

Talking to children and young adults about a BRCA gene change in the family

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Inheritance is
random

- ❖ 50% chance of passing it on
- ❖ boys and girls

No increased
risk of cancer
during
childhood

- Most parents report feelings of worry for their children
- And guilt about potentially passing this on
- Children are not at an above risk of developing cancers during childhood
- Having a BRCA gene change does not mean you will get cancer

What questions will my children ask? Will I be able to answer them?

How and what should I say? What words should I use?

I feel guilty about my children having to deal with this, I don't want to take away their innocence

I am honest with my children and I don't want to have secrets

Should I tell them all together?

Why tell my young children when there's nothing they can do about it now?

One of my children worries about health issues

Do I have enough information? Do I know enough scientific information?

How will they react? Will telling them traumatise them? Will they resent me?

I am struggling to cope with the information myself – I don't feel able to face this right now.



What helps children?

Benefits of talking to children:

- ❖ In general children cope better with a shared reality and understanding
- ❖ Helps children understand what is going on rather than trying to make their own sense of things
- ❖ Children feel valued and respected by parents which helps them cope better
- ❖ Provides an explanation about cancers in the family
- ❖ Can provide reassurance and relieve concerns

References:

Metcalfe A., et al., 2011

Patenaude AF, and Schneider KA., 2017

Helpful to know

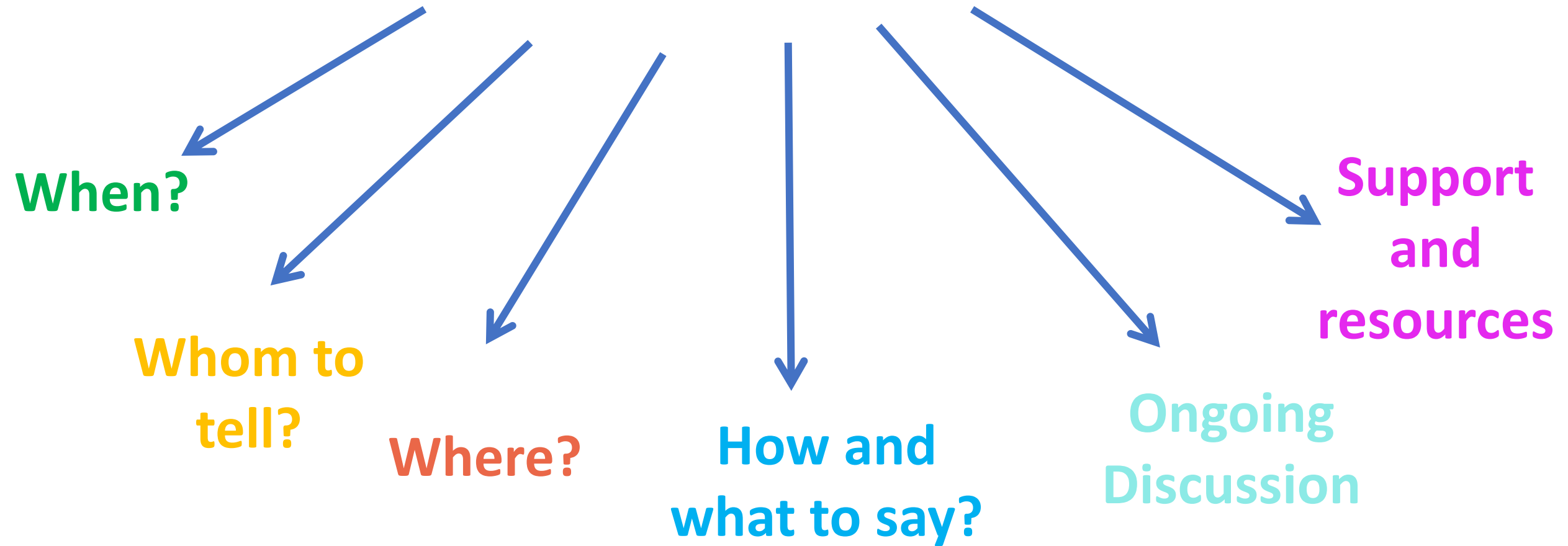
Research suggests that most parents report that their children were not concerned following the discussion of parent's BRCA result

Bradbury et al., 2012

Parents have reported that typically they have not experienced upset or disruption in their relationships with their children

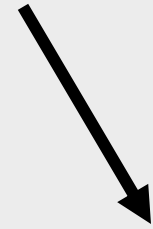
Patenaude and Schneider 2017

Preparing to talk to children



When to tell

Am I ready to tell?



