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Sharing genetic testing results with family
A practical guide

"These conversations can feel heavy, but choosing to share this information is an act of care." – Sarah, BRCA2

This resource draws on lived insights to help you prepare for conversations about sharing genetic testing results with your family. It focuses on what can help before, during, and after those conversations, especially if they feel hard.

Step 1: Start with yourself

"I realised that if I hadn't grounded myself first, I would have been sharing from a place of fear or uncertainty, which can make those conversations harder."

It's okay to take some time to understand what this means for you before sharing it with anyone else. This information can be a lot to take in, and it's understandable if you need space to process it. Giving yourself some time to reflect, regain your footing, and think about what you want to say can help you feel more prepared for these conversations.

What may help:

- Take some time to sit with the information and notice what thoughts or feelings come up.
- Work out what still feels unclear or what questions you may have.
- Talk things through with someone you trust, or with a healthcare professional such as a genetic counsellor.
- Remember that you do not need to have everything figured out before you start talking about it with others.

You can move at a pace that feels right for you.

Step 2: Be clear on why you are sharing

"There's a difference between sharing information and forcing acceptance."

Knowing your reason can help keep the conversation clear and grounded.

Ask yourself: **Why am I telling them this?**

These lived insights may help you think about your own reason for sharing:

- **This information could matter for them too**
  - You may want family members to have information that could be relevant to their own health or decisions.
- **You care about the people in your family**
  - Sharing may come from wanting people you care about to have the opportunity to understand what this could mean for them.
- **You want them to have access to advice or support**
  - Sharing information may give people the chance to seek support, ask questions, or speak with a healthcare professional if they choose.
- **You do not want to carry this on your own**
  - For some people, sharing can help bring things into the open and make it easier to ask family for support too.

"I don't see it as creating a problem. I see it as bringing something into the open that already exists."

Once you feel clearer on why you want to share, the next step is thinking about who to tell first and how.

Step 3: Decide who to tell first and how

Deciding who to tell first can feel hard. It may help to start with the person who feels safest, or the person most likely to listen well. You may also choose different approaches for different relatives.

Need more help deciding who to tell first, who else may need to know, or how to approach these conversations? See **communicating with family about genetic cancer risk**.

Step 4: Work out your key message, then stick to it

"Keep it simple. You don't need to explain everything in one go. Start with the key message."

The first conversation does not need to cover everything. It can help to work out your key message before you begin, then come back to it if the conversation starts to drift.

Your key message might be:

- There is inherited cancer risk in the family.
- This information could be relevant for you too.
- This is inherited; its not about blame or fault.
- You do not need to make decisions right now.

If you would like more help shaping what to say, see our **communication guides and templates**.

Step 5: Practise this conversation with someone

"Role play with a friend of yours, someone, a trusted individual, have a conversation with them and see how you feel saying it out loud, because it does get easier saying it the more times you do it."

Saying it out loud before the real conversation can help you feel more prepared and steady. You might choose to practise with:

- A trusted friend or family member
- **A peer support mentor**

A healthcare professional such as a genetic counsellor can help you clarify the key message and point you to useful information to share. It may also help to think through different reactions or scenarios, so you feel more prepared if the conversation becomes emotional, defensive, or unexpectedly difficult.

If you would like more support preparing for different family situations, see **communication guides and templates**.

Step 6: When reactions are hard

"Those reactions are often coming from fear, not from a rejection of what you're saying."

People respond in different ways. Some may feel grateful or relieved. Others may seem quiet, overwhelmed, angry, dismissive, or not ready to take it in.

"Seeing those reactions can be painful, especially when it took a lot to say it. But a hard reaction does not automatically mean you did the wrong thing."

What may help in the moment:

- **Pause, rather than push harder.**
  - Sometimes giving the conversation space can help everyone process what has been said.
- **Come back to the key message.**
  - Try to return to the main reason you wanted to share the information.
- **Remember that you do not have to convince them immediately.**
  - People often need time to take in new information.
- **Leave space for processing.**
  - Not everyone will be ready to talk straight away.
- **Step away if the conversation is becoming unhelpful or overwhelming.**
  - It's okay to come back to it later.

"Sometimes the most you can do is plant the seed and let them come back to it when they're ready."

Helpful words you can use in the moment

If someone starts talking about fault, blame, or what caused this

Quick words to use:

- **"It's inherited, not caused."**
- **"This isn't about fault."**

More to say, if helpful: *"A pathogenic variant (gene mutation) can run in families. It's a bit like family traits that we inherit, such as eye colour, or a parent's smile. We wouldn't say inheriting eye colour is anyone's fault. In the same way, this is something we are born with, not something we cause through our actions."*

If someone asks, "Why are you telling me this?" or "Why bring this up now?"

Quick words to use:

- **"I'm telling you because this may matter for you too."**
- **"The risk is already there whether we talk about it or not."**

More to say, if helpful: *"I'm telling you because I care about you, and because this may matter for you too. We may already have seen a pattern in the family before we had the words for it. The risk is already there whether we talk about it or not. I'd rather share the information than leave people without the chance to act on it."*

If someone gets angry, dismissive, shuts down, or says they do not want to know

Quick words to use:

- **"We don't have to keep going with this right now."**
- **"Take some time with it."**
- **"I just wanted to make sure you had the information."**
- **"I can leave you with something to read if and when you want it."**

More to say, if helpful: *"I know this is hard to hear. We don't have to get into it any further right now. This is a lot, so take some time to process it. I'm sharing this because I think it is important for our family, and because I care about you. I can leave you with some information and resources. You do not have to decide anything right now. It is there if and when you want it."*

Step 7: Protect yourself

"You have to pick your battles. Not every moment is a moment for you to stand your ground. Sometimes you just walk away."

When the conversation starts to drift or is no longer helpful, you might notice:

- The conversation turns into blame, guilt, or finger-pointing.
- The conversation shifts away from sharing information and into conflict or defensiveness.
- The other person is not taking in what you are saying.
- The conversation becomes controlling, alarmist, or overwhelming.
- You feel yourself becoming overwhelmed, shut down, or pulled into an argument.

What may help:

- pause the conversation
- say you can come back to it later
- check in with someone you trust afterwards
- remind yourself that sharing information does not mean managing every response

"It's okay to step back and not carry the weight of their reaction. It's also about protecting your mental peace."

Step 8: After the first conversation

"Go at the pace of the other person, not just your own, and expect that this is not going to be a one-off conversation. It's an ongoing one. It's a process, not a single moment."

The first conversation is rarely the whole conversation. For some people, this may be the beginning of an ongoing discussion. Others may need time to sit with the information before they are ready to talk again or take any next steps.

After the first conversation, you might:

- **Check in again** later if it feels appropriate.
- **Share a resource** they can read in their own time.
- **Suggest speaking with a healthcare professional** if they have questions or concerns.
- **Leave the conversation there for now** and come back to it later if needed.

You do not have to resolve everything in one conversation, and people may process information at different speeds.

"I think early on I may have overestimated how ready others were to receive the information. Just because I had processed it didn't mean they had."

"Having clear, trustworthy information would have definitely made a big difference. Something not too clinical, but written in a way that actually speaks to people's lived realities."

You may find these resources helpful:

- Communication guides and templates
- Communicating with family about genetic cancer risk
- Understanding inherited cancers guide
- Genetic testing in the context of culture and community

If you would like more support, you or your family members may find it helpful to speak with:

- Your GP, healthcare team and **genetic counsellor**
- ICA's genetic counsellor through our **Inherited Cancer Support Service**
- a peer support mentor through our **Peer Support Program**