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Hurry Up and Wait Your Turn

How to win at the waiting game

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“I feel angry, sad, and anxious...they attend to others before me.”

- Paulo Zago

Many of us have experienced the challenge of having to sit in a packed waiting room for a long time before getting to see a doctor. Whether you need to visit the doctor's office, dentist, emergency room, or a walk-in clinic, waiting can be especially difficult for people with developmental disabilities. People with developmental disabilities and the staff/direct support professionals (DSP) who support them have described waiting rooms as frustrating, discouraging, frightening, and overwhelming. These feelings can foster negative interactions between healthcare providers, individuals with developmental disabilities and their DSP. As a result of this increased anxiety and agitation, appointments may feel rushed, go poorly or be missed all together.

The waiting room can be a very difficult and often chaotic environment for anyone. It can be crowded, noisy and unpredictable. For people with developmental disabilities who have unique needs, the wait can be even harder. For some people with developmental disabilities, the waiting area can also be a difficult sensory experience. They may be sensitive to the lighting, the crowding, the noise that might come from the loudspeaker, young children that are present, or someone listening to loud music with headphones.

There are lots of reasons why waits happen. A prior patient may need more time than was scheduled, or an urgent appointment may get squeezed in. Once one appointment starts late, a domino effect can happen so that, by the end of day, appointments are really pushed back.

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Waiting is hard for lots of different reasons. For people with developmental disabilities, time is often a very difficult concept to understand. Many do best with a structured and predictable schedule. When faced with an activity or event that is unpredictable (such as waiting for an unknown time), it can become overwhelming. To add to that, some people with developmental disabilities may already be worried about the doctor's visit for other reasons. For some, having to interact with a doctor can cause anxiety. Others may be worried about how the appointment will go, or about uncomfortable procedures such as having blood drawn.

Waiting for a health care visit can look very different depending on how much support an individual with developmental disabilities needs. For those who require little support, challenges are often centered around boredom and anxiety. For people who require a lot more support, problem behaviours may be common, ranging from loud vocalizations to intense aggressive outbursts. Waiting may be especially hard because they may not understand what is happening, or what they are actually waiting for. It is often the responsibility of the DSP to support the person with developmental disabilities to wait for their healthcare visit while maintaining safety; this can sometimes be difficult, especially when there is a crowd of other people sitting and watching. No matter how chaotic the waiting experience can get, there are some things DSPs can do to make the appointment including the waiting period successful.

What Can We Do to Make Waiting Easier?

Below are some helpful tips and tricks to help win the waiting game. It is important to remember that the way one can support a person during a doctor's visit will depend on their individual needs and preferences.

1) Before you go to the appointment...

Suggestions from family doctors:

1. Try to book the appointment first thing in the morning or after lunch. These appointment slots will typically have shorter wait times. You can explain to the administrative office staff at the clinic when you book the appointment that the person coming to the visit has trouble waiting.
2. When you contact administrative office staff ahead of the visit to let them know that waiting can be difficult for the person you are supporting, you may then ask them:
 - a. To potentially secure a separate room for the individual you are supporting once you arrive.
 - b. If you will be using a specialized mode of transportation with a set pickup time, ask them what time to book the pickup.
 - c. If they have other suggestions (any other accommodations that can be made).

Remember, building a good and collaborative relationship with the administrative office staff is very helpful since they are the ones that can provide and plan for accommodations during the visit.

3. Request administrative office staff/doctor to put an alert in the person's health record explaining they have trouble waiting so that the office is aware ahead of every visit that the person may need a separate room to wait in or other accommodations.
4. When letting the administrative office staff know of the difficulty waiting, you may also ask them if you can book extra time with the doctor if you think the person may need it.

Other things you can do:

- Plan for it to take longer than expected, and talk about this with the person you are supporting.
- Prepare preferred activities, comforting objects, and sensory items (may include fidget and textured items). Asking the person you are supporting what they might want to bring to the doctor's visit can help prepare them to wait, and can help ensure that they stay distracted.
- Role play the process of waiting in a waiting room at home before the appointment.
- Practice waiting for short periods of time. When the person can tolerate waiting for that length of time, gradually start to increase the wait time.
 - Remember that the best time to practice a new skill is when the person is calm, and there is no pressure to be successful (i.e., it will be harder to wait during a doctor's visit, so it is best to practice ahead of time in order to gain the skill).
- Ask administrative office staff if you can practice waiting at the doctor's office, prior to the appointment, just to get used to things. Perhaps after a short wait, the person you support could be seen by a nurse or someone from the team.
- Practice self-calming strategies like deep breathing when the person is not under pressure. You can then remind them to breathe while waiting if they are becoming anxious.
- Creating social stories is another helpful way to help explain the waiting process when visiting the doctor. The following are some helpful websites for making social stories:
 - Touch Autism: <http://touchautism.com/app/social-stories-creator-library/>
 - ConnectAbility Visuals Engine: <https://connectability.ca/visuals-engine/>
 - Picto-Selector: <https://www.pictoselector.eu/>
- If forms need to be filled out before the appointment, ask the administrative office staff to send you the forms ahead of time.
- Try to arrange for a DSP who knows the person with a developmental disability very well and has a good relationship with them to accompany them to the appointment.
- Research parking and location so that you arrive on time. If you are going to be late, call and let the administrative office staff know ahead of time so they can be prepared.

