

Cystic Fibrosis (CF) Carrier Screening

Discussing cystic fibrosis and carrier testing with your children

Parents often have questions about how and when to talk about an inherited condition, such as cystic fibrosis, and carrier testing with younger members of the family. This fact sheet provides some suggestions from research in this area to help parents start the conversation.

When is a good time to start talking to your children about CF?

Open and honest conversations with your children about CF in your family can help them to understand and feel comfortable about seeking more information and asking questions. If your child is told early on, it may avoid them feeling like a secret is being kept from them or coming to their own conclusions about what may be going on.

Talking to your children about CF in your family should be an ongoing conversation, rather than a one-off discussion. Repeated conversations can help your child learn more and feel more comfortable about the information that you are giving them. Discussing CF regularly can also allow you to break the information down into more manageable pieces, instead of giving it all at once. It makes the topic more approachable for your child. Having repeated discussions can help your child to understand the information as they grow up.

Regardless of when you start talking to your children about CF, it is important to think about their age and developmental stage when deciding what information to give them. Tailor the information to the age of your child and remember that learning this sort of information is a process that can happen over time, as your child is able to understand more. Support their interest by providing them with information if they ask for it, and by answering their questions. If children believe they will be answered honestly when they ask questions, they will be more likely to ask them.

“At the moment we do feel that we’re equipped (to tell them about CF) and probably just because of our approach or our philosophy is about answering questions age appropriately but being honest. That hasn’t failed us so far with anything else we’ve done so we’ll use that with <our child> with being a carrier.”

Mother of child with CF

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How should we discuss this information with our children?

For children who do not have CF but may be carriers, it is important to explain that for a person to have CF, both parents need to be carriers. This means that even if they are a carrier of CF, their future partner would also need to be a CF carrier for there to be a chance of having a child of their own with CF. For children who grow up in a family with a sibling with CF, it is important to emphasise that even if they are a carrier, there is a much greater chance that their partner will not be a carrier and they are unlikely to have a child of their own with CF. Getting carrier testing for themselves and their partner will help provide them with more accurate information about these chances.

When you talk to your children think about not only what you are saying but also how you are saying it. They may not remember exactly what you said, but they will remember the emotion that you expressed while talking about it. Speak calmly and positively about the topic. Be honest and encourage them to ask questions whenever they think of them. Discussing the topic of inheritance can be done by giving them real examples that they can see, such as hair or eye colour in their family, and then extending it to genetic conditions, like CF.

When talking to your child about the possibility that they might be a carrier, reassure them and normalise it by pointing out other family members who are also learning about CF and who are or might be carriers. Identifying other family members can help the child to feel more supported and can help them come to terms with the information, as well as understand the issue of inheritance. Help your child to understand that people who are carriers of CF are healthy.

“I think it almost just normalised it for her. That that’s OK, you know. I’ve got a CF gene in my body. Someone else has got the gene for blonde hair. Someone else has got the gene for blue eyes. Everyone’s got something different. You’ve got that gene... you just carry it. It’s just part of you.”

Mother of child with CF

When can carrier testing for CF be done?

Carrier testing in healthy children is generally not recommended and often parents are encouraged to postpone testing until children are able to understand the testing process and its implications. Some parents may feel knowing whether their child is a carrier is important to them and a genetic counsellor can talk with you and your child about genetic testing before any decisions are made about it.

If you decide to wait and discuss the option of testing with teenagers as they approach reproductive age, having earlier conversations with your children about the fact that they could be a carrier may be helpful.

Further Info:

www.nhmrc.gov.au/health-topics/genetics-and-human-health/health-practitioners/genetics-family-medicine-australian-handbook
Patient and Family Fact Sheet: Genetic Testing and Screening - Genetics in Family Medicine: The Australian Handbook for General Practitioners (2007)
www.cfscreening.com.au

References:

Sullivan, J & McConkie-Rosell, A (2010). Helping parents talk to their children about genetic diagnosis. In Gaff & Bylund editors. Family Communication & Genetics, Oxford University Press, NY.

The content of this information sheet was checked by representatives of the Victorian Clinical Genetic Services, RCH Respiratory unit and Genetic Support Network of Victoria (GSNV).

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