

Siblings – a guide for parents

By Sharon Baker



“Siblings play a critical role in our lives. Brothers and sisters know us like no-one else. They have been with us during the good times and the bad. Siblings constitute our first social network, and their early influence affects us throughout our lives. Our sibling relationships are typically the longest relationship we will have in life. With all its importance, seldom do we take time to consider this relationship; seldom do we take time to recognise it; seldom do we take time to celebrate it.”

‘Brothers and Sisters –
A Special Part of Exceptional Families’

T. H. Powell and P. A. Gallagher

Introduction

My daughter is four years older than her brother who has Arthrogyriposis. Before my son’s birth I had prepared my daughter for the birth of a baby brother or sister. I had prepared her for the fact that a little baby would come along and take up a certain amount of my time and attention.

On my son’s birth I asked that his sister remain in the hospital at least for the first night. She was in need of support, she needed answers, she needed them put into a context she could understand, she needed them put in a way that she could cope with. As a parent I had the responsibility of two children and I felt the first days would be crucial if my daughter were to form a positive attitude towards her new extremely contorted and ‘different’ brother.

Ironically, I had given my daughter a new born baby doll as a present on her brother’s birth – already bought and wrapped up, so that we could do together what mummies do with their little babies. But her little baby did not look very much like mine, and this ‘perfect’ bundle of plastic probably accentuated for her the fact that her new brother was apparently very different to most babies.

I like to think that my daughter did come to terms with her new and unexpected situation. She seemed to cope with all the hospital appointments; she seemed to cope with the extra attention that had been taken away from her. She most certainly learnt to accept her little brother. She most certainly loves him dearly, perhaps even more than if he were not disabled. But I believe that neither I, nor she, will know quite how well/badly we have dealt with things as a family until she is much older.

I know that through stress, strain, exhaustion or ignorance I have sometimes dealt with 'sibling issues' badly and inappropriately. There will certainly have been occasions when I was not even aware of just how badly I have managed a situation because my daughter, like many other siblings, wants to protect her parent as much as she does her brother.

It is important to recognise that we all get it wrong sometimes and that we must not be too hard on ourselves. Also the nature and intensity of a sibling's individual needs and worries will vary considerably. Some siblings have few issues, others many, and each family's response will be different. This booklet offers suggestions on how to support siblings of brothers or sisters with Arthrogyrosis. By no means will all points be appropriate for all siblings and every family.

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Each sibling of a disabled child is a member of a unique family system and the immediate and future influence that the sibling with disabilities will have on his or her brother or sister will differ according to a number of the family's individual characteristics. Nevertheless, many of the special concerns and unique needs of siblings are universal. Siblings typically discuss the same feelings and emotions, joys, fears and problems, whether their brother or sister has a physical disability, learning difficulties or behavioural problems.

Common issues for siblings of children with disabilities:

Positive

- love for their brother or sister
- maturity beyond their years
- heightened awareness of issues such as disability rights and equal opportunities
- togetherness as a family
- pleasure at sibling's achievements
- learning new skills to help sibling
- meeting with other siblings
- taking part in different activities e.g. integrated play schemes
- developing patience and tolerance
- more caring, protective and proud
- compassion and empathy

Negative

- feelings of loss and isolation when a parent's attention is consumed by the disabled child
- finding it difficult to play with brother or sister
- embarrassment caused by being 'different' from friends
- feeling uncomfortable about bringing friends home
- feelings of guilt about having caused the disability – especially if a sibling twin
- feelings of guilt because they have been spared the condition – especially if a sibling twin
- jealousy and resentment when the disabled child is the focus of the family's attention
- teasing or bullying by peers
- not understanding the disability – siblings often believe they can catch it or can pass it on to their children even if it is not an inherited condition
- feeling unable to explain their sibling's disability to others: how/why...
- limited family activities – access to public/private buildings; public transport issues...
- sadness
- concern about responsibilities and fears about the future
- being left out when parents and professionals do not share information about the sibling's condition
- perceived pressure to achieve
- not feeling loved
- angry at personal space being invaded

The things siblings say...

Having a brother or sister with additional needs is a bit like having a new born baby who never grows up... Your parents are constantly busy attending to his or her needs. Time to just talk to your mum or dad, which every child needs, is an impossible luxury...

Brothers and sisters of children with a disability are often forgotten and they need support too, just like their parents...

The issue of fairness is difficult. It is hard to make it 'fair' when one child demands so much more attention, time and patience. Sometimes the non-disabled child gets disciplined when the one with special needs does not...

Most of us feel we are different people because of them, that we're more understanding and sensitive than we would have been...

There's this tremendous sense of loss in a family like mine. Often it's something you haven't had the chance to work through because, quite simply, everyone else in your family is too busy dealing with their own emotions to help you with yours...

