



genetic alliance  
australia

# SIBLINGS

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Filling the Void Seminar

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# Diagnosis of a Genetic Condition



# The Journey:

We're all in this together



# Issues

- The sibling relationship will usually be longer than any other relationship within the family.
- Young siblings are prone to feeling responsible for their sibling's and their parents' well-being.
- Siblings often feel a sense of responsibility for their sibling beyond that felt by their peers.
- Siblings may assume guardianship for their brother or sister when their parents die or are no longer able to care.

# Some points to consider

- Sibs often develop a range of admirable personal qualities and feel enriched by growing up in their family
- Some sibs are more tolerant and understanding of individual differences
- Some sibs take great pride in their brother or sister's achievements
- Some sibs go on to work in helping professions

# Concerns Siblings May Have

- Siblings grow up with much stress but do not have the coping skills to deal with their experiences.
- Various fears, anxieties
- May worry that the condition is contagious, or was caused by something they have done
- Older sibs are probably concerned about their own reproductive future
- Fear that they will be expected to take over care of their brother or sister as an adult
- Feel anger, embarrassment, guilt
- Feel the need to be the “good child”, to achieve - and then feel guilt about their abilities

# How these concerns might affect children

- Withdrawal
- Anxiety
- Lowered self-esteem
- Act out feelings with aggression or attention seeking
- Develop sleep problems or physical complaints, self harm
- Social difficulties

# Siblings need:

- Information about the special needs
- Opportunities to express feelings
- To feel special themselves, and valued
- Strategies to deal with difficult situations
- Contact with siblings in a similar situation
- Social support



# Comments from sibs

*Some concerns mentioned by siblings include:*

- Feelings of isolation
- Lack of information
- Attention
- Anger and resentment
- Guilt



# Comments from Sibs

- Pressure to be perfect
- Grief and sorrow
- Independence
- The future



# Comments from sibs

## What is it like to be a sibling?

- “Sotovf harde” (sort of hard)
- “My brother makes me happy”
- “They get all the attention”
- “Good sometimes”
- “I wish I was the only child”
- “Fun”
- “How come HE never has to wash up?”

# How can we help our kids?

- ▶ One:one time with parents
- ▶ Encourage own interests
- ▶ Source age-appropriate information and peer support for them through:
  - #Genetic counselling
  - #Other siblings with the same or different conditions
  - #Condition-specific support groups
  - #Genetic Alliance Australia

# Give Siblings opportunities to build their own support networks



- Friends
- Other special needs siblings
- Family - cousins, aunts, uncles
- Interest groups
- Sport
- Drama
- Play dates at home and outside the home
- Time and space to just “be”

# Supporting Siblings

Build a resilient family through:

- Communication
- Making time a priority
- Keeping perspective
- Building support networks
- Seeking professional assistance
- Respite



# Allow siblings to express their feelings



# Fact:

- Most children will cope better with stress if they feel listened to and understood



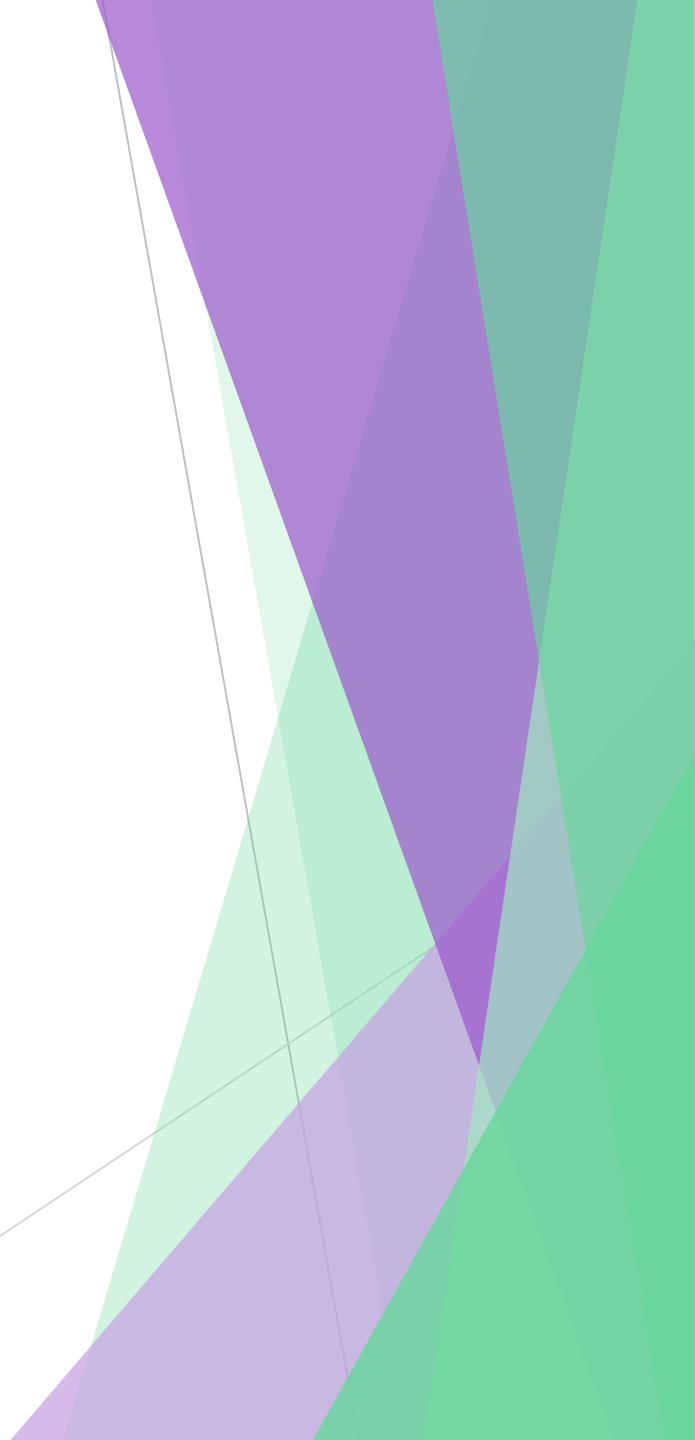
Celebrate!



# Positive Outcomes

- With support the whole family will function more positively
- Siblings are more likely to develop strength, tolerance and responsibility.

Supportive  
relationships  
as  
adults...where  
every  
member of  
the family  
recognises the  
value of the  
others



<https://www.sbs.com.au/ondemand/video/981972035757/insight-sibling-carers>



# Thank you

- Siblings Australia - [www.siblingsaustralia.org.au](http://www.siblingsaustralia.org.au)
- Carers NSW - <http://www.youngcarersnsw.asn.au>

Genetic Alliance - Filling the Void

[www.geneticalliance.org.au](http://www.geneticalliance.org.au)