Communicating with primary aged children about genetic cancer risk

inherited
CANCERS AUSTRALIA

Deciding when and how to talk to your child about a genetic mutation that increases their cancer risk involves many considerations. When a parent learns they carry a gene mutation, it’s natural to feel concerned about the potential impact on their children and to experience guilt over possibly passing the mutation on. A parent with a gene mutation has a 50% chance of passing it to any child, whether son or daughter, meaning it could affect some, all, or none of their children. This uncertainty often leads parents to wonder when and how to have this conversation.

There are several reasons why it may be important to help your child understand genetic risk. For example, your child may need to undergo genetic testing, or they may need screening or preventive procedures to manage their risk. Additionally, your child may be witnessing you or other family members undergoing treatments or surgeries related to cancer risk, making it important to have an open discussion about what’s happening.

What are the genetic testing options available?
When it comes to children in your family under the age of 18, most experts advise against testing for abnormal genes. This is because under 18 children’s health risks if they do have a genetic mutation for inherited cancer 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. A predictive test’s goal is to identify individuals who possess a genetic variant that may elevate their risk of developing a particular disease or condition later in life, even before any symptoms appear. Essentially, it's a predictive test for asymptomatic people, using their genetic profile to assess future health risks.

Why is it important to talk to your child?
Conversations with your child are important. These conversations can help your child to understand the family situation and to make sense of what they are experiencing. When your child does not understand what is happening in the family they can worry, feel alone and/or fearing the worst, which is very common in late primary and early teens, and misunderstand the situation. They may feel personally responsible and worry about you and your health and safety. Helping your child to understand genetic risk and what it means for them and your family will:

- Help your child to know that it is okay to talk about it.
- Allow your child to ask questions and get the correct information.
- Help them come to you (or others) when they are worried or feeling overwhelmed.
- Build a shared understanding that can strengthen relationships.

Don’t be afraid to talk to your children—they’ve likely supported you through your own journey and are more resilient than you might think. Some may need more time to process the information, but the goal is to give them the facts so they can make informed decisions about their future.

While it’s tough, try to stay calm and focused during the age appropriate conversation. Your child may feel a range of emotions—fear, guilt, anger, confusion—and that’s okay. Be there to support them, and if you need to cry together, do so. Ultimately, the decision about genetic testing is theirs, so avoid pressuring them.

Try not to let guilt take over. You didn’t choose to carry this gene, and you certainly didn’t mean to pass it on. What matters now is using the knowledge you have to protect your child through awareness and regular monitoring. If your child reacts with blame, that’s a normal emotional response. With time, they’ll come to see that you never wanted this for them and would change it if you could. Having this conversation takes courage, and it’s an act of deep love — one that could help protect their future.

This resource will help you to prepare for conversations with your child about genetic risk so you can help them to understand what it means. It steps you through:

- How your child might understand health and illness
- Thinking about how you feel about your genetic risk
- Thinking about what your child notices and experiences
- Preparing to talk with your child

How do children understand health and illness?
Thinking further about what children understand about health and illness can help you in thinking about how to approach a discussion with your child.

Children hold complex concepts of health and illness and these concepts change as they develop. Much of how children understand these concepts comes from their personal experiences of illness and learnings about health promotion. Younger children’s concepts are often different to older children and adults who use more abstract experiences of health to inform their understanding.

Children view the general concept of being ”healthy” as being able to participate in activities, maintaining their normal routine, not taking medications or feeling sick and being happy.

As children less commonly experience serious or chronic disease, most children's personal experiences of illness come from their experiences of contagious diseases such as colds and viral illnesses. This forms a 'causal and effect' concept of illness e.g. that one event leads to another.

Children's experience of health promotion also informs their understanding of illness. Children understand the importance of behaviours such maintaining personal hygiene, eating well and not being around passive smoke and how these exposures relate to illness. Because of this they link healthy behaviours to the concept of health.

