

Talking to Your Child About Their Disability and Needs

An important part of a parent/care-giver's role is to support your child's understanding of their strengths and needs. This is an ongoing process that will develop and grow as your child does.



We have compiled some information, tips and insights from other parents below that we hope you will find useful. Also, think about who else your child may talk to, their teacher, grandparents, child-minder? It may be helpful to let them know what discussions you have had with your child, so that they can be prepared for any questions and are giving the same information and messages.

Some parents find having these types of conversations challenging and they can sometimes bring up difficult emotions. If you would like more support, please contact your Enable Ireland social worker.

Why is it Important to Talk to Your Child?

Encourages good communication: Having open discussions about disability gives your child the message that they can come to you with any questions or worries in relation to their disability or needs.

So your child 'has a story': this helps them respond to questions from friends and others.

Accurate Information: To ensure your child has the correct information. Not having the right information can lead to 'magical thinking' in younger children (i.e. coming up with their own, inaccurate reasons why they have a disability) or getting information from the internet or peers that may not be accurate for older children.

Self Esteem: Talking about your child's needs or disability in a positive and open way will help build their confidence and self-esteem.

Identity: Your child's needs or disability is part of who they are.

Medical Care: It is important for your child to have age appropriate medical information so that they can be responsible for their health and medical care when they are older.

Independence: To gain independence as your child grows, he/ she will have to know about their needs and how to have them met.

Experiences and Thoughts from Other Parents

"I sat her down and told her they have a name for this. I said, right now there's not a cure for it, but there are things we can do to make things better for you. We have all these doctors that are going to help, and we're going to get you what you need."

"If children don't ask about the future, don't bring it up. If they do ask, answer honestly but keep the door open to possibility... 'We don't know for sure what's going to happen. We'll make sure we do what we can when things happen. When the time comes, we'll handle it. We will handle whatever comes along.'"

"I know now not to be so hard on myself if I don't know what to say or how to say it. I try to listen more, interject less. I strive to understand the message. Is he venting? Is he asking for information? Maybe he just wants me to listen. As hard as it is I try to be honest. As his mother, I want him to know he can trust me to be there and to give honest answers to his tough questions."

Tips for Talking to Your Child About Their Diagnosis/ Disability/ Needs

- **Be clear.** Try to use simple language that your child will understand.
- **Be prepared.** Think about what you want to say, where and how you will say it.
- **Talk to others.** It can be helpful to hear other parents' experiences of talking to their children about disability.
- **Be positive** and reassure the child about finding solutions.
- **Get informed.** There is lots of information (books, films, articles, websites) available to support you in talking to your child, or to look at with them.
- **Be open.** Try to be honest with your child, 'sugar coating' or avoiding information can be confusing.
- **Be aware of non-verbal cues.** Your child's body language can tell you how receptive they are to the discussion, and how it is making them feel.
- **Pick your moment.** Use opportunities where your child may be more likely to talk, for example in the car where they do not have to make eye contact.
- **Communication is two way.** Allow your child sufficient time to ask questions and tell you what they already know or have heard. Let them know they can come back to you with any questions.

- ***Drip feed.*** Don't feel you need to give your child all the information at once. Think of it as a process rather than a once off conversation.
- ***Both parents on one page.*** Talk to your partner about what you will say to your child, and make sure you are in agreement with what information to give and have a united approach. (This is particularly important where parents might have different feelings about their child's diagnosis or needs, and different ways of coping themselves).
- ***Respond as questions arise.***
- ***Don't expect your child to react or feel a certain way. Help your child name their feelings,*** without trying to fix them.
- ***Your child's need for information will change over time,*** depending on their age, level of understanding and developmental stage.

More information about discussing disability with siblings and others is available from informingfamilies.ie.