



## Office of Developmental Primary Care

Improving outcomes for people with developmental disabilities

### What I Wish My Doctor Knew About People who Accompany Us to OUR Medical Appointments

#### Medical Alert

- We are your primary patient.
- Bringing an attendant is not an indication of a lower level of competence.
- Educate your office staff and medical assistants.
- Obtain a basic understanding of the relationship that we have with our attendant.
- Our attendants may request additional help when assisting us with physical activities.
- Evaluate the needs and capabilities of our primary support system.
- Acknowledge and respect our privacy.
- Don't worry if we come to our appointment alone.

#### **Background**

Some of us with physical and cognitive disabilities may come to a medical appointment with another person to help us during our visit. This person may be a paid attendant, a staff member from an assistive living facility, a family member, or a friend. These health advocates can serve a variety of important functions during the appointment, including transporting us to your office, filling out paperwork, and helping with physical tasks such as undressing and climbing onto an exam table. They can also facilitate our communication attempts. Each advocate will serve a different and unique role depending on our specific needs.

There are some things we would like you to remember when we visit your office with another person.

#### **Acknowledge our Autonomy**

First, we are your primary patient. Please avoid such phrases as, "How is she doing?" or "Where does he feel the pain?" Acknowledge the fact that we live inside our bodies. Try speaking directly to us. Many of us are aware of changes in our bodies and can answer your questions.

## Don't Make Assumptions

Please don't assume that the presence of a personal attendant or an individual's diagnosis is an automatic indication of competence. It may be easier and quicker to communicate with the attendant or family member, but we will not feel empowered or respected as your patient.

## Train Your Staff

Your office staff and medical assistants often set the tone for our visit. Please demonstrate and teach everyone on your staff respectful ways of communicating with patients who have disabilities. They should remain patient and maintain a dialog with us. Other examples of helpful tasks might include: moving furniture out of our path of travel or assisting us in filling out paperwork when needed.

## Understand Our Relationship

Sometimes it might be helpful and necessary to include our attendant or health advocate in the conversation. This is usually fine, especially if you have our consent. If possible, try to get a feel for the nature of our relationship. Is this person actively involved in our lives? Do they appear to treat us with dignity and respect? Are they advocating on our behalf? Is our best interest their top priority?

## Evaluate Our Support System

When prescribing an at-home treatment or a lifestyle change, it can be useful to evaluate the needs and capabilities of our primary support system. Will the additional treatment have a direct impact on our attendant? If they are expected to assist us with this new task, are they willing and able to meet any physical or psychological requirements? If not, is a referral or alternate plan needed?

## Ask if Extra Help is Needed

Our attendants or family members can be very helpful with certain physical tasks, but they may not be able to do everything. For example, they may need help with high and awkward transfers or other unusual physical activities.

## Respect Our Privacy

We may not wish to discuss certain issues with our paid attendant or family member in the room. Please ask us if there is anything we want to discuss in private. For those of us who have trouble with verbal communication, provide us with a secure email address or another channel of private communication.

## We May Come Alone

Don't be surprised if we sometimes show up to our appointment without anyone else in tow. We may not always need or want help. We can figure out the logistics of our solo appointments with you.

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