



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!



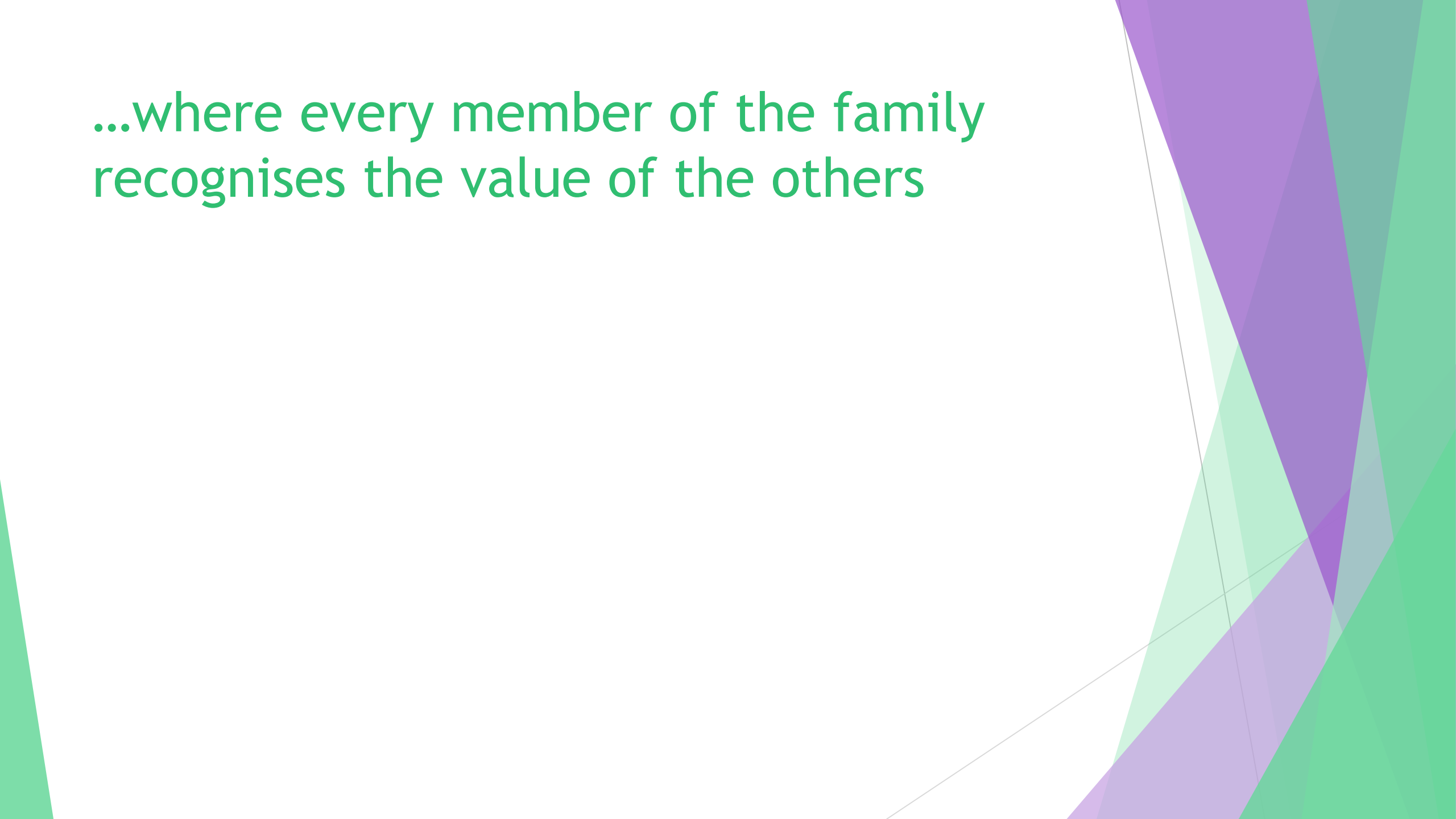
Positive Outcomes

- 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>



Movie recommendation:

Wonder - Julia Roberts & Owen Wilson

The film follows a child with Treacher Collins syndrome trying to fit in. It explores issues from many perspectives, including that of a sibling.

Thank you

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

Genetic Alliance - Filling the Void

www.geneticalliance.org.au