Caring for a Person Who Has Mental Retardation or Developmental Disabilities (MR/DD)

Who is a caregiver?

A primary caregiver is someone who provides basic care for a person who has mental retardation and/or developmental disabilities (MR/DD). As a caregiver, you may be doing the following things for another person:

- Bathing
- Dressing
- Feeding
- Cooking
- Shopping
- Paying bills
- Running errands
- Giving medicine
- Keeping him or her company
- Providing emotional support

Sometimes it is difficult for people who have MR/DD to communicate, especially with their doctors or dentists. You may need to speak on behalf of the person you are caring for with his or her doctor. Here are a few tips to help:

- Tell the doctor about the patient's current and past health issues.
- Create a "health journal" in a notebook for the person you are caring for and bring it to doctor's appointments. See the handout, "Creating a Health Journal" for more information.
- Tell the doctor about any medicine the patient is currently taking. Bring the medicines to the appointment or create a list of all of them. Include information about when and how often the person you are caring for takes the medicine. You should also write down the strength of the medicine (for example, does the person you are caring for take 150 mg or 200 mg?).
- Tell the doctor about any noticeable side effects the person you are caring for has from the medicine(s).
- Don't be afraid to ask questions.

Who should make medical decisions for someone who has MR/DD?

When your child is a minor, you will make all of the medical decisions. If your child is unable to make his or her own medical decisions as an adult, a person who is legally responsible for making these
decisions for him or her must be named. This person should be named in a legal document called a health care "durable power of attorney." The document allows that person to make health care decisions for the patient. This person is called a health care attorney-in-fact. The attorney-in-fact should talk to the doctor about treatment decisions or end-of-life care for the patient. The doctor should write these decisions in the patient's medical chart.

How can I tell if caregiving is putting too much stress on me?
Caregiving can be very stressful. Common signs of caregiver stress include the following:

- Feeling sad or moody
- Crying more often than you used to
- Having a low energy level
- Feeling like you don't have any time to yourself
- Having trouble sleeping or not wanting to get out of bed in the morning
- Having trouble eating or eating too much
- Losing interest in your hobbies or the things you used to do with friends or family
- Feeling angry at the person you are caring for

What should I do if I'm feeling overwhelmed and stressed?
These feelings are not wrong or strange. Because being a caregiver is so hard, some doctors think of caregivers as "hidden patients." If you don't take care of yourself and stay well, you won't be able to help anyone else.

Talk with your family doctor about your feelings. Stay in touch with your friends and family members. Ask them for help in giving care. Asking for help doesn't make you a failure.

Look for help in your community. You may start by asking your church or synagogue if they have services or volunteers who can help you. You can also ask for help from support organizations (see "Other Organizations").

Other Organizations

References

1. Medical Care of Adults with Mental Retardation by CD Prater, MD; and RG Zylstra, EDD, LCSW(American Family Physician 06/15/06, http://www.aafp.org/afp/20060615/2175.html)

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