Communicating with young people about genetic cancer risk

Most parents wonder about how and when they should talk to a young person about genetic risk. There may be many reasons why it is appropriate to begin or continue conversations with a young person to help them understand more about genetic risk.

Reasons include; they may decide to have a genetic test, be recommended to have procedures to screen, treat or reduce risk and/or a young person may be witnessing you or other family members having procedures or surgery to manage risk.

What are the genetic testing options?

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 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."

Common concerns of parents?

Parents can often be concerned about whether telling a young person about genetic risk during adolescence or young adulthood is the right time. Many parents often make statements such as;

“I am worried that my young person is experiencing so many changes and stressors in their life that this information may add further stress?”

“I am not sure my young person is able to cope with this information at this point in their life?”

“I worry that my young person make different life choices because of their risk”

Whilst is it natural for parents to express these concerns, it is important to consider how much your young person may already know or could inadvertently uncover. Young people often pick up on what is happening around them.

Young people often want to protect parents as much as parents want to protect young people. The risk of not discussing information openly with a young person is that the young person may not feel able to ask questions or coming to a parent with a health concern.

Trusting relationships are very important for parent’s and young people so it is important to consider this in any decision to communicate genetic risk information with a young person.

Benefits of talking to a young person

When a young person does not understand what is happening they can worry, feel alone and misunderstand the situation. They may worry about you or their own health and safety. Helping a young person to understand genetic risk and what it means for them and your family will:

- help to know that it is okay to talk about it.
- allow them to ask questions and get the correct information.
- help them come to you (or others) when they are worried or if relevant have any worrying physical changes
- build a foundation of honesty and respect that can strengthen relationships.

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

- thinking about how you feel about your genetic risk
- thinking about what a young person may notice and experience.
- preparing to talk with a young person.

Preparing to talk with a young person

Young people have a much more adult understanding of illness than children, such as illness can lead to death. Young people may wish to know what is happening for your health, how the genetic risk could affect their health and if the risk will change their life in ways that are different to their peers. Young people may or may not want to explain or feel able to explain these issues to others, including friends.

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.

Don't let guilt take over. It's not your fault that you carry the gene, nor that it was passed on. All you can do is protect your child with knowledge and monitoring. If your child blames you, that's a natural reaction. Over time, they'll understand you didn't want this for them and that you'd change it if you could. Having this conversation is a brave and loving step toward potentially saving their life.

Thinking about how you feel about genetic risk and how you feel about your young person's situation is important in how a young person may understand and adjust to any information you share.

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
- You feel that knowledge is power
- You believe that your child 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. It is best to have these discussions around genetic cancer risk when both you and your child are in a positive headspace .

TIP – We recommend speaking with a healthcare professional 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 a young person notices and experiences is also important, the questions below may help you in thinking about this further or may be questions you wish to ask a young person;

- what may have they 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 about the most?

Practical tips in preparing for conversations

The main aspects to consider in preparing for a conversation are;

- the environment – when and where to begin conversation/s
- content – what to say and what language to use
- asking questions – how and when to ask questions
- support and follow up – what other resources or supports are available to them.

When and where to start the conversation/s?

Timing and location is important, questions that may be helpful for you to identify a good time may be;

- is your young person having a particularly difficult time at school or with social groups? (would delaying a short time be possible?)
- what time of day is best able to focus and concentrate on what you are saying and for the young person to listen and process
- what you are saying?

- where do you have the best conversations, 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 children at different ages you may need to consider if different approaches)
- who else may be able to help support you in sharing information and/or keeping an eye on how your young person may respond e.g. other relatives, friends or school teachers.

Content
What to say and how, it can be helpful to start small and be prepared to have multiple conversations. It can be helpful to understand what they may already know and what most concerns them.

Young people often to want to understand what it means for them at their life stage, e.g. am I different from my friends, do I need to do anything about this now, will it change my plans for study or ability to participate in extra circular activities sports etc? Some may have the same worries as adults such as will they are able to bear children or live a long life. Remember the information you need to share with them, may be different from what you received about how the information impacts your health at your life stage. If you need help in understanding this do it before you begin the conversation. Take it slow. Stop and pause after each new bit of information. Sometimes the conversation may be very short – don’t worry if this happens, small conversations are just as important as big ones, they all add up and help people learn at their pace.

Focus on the positives. Communicate how the information about their genetic risk is of benefit to them and what is in their control can help allay fear caused by the uncertain nature of the information.

Asking Questions
Give your young person time to think and to ask questions (the questions might not come straight away, they 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 young person 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. Questions can arise when you least expect them to!

Support and Follow-up

Young people access and receive information from a number of different places such as friends, television and online including social media. This information may not always match your experience, listen to your young person about what they understand and then explain. You may want to give them written information or direct them to reliable online resources.

Set up a support network so that your young person also can seek answers from a person that you both trust (e.g. a family member, a family friend, teacher 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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