

Discussing Genetic Risk with Your Children



There are many considerations when deciding to have a conversation with your child that they may carry a gene mutation that increases their risk of cancer. When a parent receives the news that they are positive for an abnormal gene or familial mutation, it is natural that they become concerned for their own children and may experience feelings of guilt about potentially passing the abnormality on. A parent with a gene mutation has a 50% chance of passing that gene mutation to any child, both sons and daughters. This means it could affect some, all or none of a person's children, as the 50% risk applies to each child.

So how can you be prepared to discuss genetic risk with your children?

Tip #1: Lean on medical professionals

We recommend that you discuss any concerns you might have with a healthcare professional, prior to discussing genetic risk with your child. This will help ensure that you have the facts and may help you think about the questions your child may have and equip yourself with the knowledge to answer them or develop a strategy that will let you find out more together.

If you feel you are unable to broach the subject yourself with your child, work with a genetic counsellor to find the best way to discuss it with your child. They have the knowledge and experience regarding genetic mutations and testing. Your child can then ask a multitude of questions to a professional so they get the answers they need.

Tip #2: Understand what testing options are available

When it comes to children in your family under the age of 18, most experts advise against testing for abnormal BRCA and PALB2 genes. This is because under 18 children's health risks if they do have a BRCA1 or 2 mutation is very, very low. Testing is more informative when there are actions that can be taken on the results, and when the child is able to consent to testing themselves as an adult. Sharing genetic information and cancer risks can be done earlier though, as this does not require the child to have a predictive test.



If you have children who are over the age of 18, discuss the familial mutation and the possibility that they also carry it, with them. When you do choose to sit down with your child or children to have this conversation, frame the information in a positive way. For example: “We all carry mistakes in important genes. In our family, we are lucky enough to know what the mistake is, so we can do something about it.”

Tip #3: Think about timing

It is important to understand if you are ready to share the information with your children. There are signs that you are comfortable with your emotions and ready to share such as:

- You feel calm when you talk about the gene abnormality
- You feel positive about your own medical decisions
- You are confident that you do what you can to avoid cancer
- The future holds more promise than the past
- Knowledge is power
- You know your daughter/son can handle it

There are also signs you may not yet be comfortable and ready to share:

- The thought that your daughter/son inherited the mutation is unbearable
- You get upset when you think or talk about it
- You feel very emotional when you think of your children’s futures
- You try to avoid thinking about it or talking about it
- You often feel angry, fearful, worried or guilty about your family’s familial mutation

It is common, just after your own diagnosis, to have some or all of the above feelings of discomfort. However, they should not persist. If they do, it is important to discuss your anxieties with a counsellor or psychologist.

It is also important that not only are you ready to have the conversation, but your child is also ready. Ideally, we recommend they be “emotionally ready” for this conversation; somewhere between 16 and 22 years of age when you approach the subject. Each child is different, you will know their emotional age. Try and tell them when they are ready, not just when you are.

When you do decide they are emotionally ready, ensure to approach this conversation in a quiet time. Perhaps not in front of the TV or not straight after your own surgery. Don’t talk about this subject during times of stress for your child such as during exams. This is a large subject and will take some time to discuss and sink in. Both you and your child need to be in a good place mentally to be ready to discuss this.



Tip #4: Prepare for emotions

Don't be scared to tell your children. They have probably witnessed your own experience and have supported you this far. Children are resilient creatures and can bounce back quickly. Others may need more time to adjust. But remember you are having the conversation so they can make their own decisions about their future.

Although it may be hard, try to keep your own emotions in check and start the conversation with a level head and focus. They need facts and open discussion. Of course, they may get upset and you need to be that support person. If you need a good cry together, do so. Your child will experience a varied number of emotions from fear to guilt, to hate, to indifference and confusion etc. All this is okay. This is a lot to take in. All you can do is guide them, but ultimately, they must make the decision regarding their genetic testing. You should not push them into it.

Try not to let guilt control you. It is not your fault that you carry the gene. Nor is it your fault that the gene passed onto your children. All we can do is be proactive and protect our children the best way we can with monitoring and knowledge. Your child may blame you for passing on the gene, this is an initial reaction. But in time they will understand that you didn't wish this on them and that you would take it back if you could. Remember, this is not your fault. You're being a great parent by having this conversation, and potentially saving their life.

Tip #5: Prepare yourself to support their experience

Let your child decide how they wish to proceed. If your child decides to go ahead with testing, there can be challenges and emotions that come from both a negative and positive result. Try and let your child's emotions guide you. They may be shell-shocked, scared or not ready to accept it. Whatever happens, let time pass and wait, sleep on it, whatever you need. If the test does come back positive, there is no need for hasty actions or decisions. Just be there when they need you. Let the tears come if you feel appropriate. You know your child best; each situation is different. Some children feel empowered and ready to face it, others not so.

Monitoring or surgery is one piece of the puzzle. A genetic counsellor is probably the best to keep in touch with as they will be aware of the family history and can advise on monitoring strategies, such as yearly mammograms, ultrasounds, MRIs, manual check-ups etc. Surgery is something that may take years to come to terms with. Ultimately it's your child's decision what they do.



Tip #6: Equip you and your child with support

There are many resources available to you to support the ongoing conversations with your children. These include:

- Support groups like **Inherited Cancers Australia**
- Your genetic counsellor
- Counselling with an oncology psychologist or other mental health professional

Visit our website for more information:

inheritedcancers.org.au