

# Autism & Grief Project

## Fact Sheet

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### Understanding Serious Illness

Serious illness can affect a person physically and cause changes in their mood, behavior, and abilities. Treatment for some of these illnesses can cause a person to be very sick, tired, or weak. They might need surgery and will have to spend time recovering. They also might need to stay in the hospital or move to a different place to receive medical care.

It can be distressing when someone you care about is seriously ill. Some illnesses can be treated and cured, or their progression can be stalled, with the help of modern medicine. For other illnesses, medical intervention may be unsuccessful in preventing death. A person can also live a long time or a short time after receiving a diagnosis, depending on what is medically possible. It can be difficult to see someone's mood and physical appearance change as they cope with a significant illness.

You might begin to feel grief during a person's illness as you see their health decline and think about a future without them. It may help to share your feelings with someone you trust. Sharing verbally or through written words, pictures, music, or references to stories or movies can relieve anxiety. It may also provide answers to questions you might have about what will happen to the person who is sick, or to you if the person dies. You can have a role in making decisions about your future. Adjusting to the changes that may happen will be easier if you know about what might happen and a plan is in place.

### Questions You May Want to Ask About an Illness

If you have questions, you can ask the person who is sick, or you can ask a healthcare provider, family member, or other support person. You can also find information from valid sources online or in books. As you read information, beware that not all of it will be applicable to the person's specific situation or it may not be reliable. Everyone's illness and their response to it can be different.

Some questions you might want to ask are:

- Are they in pain?
- What made them sick?
- Will I get sick if I go near them?
- If they need surgery, what is it for and what will it be like for them?
- How long will it take for them to feel better?
- If they are in the hospital, when will they leave?
- Will they recover at home or another place?

- What can I do to help the person?
- Will the person need medicine and how might that affect them?
- What is the likelihood that the person will die because of their illness?
- How could their serious illness or death affect me?

Sometimes you might not get a complete answer to your questions. The person may not know the answers or they may be feeling uncertainty and anxiety. They may not want to talk about their illness at all or may not want to talk about it at the same time you do. It is important to respect their privacy.

Most people will want to help you get the information you want to know, especially if it will affect you.

## Visiting the Hospital

### What to expect

If the sick person is allowed and wants to have visitors, you can visit them in the hospital during visiting hours. If you haven't visited a hospital, it can help to communicate with your family, friend, support person, or hospital staff before you go about what you might experience. Most hospital websites can provide you with information such as what the place will look like and where things are located.

Before visiting a hospital, here are some questions you might want to ask:

- Does the person want visitors?
- Will there be machines in the room? What do those machines do and what do they sound like?
- What will the person look like? Will they be able to talk? Will they be able to get out of bed? Will they be awake? Will there be other physical changes, like bandages or hair loss?
- How will you let people know when you need a break or are ready to go?
- What should you bring for the person?
- What should you bring for yourself to provide comfort if you need it?
- How will I know when/ if the person wants me to leave? Will they just tell me?
- How will I know when visiting hours are over? Can I be in the room when visiting hours are over or do I have to be out of the building before visiting hours are over?
- Are there hospital rules? What are they?
- Can I talk to other people? What if they have a roommate? Can I talk to them? What if the roommate needs something, can I get it for them?

### What to bring if you decide to visit the hospital

Many people who visit people in the hospital bring a card, flowers, or balloons. Ask your friends, family, support person, or hospital staff first if this is okay. Common things to write in a card is, "Get Well Soon" or "I hope you feel better." Bringing something that

you know they would like can be a great way to let the person know that you're thinking about them and that you care about their recovery.

Visiting the hospital can sometimes be stressful with unfamiliar sights, sounds, smells, and people. If you are worried about what you might experience when you visit, it may be helpful to bring something that helps you cope with the stress, such as earphones to listen to music or an object that you find comforting.

### **What to say if you decide to visit the hospital**

A common thing to say when visiting someone in the hospital is, "Get Well Soon." You may also want to say, "I hope you feel better" or "Can I bring you anything if I visit again?" Common things to talk about might include topics such as sports, hobbies, family, job, home life, movies, shows, and current events. If you are not sure what to say, that's okay. Simply being there to visit shows the person that you care about them.

### **What to do if you decide *NOT* to visit the hospital**

If you decide that a visit to the hospital might be too difficult, you can send a card, or set up a phone or FaceTime call instead. A trusted family member, friend, or support person can help you send your "get well" wishes without visiting the hospital.

## **Hospice Care**

When a person is very sick and will not get better, you might hear your family talking about hospice. Being in hospice care means that a person is probably close to the end of their life and will die soon. To receive hospice care, doctors have used their best information to decide that the person is expected to live about six months or less. Hospice care provides grief support to family members if need it after the person dies,

The goal of hospice is to make the person comfortable. A team of healthcare and other professionals work together and make a plan for the person's care, which often involves medications and helpful equipment. Hospice care is not for people with a chronic health condition unless they are close to death. Many people live for years or their entire lives with chronic health conditions.

Most hospice care occurs in a person's home, which could be their private residence, a nursing home, or a similar facility. Hospice care can also be provided in a hospital or something known as a hospice house.

### ***Hospice at home***

Hospice care at home means the person receives care wherever they call home. They might be at their house or apartment, the home of a family member or friend, or in a nursing home. To keep them as comfortable as possible, a hospital bed might be used and they may use some equipment or machines that would be used in a hospital, such as an oxygen tank with a mask to help them breathe.

A lot of people, such as physicians, nurses, nursing assistants, clergy, and social workers will visit the person in their home several times a week to help take care of them and the family. Family members and friends also provide a lot of care for the person who is sick. It can feel a little strange to see new equipment and people. It may make you feel sad or worried to see that the person who is sick doesn't look the way they usually did.

If it is helpful to you, speak with a hospice staff person about who will be visiting and how often they will visit. You can also ask about how they will communicate when they will be arriving and how long they will stay. You may also want to know how they will communicate if there is a change in plans or if there's anything you can while they are visiting.

Note: There are other times when a person needs medical equipment and help at home, and it's not because they are in the care of hospice. Many people with different types of illnesses who are not expected to die need medical and caregiving assistance

### ***Hospice in a hospital***

If hospice care is provided while the person is in the hospital, you probably will not notice a lot of changes if the person was already hospitalized. The person will stay in the hospital and they will probably be resting a lot. They will get medication to manage their pain and other symptoms.

You can speak with a hospital staff person about visiting hours so you will know when you can visit. You may also want to ask about hospital rules that you should follow when you visit.

### ***Hospice in a hospice house***

Hospice care is sometimes provided in a place that provides only hospice care. The rooms are comfortable, and the hospice staff is there all day and night to take care of the sick person, like in a hospital, but it also allows the family to spend private time with the person.

If it is helpful to you, speak with a staff person about visiting hours, so you will know when you can visit. You may also want to ask about any rules that you should follow when you visit.

## **Palliative Care**

Another care choice for someone who is seriously ill is palliative care. Palliative care is similar to hospice care because the goal of palliative care is to help someone be comfortable. Palliative care is not only for people who are expected to die. Someone can receive palliative care for any health condition at any time if they need relief from pain and other symptoms caused by an illness or another condition.