

Finding Reliable Information



Educating yourself about your child's illness is an important part of managing their care. Knowledge about what might happen and how to respond will also help you be more informed and give you a greater sense of control. There may be a large amount of information available about your child's illness but it is important to try and ensure that it is reliable and relevant to your situation.

Speak to your care team

The best source of health information is your child's care team. Don't be afraid to ask for more information. Sometimes, your questions may not be answered with absolute certainty. A child can have a set of life-limiting symptoms but not a complete diagnosis of what the illness or causes are. Even if there is uncertainty about your child's illness, you can expect to have your questions answered honestly by your care team.

Some questions that you may want to ask your care team are:

- › What can I expect as my child's illness progresses?
- › What can I expect from this treatment or procedure?
- › What can be done to keep my child comfortable?
- › How and where can my child receive care?
- › How are services provided after hours?

It may also be helpful to:

- › Write down your questions or concerns beforehand so you do not forget anything when you meet with the care team.
- › If you do not understand something, ask the care team to repeat and clarify the information.
- › Ask the care team for advice on where to get more information.
- › After attending a meeting or an important decision-making session, it may be helpful to ask one of the care team for a written summary of what was discussed and decided.

Other sources of health information

While health information can be found in many places, it may not be as reliable as those from your care team and other health care providers. It is best to carefully assess other sources of information as they may not be accurate and can be dangerous or misleading.

Chatting with friends on social media sites can be very helpful for social support, but is not a substitute for proper medical advice. You may also be thinking of fundraising by using your personal community but these efforts can come with their own stresses on families. If you are interested in learning more about a specific treatment that you have heard about, you can discuss the information with your care team so that they can work with you to find the best option.

Some questions to ask when searching for additional information include:

- › Who is providing the information? Are they qualified in health care?
- › How up to date is the information?
- › Is the information understandable or is it full of unknown words?
- › Are there links to other reliable sources?
- › Is there a reason why a source is promoting a particular product?
- › Does the source discuss the benefits and risks?
- › Is there a way to contact the author?