Am I confident and comfortable in explaining the medical and genetic facts?

Am I emotionally prepared?

When to tell

Are my children ready?

- ❖ What age to tell?
There is no right answer for a '*suitable*' age.
- ❖ Consider each child's ability to understand.
Age and developmental stage will influence understanding
- ❖ Consider each child's potential reactions and response
- ❖ What else is going on for my children?
e.g Exams, school etc.

When to tell

**What is going on in our lives
and how does that impact on
when to tell?**

Possible consequences while information is not shared

Possible consequences

- ❖ Burden of keeping a secret
 - talking can be a relief and easier than secrets in long run
- ❖ Accidental disclosure
 - Children may find out accidentally through overhearing parental conversations or from relatives
- ❖ Children may worry and feel left out
 - Children may observe changes in parent's behaviour/feelings
- ❖ Unplanned discussion
 - Children may raise a question at any time

Whom to tell?

One-on-one



OR



Children all together

Anyone else present?

Where and time of day?



- ❖ Try to take naturally occurring opportunities
- ❖ Consider where you have your best conversations with your children
 - driving,
 - gardening,
 - cooking,
 - on a walk,
 - tidying bedroom
 - around the dinner table
- ❖ Timing:
Consider when is a good time of day for your child/children

Preparing how and what to say

**Anticipate children's
reactions and questions**

**Recognise each
child's
understanding,
needs,
strengths
vulnerabilities**

**Think about own
strengths, coping
and reactions to
telling**

**Think about how you've
talked about other
important/difficult issues in
the past**

**Family communication
style**

**Think about
what child
already knows**

Drip feed approach

- ❖ **Gradual process**
- ❖ **Providing small amounts of age-appropriate information gradually is likely to help children understand and cope best**
- ❖ **Initial conversation *'opens the door'* for further discussions through-out childhood in stages directed by the child's questions and needs**

Communication tips

❖ Be open and honest

❖ Language

- Keep it simple
- Use clear age-appropriate language and terms
- Use correct medical terminology
- Give the gene its name - BRCA gene

❖ Questions?

- Encourage children to ask questions – respect child if doesn't want to ask questions; may ask days or weeks later
- Check what they really want to know
- Honestly respond to children's questions – say if you don't know the answer

❖ Follow children's cues

- Be guided by their informational needs

Communication tips

❖ Emotions and feelings

- Acknowledge and normalise children's emotions and reactions
- Explain parent's behaviour if anxious and upset

❖ Role model for children

- Children will learn from what you do- will look to see how you are coping with information

❖ Check understanding

- Children's understanding is different
- Check each child's understanding and explore misconceptions, misunderstandings.
- Children can worry about upsetting their parents
 - may not ask if they don't understand
- Discuss information they have from internet, school, newspapers

❖ Check impact of information

Communication tips

- ❖ **Body language**
 - Look at child's body language
 - Children will pick up on body language and tone of voice
- ❖ **Provide reassurance and positive emphasis**
- ❖ **Support and guide decision making**

Support and resources

❖ Support

- Peers – such as relatives in similar circumstances may be helpful
- ‘Someone like me’ Service (Breast Cancer Care)
- BRCA support groups
- Genetic service – BRCA carrier clinic

❖ Resources for further information

- A beginner’s guide to *BRCA1* and *BRCA2*
- Information about how to talk about genes and mutations
 - Jeans for Genes website
<https://www.jeansforgenesday.org>

Each child is different and every family is unique in their values, beliefs, issues, needs, experiences, circumstances and strengths

Genetic counsellor's role

BRCA Carrier clinics at St George's
Hospital and The Royal Surrey County
Hospital

Future research

- ❖ What would have helped you most to talk to your children?
- ❖ What advice would you give to another parent?

Acknowledgments

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