In essence children's understanding is complex but the conclusions they draw may appear simplistic. This can be of relevance when children come across a new illness scenario. Researchers have found that children may often 'fill in the gaps' and find ways for their experience to fit within their known illness construct. Examples of this might be that children report that their illness is a punishment for something they have done or that things like their natural environment such as 'cold air' or 'pollution' may have caused their illness when the reason is not able to be identified.

It may be helpful to think about how you can describe the impact of genetic risk information in ways that can fit into the constructs your children hold.

For example, if you are considering genetic testing for your child it may be explained in ways such as;

"We have lots of genes in our body, these make up who we are and what we look like, for example what colour eyes we have. Genes are not something we can change, we get them when we are born. They are not like germs that give us a cold. Sometimes we get genes that mean we have to do extra things to help us stay healthy. We can do a test on our genes, to see if we need to have extra check ups or speak with other doctors, to make sure we stay as healthy as possible."

How do you feel about your genetic risk?

For primary school aged children parents are often the most important people in their life and they look to their parents for guidance in understanding the world around them. Because of this, children of this age are often very sensitive and attuned to their parents' emotions and behaviours (even when parents try to hide them). How parents behave and the emotions they experience often inform how children feel and understand new information and situations.

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 seek support from a counsellor or psychologist.

When you do decide your child is 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. 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 - We recommend speaking with a healthcare professional such as a genetic counsellor before discussing genetic risk with your child. This will help ensure you have accurate information and allow you to anticipate your child’s questions, preparing you to answer them or work together to find more answers. If you're unsure how to approach the conversation, consider working with a genetic counsellor. They can guide you on the best way to talk to your child and provide expert knowledge on genetic mutations and testing. Your child can also ask a professional directly, getting clear answers to any questions they may have.

Understanding what your child notices and experiences is also important, the questions below may help you in thinking about this further;

- What may they have noticed or experienced that has changed since I learnt of the genetic risk?
- What have you noticed about their reactions?
- What do you think they might be feeling?
- What might they understand or not understand?
- What do you think might worry your child the most?

Practical tips in preparing for conversations

Children best understand information over time. As your child grows, their need for information will also change, so be prepared to have multiple conversations.

When and where to start the conversation/s?

Timing and location is important and it may be helpful for you to identify what a good time may be;

- Is your child have a difficult time at school or with social groups? (would delaying a short time be possible?)
- What time of day is your child best able to focus and concentrate on what you are saying?
- Where do you have the best conversations with your child, when they are in the bath, at the breakfast or dinner table, at bed time, in the car?
- who else will be around when you plan to share the information? (if you have more than one child you may need to consider if different approaches or times may be best)
- Who else may be able to help support you in sharing information and/or keeping an eye on how your child may respond e.g. other relatives, friends or school teachers.

Tips for talking to your child?

- Think about what words or language they will understand
- Stop and pause after each new bit of information. Sometimes the conversation may be very short – don't worry if this happens they small conversations are just as important as big ones, they all add up and help children learn at their pace.
- Children will be often worried about if it will impact on your ability to take care of their needs and if on their health they may only understand concepts such as will I get better and when.
- Give your child time to think and to ask questions (the questions might not come straight away, your child may need thinking time).
- Know what to do if you don't know the answer. E.g. tell them that you will find out, or even find out the information together and follow through.
- Encourage your child to ask questions or raise concerns whenever they want and make sure when they do, answer them or make time to answer them as soon as possible so they feel valued and trust that you aren't avoiding the topic. Often children may ask questions when you least expect them to!
- Watch your child's behaviour or for signs such unexplained tummy aches, wanting to stay home from school as this may be a sign you need to check in with them about whether there is anything worrying them.
- Set up a support network for your child so that your child also can seek answers from a person that you both trust (e.g. a family member, a family friend or a health professional).

These resources were researched and produced by Garvan Institute of Medical Research, who have kindly given ICA permission to repurpose them for our community.

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