

Supporting Someone who has a Catastrophic Illness

Receiving a diagnosis of a catastrophic illness is difficult. It's difficult for the person who receives it, it's difficult for those who support that person, and it's difficult for the family. The diagnosis affects everyone differently but everyone needs to create time and space for the person most affected.

Shock, grief, and a sense of being out of control are common responses to hearing of a catastrophic illness and dealing with shortened time, and the expectation of loss. However, there are some things that can be done to bring everyone together and focus on what happens next.

Here are 5 tips for social and emotional support:

1 If there are family and friends involved (by friends, we also mean friends with and without intellectual and developmental disabilities; IDD), look at what kind of care and support the person wants from them. In this sense we are not talking about the day-to-day support that the staff provide to the person. These steps may be helpful:

- Find out from the person how they want to spend time with family and/or friends. What are some of the things they want to do? What are the things they don't want to do anymore?
- If possible, create a week by week calendar that schedules in time for the person to be with their family and friends, either at home, at a special event, or just having a coffee together.
- There can be a sense of aloneness, even by people who are well loved, when facing a catastrophic diagnosis, so knowing that people can and will come matters. It is also important to find out what bothers the person, and what they would like others to avoid doing when they are around them.

2 Now is not the time for you to talk about your health experiences, the experiences of your friends, or of people who have it worse. These are often brought up as 'sharing' but in fact they can make the person feel that their experiences are not of importance. **Right now the only narrative that matters is the one that the person has to tell.** Don't shy away from talking about the diagnosis but don't force it either. When someone says they don't want to talk about something that may really mean they don't want to talk about it. "Talking doesn't always make it better." Let things happen naturally and let the person lead. When they want to talk, they will tell you.

If you are interested in learning more about this, check out this video, Brené Brown on Empathy. It describes the difference between sympathy and empathy:

<https://www.youtube.com/watch?v=1Ewvgu369Jw>



5 tips for social and emotional support (continued)

3 **Don't overwhelm the person with sympathy.** This can be both burdensome and frightening. Try to get back to a normal style of communication. Let the person feel comfortable to joke about themselves or the situation – this can ease the tension they are feeling. Doing ordinary stuff, as long as that is possible, can be therapeutic. Watch a television series or go for a drive somewhere they like. Do things that they normally do, bring back a sense that while life may not be long, life still goes on with its ups and downs.

4 **Beware of false hope.** “Everything will work out, you’ll see,” “It’s all going to be just fine,” are lies. You don’t have to be blunt with the truth but you also don’t need to provide false hope. People with disabilities don’t need to be persuaded into happiness. Some things are sad, or scary, or frustrating, they just are. Let them figure out for themselves how they will view what’s happening.

5 **Bring as much choice and control back to the person’s life as possible.** One of the scary things about having a catastrophic illness is that you feel out of control. So ensuring that people with disabilities can make choices and can take control of their time and their needs, calms the panic. Being out of control is terrifying; reestablishing it can be as good as any medication.



Here are tips for working with the health care system:

- 1)** Read this toolkit very carefully. In it you will get advice about preparing for a health care visit, ensuring that you have the necessary information, and that the person you support will have their voice heard in the process. Study those sections and use them well.
- 2)** Be sure to communicate with health care providers about your role as a direct support professional (DSP). Ask them what information they want from you and what observations need to be made. Ensure that your role on this team is made use of. Ensure that the person you support is as involved as they want to be.
- 3)** The health care provider may have information about how to support someone with a particular diagnosis. Seek that out. If it isn't offered, ask. Find out if there are places where you or the person you support can find information and resources. Contact those places and find out what is offered. No matter how good something may sound, and how much you think they may benefit, it is the person's choice to attend or not.

Here are some tips for taking care of yourself:

- 1)** Besides being a professional, you are also a thinking, caring human being. You will be having an emotional reaction to what's going on around you. If your organization has a service for staff to receive counselling or guidance, you may want to access that resource. It's private, and you can say what you want to say and ask for the help you need and none of this is shared with your employer.
- 2)** Make sure you have some time to yourself. You will need time to process what's happening and to recharge your physical and emotional batteries. Make time for the things that help you feel relaxed. Purposefully and intentionally care for yourself.

This may be the hardest work that DSPs have to do in their work with people who have disabilities. Focus on how you can best support them, while you are providing the best support for yourself. The needs of the person with a disability are valid, so are yours, don't ignore them.



If you would like more resources on this topic, please visit:

<http://www.breakingbadnews.org/>

To learn more about palliative care, please visit:

<https://www.caresearch.com.au/caresearch/Default.aspx>