed in the kit, it can be helpful as a reference when completing the TODAY'S VISIT form.
- **URGENT CARE OR HOSPITAL VISIT (Pink)** – This form should be partially filled out and filed in the kit. It should be fully completed when preparing for a visit to urgent care/emergency visit and/or hospital stay.