

Cancer Predisposition: Communicating with Your Child and Others

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Learning Objectives

After reviewing this Guide you will be able to:

- Understand how to share genetic test results and implications with your child
- Adopt strategies for tailoring information to your child's development
- Describe considerations for communicating information with others outside of your family

Introduction

Communicating medical information to your child can feel overwhelming. For any serious topic, parents have a strong desire to say the right thing at the right time. You want to protect your child from some of life's challenging realities in order to preserve their wellbeing. Yet, you carry the responsibility of introducing them to these topics and supporting them as they learn to understand and cope with difficult things. It will feel especially difficult—maybe impossible—to tell your child that they have a condition that can affect the quality or duration of their life. Know that your child's care team, and others, can support you along the way.

Speaking about Cancer Predisposition with Your Child

Although there is no single right time to share genetic results and associated risks, honest communication can foster trust and safety. Limited communication or secrets can create anxiety or misperceptions for children. Children and adolescents who hear about their genetic condition during medical appointments sometimes seek information from other sources (e.g., online) that may turn out to be inaccurate or misleading. As a result, they may experience even greater levels of anxiety or, worse, mistrust.

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It can be helpful to view discussing genetic cancer risk with children as an ongoing, evolving dialogue rather than a single event. Not all details of genetic cancer risk need to be shared at once. In fact, sharing a lot of information at once can be overwhelming for both children and adolescents. It may not be the level of detail discussed that is important but rather establishing a foundation of openness to discuss their genetic risk and medical care. This openness allows children and adolescents to feel comfortable returning to their parents with questions.

Consider Your Child's Age and Development

Disclosure and discussion of genetic cancer risk should balance the child's developmental stage with honesty and transparency. Take into consideration how your child tends to respond to new medical information. Because a child's capacity for understanding genetics and cancer predisposition evolves over time, many parents find it helpful to present information as a series of dialogues tailored to their developmental status and life stage.

For example, parents of children found to have genetic risk at a young age may start with simple wellness concepts (e.g., "The goal of today's visit is to keep you healthy", "They're taking pictures of your brain [MRI] to keep you healthy"). It is helpful to ground surveillance or medical information in things children already know or are familiar with, such as doctor or dentist check-ups. If children have a history of cancer or a family member also undergoing surveillance for the same genetic condition, it can be helpful to build on established language or familiarity with medical procedures (e.g., "Kind of like when they take pictures of your brain, this doctor is going to take pictures of your tummy so we can keep your tummy healthy too", "You know how mommy goes to the doctor to make sure my body is healthy?").

As children get older and progress in their capacity to understand complex medical and abstract concepts, they benefit from gradually increasing the scope of topics discussed, like genetics, cancer risk, and inheritance. As adolescents approach early adulthood it is also important to balance educating of their genetic risk with fostering their developing autonomy. Consider taking a step back and empowering your adolescent to actively participate in genetics and medical appointments. Hearing your child speak can help you gauge your child's understanding of their care while you are still present to advocate for them.

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Like all parents, you may grapple with an innate desire to protect your child. Your understandable impulse may impact when you choose to communicate about genetic risk and the emotional tone of the conversation. While using jokes or focusing only on the facts may be comfortable for a parent, having honest and direct discussions about potentially scary topics, about uncertainty and ambiguity, is an opportunity to model coping strategies.

At the same time, it is important to assess your own emotional adjustment and seek support as needed. Keep in mind that communication is a two-way street. Children, adolescents and young adults sometimes seek to protect their parents if they are concerned that discussing certain topics will be emotionally upsetting.

Barriers to Communicating with Your Child

You do not have to be a genetics expert to communicate with your child about their results. Remember, you have an entire care team to help you navigate these conversations. In fact, not knowing the answer to your child's questions when discussing cancer predisposition can provide an opportunity to model how to seek answers. You might suggest making a list of questions to discuss at upcoming medical visits, contacting a provider to ask questions or using previously provided resources to look up information.

Communicating with Siblings

Sibling communication is also vital. Parents often face difficult questions, such as “Why do I have to get more MRIs than my sister?”. Providing a supportive holding space where siblings can name and normalize a wide range of emotions is essential across all ages and developmental milestones.

Communicating with Others

Finally, navigating communication with peers, romantic partners, and schools presents unique challenges. Know that disclosure of your child's healthcare information is deeply personal and it is up to you and your family to decide when and to whom you disclose.

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That said, children may struggle to explain why they need frequent medical appointments when they are not sick. They may need support deciding how to respond to questions from others. Determining how much information to share in these settings is largely contingent on the child's specific relationships with peers, child preferences for information sharing, and the potential impact on their academic and overall school experience.

Adolescents frequently have questions and concerns around when and how to disclose genetic cancer risk to romantic partners. Children and adolescents may benefit from planning what information they feel comfortable sharing and role playing this disclosure. Research also suggests that adolescents with cancer predisposition think about passing risk to their own children and worry about their children developing cancer, which may be further complicated by challenges with fertility following cancer treatment.



Conclusion

Speaking with your child about these topics can be daunting. Know that you can seek support from your child's care team. Pediatric palliative care clinicians, genetic counselors, psychologists, psychiatrists, social workers, chaplains, and child-life specialists have training to help you determine when to speak with your child and what to say. They can also support you with your own emotions as you face this new information.

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