



Possible Effects on Siblings who have a brother or sister with Kabuki Syndrome

By Kate Strohm - Siblings Australia

Many siblings of people living with disability are enriched by their experiences. But many also face challenges. It is relatively easy to support siblings, so that they can feel much stronger in dealing with their experiences and, in the process, develop a range of positive qualities. NOT ALL siblings will experience all of the following but some of the concerns mentioned by authors, parents and siblings themselves include:

Feelings of isolation

Siblings can feel isolated and different from those around them. They may be unable to interact in the usual way with a brother or sister with Kabuki Syndrome. Their life often seems different from that of their friends. They may lack understanding and develop fears and worries. At home, they may be trying to be special, to be noticed, to be valued.

At school and in other social settings, they may be trying to be like everyone else, not to be different or stand out from the others. Most times it is difficult to talk to friends about what it is like to have a brother or sister with disabilities, as they feel their friends may not understand. Also it may be difficult to talk to parents – they may not want to bother parents who are dealing with other problems and they can feel guilty for complaining.

Lack of information

This can lead to misunderstandings about the disability and fears that they have caused the disability or that they too will develop special needs. They may struggle to explain the disability to others.

Relationship difficulties with brother or sister

It may be impossible to give and receive affection, play together and share other aspects of a sibling relationship with the child with special needs. There may be disappointment, frustration, fear or guilt, but at the same time, intense sorrow for what their brother or sister is going through.

Attention

Often siblings consider their feelings do not matter to the rest of the family. A child with a disability or chronic illness may require a huge amount of attention and energy from parents to ensure they get the necessary care. As a result, young siblings can feel left out or even neglected. They often perceive the needs of a brother or sister as being more important. This can lead to difficulties in the bond between a primary caregiver and a sibling, causing a child to lack confidence in that relationship and in their own self-worth.

Anger and resentment

This builds up when family routines are disrupted and when the child with special needs is treated differently. Not only does the child with special needs receive more attention but sometimes he or she is allowed to behave in ways the sibling is not, eg. acting out or breaking family rules, and it all seems so unfair. There can be anger at the child with special needs and parents, but also at other people outside the family whose reactions cause a sibling to feel uncomfortable. Siblings may feel guilt because they do not have special needs ('survivor guilt'). There can be guilt about their own successes when they see a brother or sister struggling with basic living; about typical sibling conflicts; and also shame about the negative feelings they experience toward a brother or sister.

Pressure to be perfect

Siblings may feel they have to be perfect, to be successful. This may be because they are trying to gain attention or they may want to be the 'good' child, to not 'make waves', in order to protect parents from further distress. They may worry about how parents are coping. They may also feel they need to achieve in academics or sport to make up for the limitations of the child with special needs.

Care giving and responsibility

Some children take on significant responsibilities. In some instances this can be very healthy, as children develop skills and a strong sense of their own competence. It can really add to a child's self esteem. However, sometimes these children feel they have no choice or they are attempting to appease the guilt they feel, or win parental attention or praise. In the process, they can miss out on the usual socialising activities of their peers. For some siblings, it can be difficult to participate in outside activities. It may be that parents are too stretched for time or the special needs of a child may be too unpredictable for parents to feel able to fit in regular commitments like ballet classes, sport or music lessons. The child can feel huge conflict between caring for a sibling, feeling guilt and resenting missing such activities.

The mix of sibling experience

Most siblings of a person with a disability will be able to say there were good and not so good aspects to their experience. Those who can look back and see benefits in their situation say they have found inspiration through their brothers and sisters, become more tolerant, more compassionate, more aware of their blessings and, in many ways, more mature than young people who have not had these experiences. They say growing up with their brother or sister gave true meaning to their lives, that “they made me who I am”.

Finding the positives

As mentioned earlier, many siblings are able to take very positive things from their experiences. They can gain inspiration, competence and independence leading to improved self esteem, and a range of human qualities that add not only to their own life but also those around them. They often contribute to the community in very useful ways.

In terms of resilience, when children go through difficult experiences, are given support, and learn skills to deal with their difficulties, they are able, in fact, to become stronger adults.

Some positive effects that can manifest in siblings, mentioned by families and practitioners, include: being more tolerant of differences, more compassionate, more reliable and responsible, high achieving. Many siblings also go into helping professions, pride in brother or sister’s achievements, more insight, maturity.

Support for siblings allows them to feel less isolated and it helps them build resilience. As a result, not only are they more likely to develop to their full potential, but also their relationship with a brother or sister with special needs is likely to be stronger.

More information

What can we do as parents?- by Margot Schmiedge

As parents, we are not able to, nor should we, shield our children from all life’s adversities. We can, however, take steps to minimize negative impacts.

- A certain amount of negative emotion on the part of siblings is very normal. The negative emotions themselves are not ‘wrong’. They can actually propel maturity and action. As parents, we must be willing to talk about them, to not necessarily wait for others in the family to approach the subject but to frequently initiate open discussion, both formally and informally.
- Each child in the family has needs that are separate from the child with Kabuki. It’s important we look for opportunities to spend with each child with undivided attention. Sometimes this means we need to schedule time for one-on-one opportunities, other times it may simply be taking advantage of spontaneous moments.
- Various cultures will have different viewpoints on who participates in the care for the individual with Kabuki in adulthood. Although as parents we hope that our other children will be involved, and in many cases, they want to remain involved, it should not be conveyed as an expectation. It is unrealistic and unfair to expect a sibling to take over the care of the person with the disability at the expense of their own life. It is important we don’t factor in this assumption when planning for the future of our child with Kabuki Syndrome.
- We allow our other children to have interests that do not necessarily include the child with Kabuki Syndrome.
- As parents we need to remember that our marriage comes first. Too often families become all-consumed with the child with special needs, and fail to nurture their marriages. A stress-filled relationship with one another will have a greater negative impact than dealing with disability.
- Ultimately, balance is the key. We invite and involve the siblings of the child with Kabuki to participate in the care, visits to hospital, etc, while at the same time we respect their feelings and recognize that their lives are uniquely their own.

Support Groups

Siblings Australia is a unique national organisation committed to providing support for brothers and sisters of people with special needs, <http://www.siblingsaustralia.org.au>

SAKKS SIBS: A support group for brothers and sisters who have a sibling with Kabuki syndrome can be found on the SAKKS website.