

Service, Support and Success

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In Case of Emergency, Please Read: Ideas and Strategies for Supporting People with Developmental Disabilities Receiving Emergency Care

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Adults with developmental disabilities visit the hospital emergency department (ED) as often as some of us go to the dentist. In fact, they go twice as often as adults without developmental disabilities (DD). We all know the “drill” when it comes to the dentist, but just how much do you know about what to expect out of an emergency department visit? This article offers some practical tips about how to make emergency visits as good as they can be, and also outlines some steps we can all take to reduce the likelihood of having to go to the hospital in the first place. Because, let’s be honest; like the dentist, none of us want to go the hospital more than we have to...

Some interesting facts about ED visits and developmental disabilities:

- Adults with developmental disabilities are more likely to go to the ED and more likely to go repeatedly than other adults, including adults over age 65, and adults with psychiatric disorders.
- Multiple visits to the ED, especially in a short period of time, can be a sign that something in the bigger picture is not working right or can be a sign that the system is failing.
- Sometimes the visit is for medical reasons (after a fall or accident), sometimes it is about medications, and sometimes it is about a mental health issue. And sometimes it is just about a change in “behaviour,” and we aren’t sure if it is really a medical or psychiatric sort of visit.
- The hospital staff do not always know that the patients they see have developmental disabilities. If they don’t know, they won’t give them the extra support they need.
- Many individuals come to the hospital without a crisis plan, or if they have one, they don’t remember to bring it to the hospital. Individuals who have crisis plans are less likely to go the hospital in an emergency than those without crisis plans.



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What makes ED visits harder for hospital staff?

1. **Not knowing that the patient has a developmental disability:** As people who work in the sector, it might be obvious to us, but in a busy hospital emergency department it is not “front of mind.” What we recognize as someone having



a meltdown, not understanding a question, or being eager to please and just saying what they think the doctors want to hear, might not be so obvious to hospital staff who have little experience or training in the developmental disabilities field. Elderly patients generally look old and small children generally look young. Doctors and nurses can also tell if someone is in a wheelchair or if they cannot see or hear. But these days, many of the individuals we support have invisible disabilities, meaning that when they go to the hospital, they forget to wear their “I have a developmental disability button.”

2. **Missing a medical history:** Sometimes even something that looks like a mental health issue might be related to a medical issue. Doctors and nurses need to know about the health problems that are already there and that might be contributing to the current emergency. But sometimes, each visit feels like the first visit, with no information on file. In some jurisdictions, people have handheld health records to allow people to see their medical history quickly in an emergency, but we don't yet have that here. It can be hard enough to remember medical history details when it is not an emergency, so it is a serious challenge to have that accurate information on hand in a crisis situation.
3. **Not knowing current medications:** Almost half of adults with developmental disabilities take multiple medications. But they may not remember what they are called, how much they take a day, or why they are on them, especially in an emergency. This sort of information is critical in an emergency. One of the common reasons for going to hospital can be related to medication side effects, or taking too much of a medication at once.
4. **Not knowing how to communicate best with the patient or the best strategies for how to calm the patient down:** Some of the individuals we support can get very overwhelmed in the hospital emergency department. It is loud, sometimes crowded, and without a lot of privacy. For people sensitive to sensory overload, it can be a nightmare.
5. **Not knowing who the patient's circle of care is:** Before changing a medication, or making a treatment recommendation, it is important to know who to communicate this information to, and also to get a bit more background. If someone comes to the hospital alone, unless they can give the information reliably themselves, hospital staff may not know who to contact from the DD agency, who the family doctor is, and who other key people are that are managing the problem related to the emergency department visit.

What makes visits harder for people with disabilities and direct support workers?

In some of our research, we have spoken at length with people who have visited the hospital to learn about what is most difficult for them in order to explore how to make things better. Here is what they identified:

- Feeling disrespected by hospital staff
- That the hospital staff don't take their concerns seriously
- That they don't have information about what is happening and why, or what will happen next.

In the words of one support worker, “I know that [staff] are terribly busy, however, [show] a little more compassion and [be] a little more sensitive.”

Solutions

Before the visit...

Have a hospital visit kit ready by the door

Expectant parents are told to have a bag ready by the door. This bag can include all sorts of items to take to the hospital such as the hospital card, a change of clothes, snacks, some tools to help manage pain, a book with instructions, etc. Given how likely emergency visits are for those with developmental disabilities, why not have a bag packed and ready to go? What would be most helpful to have at any hospital visit? Keep such a bag ready and make sure every month that the items in the bag are replenished and that the emergency information is still current.

Don't know what to expect?

Some people have a very hard time being in the hospital. It is loud, stressful and unfamiliar. One way to make it easier is to know what to expect. There are different ways to become familiar with the hospital emergency department. You can watch a video, read a book, look at photos describing what happens or even play a game that explains it. You can even ask to visit your local emergency department when it is not an emergency as part of crisis planning. (See the end of this article for some resources explaining what to expect).

