

To the Medical Community from The Arc of Massachusetts

EXTRA MEASURES FOR PEOPLE WITH MENTAL RETARDATION

Measures of kindness, patience, and understanding by doctors in attending persons with cognitive disabilities can improve the well-being, happiness and quality of life for special people who need all the TLC they can get.

For people with mental retardation and other cognitive and developmental disabilities, **the impressions they receive in a doctor's office can have an important bearing on how well they respond** to the doctor's diagnosis, how well they carry out his/her orders, and how well they emotionally deal with whatever medical problem it is they have. Since these impressions can be difficult to instill with individuals with IQs of 70 or below, it is essential that the doctor or other medical professional take a few "extra measures" in the communications process. Here are a few suggestions (based on real-life examples) that can make the visit a pleasant one for the patient and a productive one for the medical professional.

1) Make your entrance into the examining room with a smile on your face.

This may seem basic, but many doctors, harried and under pressure, arrive with their tensions showing. A warm smile can do wonders for relaxing and instilling confidence in your patient, and in getting the appointment started on the right foot.

2) Be sure your patient is physically comfortable.

Folks with MR frequently have a high tolerance for discomfort, and often lack the ability to communicate their feelings. Watch for facial expressions, and be sure to ask the caregiver about your patient's comfort level.

3) Find the right communications level for your patient, and use it.

This may range from gestures to normal conversation. Many doctors can make an assessment by sight. Other times, the caregiver can provide helpful information. Ascertaining the "wave length" between you and your patient is critical to the success of your appointment.

4) Be sure to communicate with your patient, not just with his/her caregiver.

Example: A young man with MR was taken to an urgent care unit with a serious condition. The doctor checked him out and explained his condition to the caregiver, without saying a single word to the patient. The patient became overwrought – not, it was later learned, because of the impending hospitalization, but because the doctor did not utter a single word to him.

5) Spend several minutes talking to, joking with, and relaxing your patient.

One doctor we know wore a special, colorful necktie on appointment days with one patient. Some doctors keep a list of patients' special hobbies and talk about them. Doctors can create brightness in most patients' eyes by asking about their special activities. These short, friendly discussions will invariably relax your patient.

6) Never convey bad news to the patient.

One doctor we know, who otherwise did everything right, let it out that the patient's tests were "terrible." The patient cried, blaming himself, obviously upset. Another doctor, who had the unpleasant task of telling his patient he must have a toe amputated, instead said, "Billy, we're going to take away the soreness from your foot." Not only did Billy survive the amputation, he asked his parents upon leaving the hospital, "How soon can we go to a Red Sox game?"

7) If you must take something away from the patient, give something new in its place.

Example: An experienced nurse found it necessary to remove two favorite drinks, Diet Pepsi and Diet Coke, from the diet of a patient with MR. She offered something new, Diet Sprite, in their places, and the young lady left the office with a smile on her face.

8) When a patient has "followed doctor's orders," be sure that he/she is properly rewarded.

When the patient has lost weight, followed the exercise regime, stayed away from fats or other no-nos, the sympathetic doctor will shake hands, pat the patient on the shoulder, or employ other means to express approbation. One doctor we know "awarded" sugar-free cookies.

9) If the visit is a long one, give your patient a cup of water.

(Offer one to the caregiver as well.)

10) Give the patient plenty of opportunities to ask questions – in his or her own way.

From your patient's point of view this is very important, so allow ample time.

11) Be sure the person accompanying the patient gets a report of the visit in writing.

Always conclude the visit with a comment such as, "Mike, we're going to make you feel better."

Examples of Extra Measures: Mike's Story

Mike, a young man with Down Syndrome, had suffered from diabetes since age 3. At age 36, his kidneys failed, and he was put on dialysis. During this time he had many medical appointments in addition to dialysis, and mostly what kept him going was the compassion and kindness of the medical staffs who treated him. Wherever he went, the nurses were his “buddies.” His doctors spoke to him, not just his parents, joked with him, and explained treatments in simple, non-frightening terms. Frequently the doctor would place a reassuring arm around his shoulder, and would conclude the visit by saying, “Mike, we’re going to make you feel better.”

Tragically, Mike died of a stroke at age 38. But the kindness and special care of his medical staffs added a measure of happiness to the last years of his life, and helped him cope with what might otherwise have been a frightening series of experiences.

All examples mentioned are adapted from real-life situations in which doctors have demonstrated the kind of sensitivity and concern so essential to the care of persons with cognitive disabilities.

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The mission of The Arc of Massachusetts is to enhance the lives of individuals with intellectual and developmental disabilities and their families. We accomplish this through advocacy of services and supports based in the community.