2) Some suggestions and quotes from DSPs while you're there include...

- When you arrive at the office, check in with the administrative office staff, and remind them of the accommodations that you require. You can also ask for an update on how long they expect the wait time to be.
- If you find out that you will have to wait, take a deep breath and try not to take it out on the administrative office staff. Instead, get out some of the activities you brought and try to make the best of the time.

- Involve the person you are supporting in the process. Get them to hold onto and show the administrative office staff their health card or other documents such as the doctor appointment form. This can be fun and helps the person play an active role in their health care.
- Check the environment for things that may be dangerous or anxiety-provoking.
- Use a visual schedule or a visual timer that shows the person you are supporting visually how much time they have left if possible (e.g., using Time Timer, or stop watch).
- Try to stay calm – the person you are supporting will pick up on your feelings if you are impatient or anxious.
- If there is a significant wait time, ask the administrative office staff if you can go out for a walk and come back, or if they can call you when the doctor is ready to see the person you are supporting.
- Consider following the appointment with a preferred activity. You can remind the person about the preferred activities throughout the doctor visit so that they have something to look forward to. Add the preferred activity to the person’s visual schedule and refer back to it throughout the waiting time and doctor’s visit.

“I make sure I have a good relationship with the reception staff at the doctor’s office. When I am supporting a Member to go to the doctor, I call the reception staff to tell them we are on our way. I ask them how long they think the wait will be, and then we make a plan from there. When we get there and check in, they know we are coming, and they can tell me how long the wait will be. If it’s longer than 10 minutes, I will ask them if it will be okay to go for a walk or car ride if it’s too cold, and if they can call us when it’s time. They usually agree because they know us well, and they know how hard it is for the person to wait at the doctor office.”

- Pat Ejenavi, Vita Community Living Direct Support Professional

“With some Members who have a really hard time waiting, and sometimes can have unsafe behaviour when they get upset because of waiting, I made sure to explain that to the doctor and the office staff. Now, if the doctor just needs to see the person quickly or do a quick check, they come out to the van when we get there.”

- Shamsa Mohamed, Vita Community Living Direct Support Professional

3) Other Tips for Scheduling Appointments:

- Ask what day and time of day has the fewest appointments
 - Avoid times when the doctor has just returned from vacation or time away from the office
 - Avoid school holidays
- Don’t pick a time when you will have to rush to do something else right after the appointment.

It is helpful to understand why waiting is difficult for each person. When the DSP knows the reasons for this difficulty, they can come up with specific ways to make it better for that person. For example:

- 1) If the person gets bored while waiting:
 - a. The DSP can try to make the wait for the doctor as fun as possible.
 - b. Ask the person what activities and/or items they would like to bring with them.
 - c. Make sure you bring enough preferred activities.
 - d. If the person likes social interaction, provide lots of it throughout the wait time.

- 2) If the person associates the doctor's visit with a really awful or difficult experience:
 - a. Practice preparing for the procedure ahead of time.
 - b. Practice relaxation techniques like deep breathing ahead of time, then ask the person to use these strategies while waiting.
 - c. Ask the person what they need to help them stay calm and, when possible, provide them with those things.
 - d. Make sure the person is told what is happening at every step of the visit.
 - e. Try to make the visit as fun as possible (see #1) to teach that the doctor visit is not always bad.

- 3) If the person gets upset in the waiting room because of the loud noise:
 - a. Bring noise-cancelling headphones, or bring music that the person likes so that they can listen to it with headphones while waiting.
 - b. Ask the office staff if you can use an empty room or quieter area to wait in.

- 4) If waiting is hard because the person doesn't like sitting for long periods or doesn't find the chairs comfortable:
 - a. Bring a pillow to make the seat more comfortable
 - b. Provide lots of breaks from sitting by walking around the waiting room, standing or stretching.

- 5) If the person doesn't like the waiting room because they feel people stare at them or laugh at them:
 - a. Ask for a private room or quieter area.
 - b. Try to make the experience as fun as possible.
 - c. Take frequent breaks outside (but make sure you let the office staff know where you are).

Other Resources:

- Click here for a social story and other resources on going to the doctor: (<https://magnusmode.com/>)
- Click here for health care resources: (<https://www.porticonetwork.ca/web/hcardd/healthcareresources/people-with-developmental-disabilities-and-caregivers>)
- Click here for a video on going to the doctor: (<https://youtu.be/6HZ6DOnXtB0>)

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