

INHERITED CANCERS

Delaying any talks can be very distressing for you

Your kids get the opportunity to explore and correct their misconceptions about the genetic risks or update their knowledge to reflect their developmental stage

Research shows that children who know about a genetic diagnosis often cope better emotionally

TALKING TO YOUR KIDS IS GOOD BECAUSE

Children naturally look for the positives and rarely let a condition become a central focus in their lives

It prevents any worry that the children will find out by chance, for example by overhearing conversations

Your kid can understand why you might be having risk-reducing treatment or screening tests

WHEN TO TELL YOUR KIDS

Most inherited cancer genes do not increase the risk of cancer until adulthood. This can make it harder for you to decide when to tell your children there is an inherited cancer gene in the family.

There is no perfect age, but family experiences and current research suggest it is best for children to learn about a genetic condition gradually throughout childhood.

Young children's understanding is more limited but they can be more accepting because they have less insight and fewer experiences to draw on.

Teenagers may have a better understanding but may be upset to discover that this information was kept from them up until this point.

Some people may say to wait until the child asks questions but unless they know that their parent has an inherited cancer this is unlikely to be a question a child will ask spontaneously.

Talking about a genetic condition is an ongoing discussion rather than a one off conversation.

Expect to need to give information more than once.



CHILDREN'S UNDERSTANDING

UP TO 7 YEARS

Begin to understand there is a biological relationship between parent and child – same eye colour for example.

8-11 YEARS

Most understand the idea of hereditary in terms of a disease being passed down through the family.

12-14 YEARS

Most understand hereditary and that if their parent carries a gene alteration, this may affect them as well.

15-17

Understand that they may carry a gene that could affect their health and begin to realise that implications for their own children. At this age, they may start to consider genetic testing themselves.

18+ YEARS

Realise how it might influence their future, personal relationships and how their decisions relating to genetic testing had impact on other family members.



HOW TO TELL THEM

Children and most young people think parents should be the main people to provide genetic risk information.

Keep it simple. Give small amounts of information at a time.

Take into account their age and individual developmental stage. Use appropriate language.

Check the information they already have about genetics and inherited diseases

Check their understanding and correct any misconceptions as you go along.

Think about creating a family story and using this as a springboard for discussion throughout childhood.

Go at the child's pace – learning about a genetic diagnosis and becoming aware of the implications is a process that takes time.

Make the conversations informal, discuss while doing something else with your child, for example, when driving somewhere in the car, when cooking a meal together or playing a game.

Where possible answer your child's questions as they arise.

Remind your child that they may find it easier to write their questions instead of asking you face to face, or ask another person they trust.

Genetics is a complex topic, and the information can be confusing – have resources to hand.

Ensure there is opportunity for continued discussion. For example, discuss information young people may see on the internet or in newspapers or on television.

Encourage your child to ask questions and answer as truthfully as possible. You don't have to have all the answers, you can learn together with your child.

Tell your child that it is OK to talk to you about this any time they want to. By saying this to them you are giving them permission and saying that this is not a taboo subject.

If you are struggling to them or answer their questions, think about contacting your local genetics centre to arrange an appointment for you and your child.

Give them permission to talk about their emotions, and give reassurance that they are not alone.

It is helpful to encourage and support your children to make their own decisions about genetic testing and making a decision that is right for them.

Your teen might like to meet with a healthcare professional, such as a genetic counsellor, to discuss the genetic diagnosis and the implications for them. You can request a referral for genetic counselling from your GP.

Children can sometimes get confused about what carrying a gene alteration means. Reassure them that carrying a gene alteration is not the same as a diagnosis of cancer.