Care Plan

Care plans or crisis plans can address many of the issues outlined here. They can have information about medical history, medications, circle of care, communication strategies and ways to calm the person down. BUT REMEMBER: How we package information is JUST AS IMPORTANT as the information itself. It makes good sense to have a comprehensive binder of information to take to medical appointments and to track issues in the community. But big binders can have too much information, or information that is difficult to find in an emergency. If you bring a big binder, don't be surprised if the hospital doesn't know which part to look at and doesn't end up looking at it at all. Short simple communication tools can be helpful here. And the more hospitals get familiar with certain simple tools, the better. So while it is true that your agency probably has their own way to package information, coming up with a similar approach across agencies in your area might be a smart approach. You can even work with your hospital emergency department to develop something that works best for you and for them.

Food and Drink

Remember that you could be there for a while, and sometimes you may have a visit to the emergency department when food places are closed. You and the person you are

supporting need to remember to eat and stay hydrated if you want to stay calm, and it can be handy to have some good snacks available at your fingertips.

Activities to Pass the Time

Some activities may include looking at a photo album, reading a book, colouring, playing a game, bringing headphones and an electronic device, such as a cell phone or tablet, for listening to music or watching videos. These days, most hospitals have free Wi-Fi. Don't forget to bring a charger in case the battery runs low.

Medications for the Next 24 Hours

The hospital will not give your regular medication when you are in the emergency department. It is important to always have an up-to-date list of medications, but you might not have one on hand. Know your pharmacy. They can send the necessary information if you call and ask. Sometimes the hospitals already have information on medications that they can look up themselves. In Ontario, hospital staff in the emergency department can check the medications of everyone who is part of the Ontario Disability Support Program, or ODSP. They are used to doing this with their patients older than 65, but they don't always remember that they can do this for the people under age 65.

Communication Aids

You want the person you are supporting to be as involved as possible in the assessment. You know how they communicate best. Is there anything you can bring to support that communication? This might involve a communication book, or board, glasses or a hearing aid. You can model how to best communicate using these tools during the assessment. Visuals can be so helpful, including visuals of what life is like outside of hospital, or before the crisis. (This could involve photos of where the person lives, activities they like to do videos of them when they are feeling better).

At the Hospital...

Patience

Remember that everyone has to wait in hospital, and the hospital has to regularly check that they are speaking with the right person and that they have the correct information. This means you have to repeat yourself. A LOT. Don't assume just because you explained something to one person that the next person you meet with will have that information. They might and they might not.

Model respect and promote dignity

Hospital emergencies make patients feel vulnerable. This can include wearing a gown, being touched in private areas, and not having a lot of say in making decisions. Anything you can do as staff to preserve dignity in a difficult situation is so important. You can help show hospital staff how to interact with the person you are supporting. Allow them to make decisions for themselves, and help them to have a voice. If a question is asked to you but you think the health care staff should be directing it to the person you are supporting, give the question back to them. Show the staff how you might ask the question differently. The hospital staff will appreciate the quick learning they can do by watching you. Remember that the Health Passport provides information on communication preferences.

Don't be afraid to offer your help if the person you are supporting would like it

The hospital staff may not realize that the person you are supporting might be more comfortable with you there during certain procedures such as taking blood or having an x-ray. You might have some great ideas about how to rephrase a question, or the best position to be in. Explain your role, and explain it more than once if you need to. It can even be written down on the simple care plan that you share (e.g., I feel less anxious when my staff are with me and can help me).

Tests and procedures

Not sure what happens next or unfamiliar with the test or procedure they have suggested is going to happen? Ask about it. "What does it look like? How long will that take? Can I be in the room? Can we watch a video about the procedure, or see some photos to prepare ourselves for it?"

Information coming out of the hospital is as important as what goes into the hospital

Some hospitals do a great job of sending information from the hospital to the family doctor, but other hospitals rely on the patient or caregivers to share that information. Even the hospitals that send information to the family doctor may not explain that same information clearly to the patient and caregivers. That means that, if there is a "plan," it is not well understood, and it is probably not followed. (Sounds like broken telephone?) This makes another visit more likely in the future.

As staff, you can play a vital role in terms of making sure both you and the person you support really understand what needs to happen after the hospital visit. Have the conversation and get something in writing about what happened in hospital and what comes next. The Exit Interview is one example of a template to help record this information.

Resources

Here are some websites/tools that you can use to learn more about caring for individuals with DD, in the emergency department and beyond!

- [Tips, tricks and tools to create the best ED experience possible for you and your client](#) (scroll down midway to the 'Resources for Patients and Caregivers' section)
- [A 'cheat sheet' for caregivers to smoothly manage an emergency](#)
- Help hospital staff understand your client better with the ['About Me' booklet](#)
- Encourage your client to fill out ["Today's ER Visit: My Exit Interview"](#) to summarize his/her most recent visit to improve the continuity of care
- [H-CARDD website](#) for more information and resources

Check out these informative and engaging videos about DD emergency department use!

- ['Using emergency services: What clients with developmental disabilities should expect.'](#) A video that explains how to prepare your client to utilize emergency services, as well as how to help the ED best care for your client
- ['Use of emergency room services by patients with developmental disabilities.'](#) Research findings on emergency departments and what to do to best prepare for your visit
- ['What to expect when you go to the ER.'](#) A walk-through of what occurs during a visit to the emergency department

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