I remember once crying my eyes out because I wanted them, and no-one came. I suppose they knew I was fine really, but I'd seen how my sister always got their attention when she cried, and I didn't understand why it didn't work for me...

I wanted him to have the chance to live on his own and to work, and I wasn't sure whether he'd have them. And I wondered, too, about who would care for him when my parents got old...

I love my brother very much – we're very close, and I can't imagine him not being around. All I wish is that I'd had someone outside my family to talk to while I was growing up. It wouldn't have solved all the problems, but it would definitely have made a difference...

Life Stages

Certain issues are particularly relevant for siblings at different stages in their lives. These will vary from one child to another and will be affected by each family's own circumstances.

Pre-school age children

- less time and attention from parents
- feeling jealous of their disabled sibling
- anxiety through not understanding a brother or sister's condition
- frequent absence of parent and child for hospital stays or visits

School age children (age 5–12)

- talking to friends and others about their brother or sister
- dealing with teasing and embarrassment
- being involved in caring
- needing information
- not having enough time together as a family
- wanting their sibling to have his/her own friends

Adolescents (age 12-18)

- dealing with embarrassment
- influence of their sibling's disability on their future career
- having space and opportunity to develop their own life
- concern about their brother or sister's future
- concern about how much responsibility they want or have to take on for their sibling's care in the future

Siblings' Special Concerns

Studies about siblings of disabled people have tended to report a mixed experience. It is often a close relationship but there can be some difficulties. Sibling relationships in general tend to be a mixture of love and hate, rivalry and loyalty. In one study a group of siblings of disabled children were reported as having stronger feelings about their brother and sister – either liking or disliking them more – than a matched group did about their non-disabled brothers and sisters.

Siblings need...

...information

Information about the disability and its implications are crucial. By providing information siblings will have a clear understanding of their brother or sister's disability and their needs. This information must be accurate and honest and explained in a way that the child will understand. Information should be given from an early age and should be ongoing. Without this information siblings may blame themselves, blame their parents, get garbled stories from their friends, give garbled stories to their friends and even to their disabled sibling. They also need to be able to answer questions about their brother or sister, their family, themselves. TAG produces 2 information handouts that might be useful:

- i) About AMC – a guide for older children;
- ii) A guide for parents on talking to children about Arthrogryposis.

...to feel included

Children have a greater sense of being included in the family and in the care of their sibling with additional needs if they are well informed. Over protection from information often leads to siblings feeling left out and isolated.

...to be listened to and to be heard

Children need to be encouraged to express their feelings and anxieties from an early age. Children often find it difficult to be open and frank with their feelings, and sometimes this is because they are frightened of adding to their parent's concerns. It is often necessary to 'read between the lines' in order to really hear what a child is saying. It is also important to look for 'messages' in a child's behaviour. Communication is very important. As children are so often unable to discuss their feelings and anxieties when specifically asked, allow them to choose their own time and pace. Be flexible.

...space

Older siblings particularly need space and privacy.

Siblings also need...

...individual attention

Individual time for siblings is important, whether within the family environment or outside.

...contact with other siblings of children with disabilities

Support groups are one way in which siblings can meet other children in the same position. Please see back cover. Such contact can encourage siblings to express their feelings and to accept the disability. If there are no support groups in the area, contact through letter or internet can be equally as supportive.

...support in learning how to cope with situations

Siblings routinely face problems that are not experienced by other children. Defending a brother or sister from teasing, responding to questions from friends and strangers, coping with the lack of attention or high expectations from parents are just a few of the problems siblings may face.

... to be like 'everyone else'

The need to be like 'everyone else' can be a common theme for siblings who do not want to be singled out or regarded as special in any way. Siblings need ordinary networks in the same way that the disabled child needs networks extending beyond the family

...to be involved in decision making

Siblings should have a voice too, as they may have clear opinions about the care for their brother or sister.

...to feel free of responsibility

Siblings need to be able to make choices for themselves that are not based on the needs of their brother or sister. Whilst it is important that siblings feel included and involved in the care of their brother or sister, they should not feel compelled to help. Older siblings often worry about who will care for their brother or sister if their parents are no longer able to do so.

... a raised awareness of disability issues

Schools are often a good starting point to raise awareness in society in general of disability and its implications. This can promote understanding and encourage acceptance.

Most importantly...

...siblings need to have fun and the opportunity to be children

A parents checklist

- give your child accessible information about the disability and help them to make sense of it
- help them to be able to give explanations to others
- be aware that they worry about brothers and sisters AND parents
- spend quality time alone with your child
- teach them coping skills
- give them chance to talk things out – not necessarily with parents
- involve them in the life of the disabled child without expecting them to be a carer
- protect their personal space
- don't hide the disability away
- be sensitive to siblings who withdraw as they probably need more attention
- try to make the problems of daily living, and the difficulties of coping, open for discussion so they can tell you honestly about how they feel
- don't suppress your own feelings
- cry with them if necessary
- allow them their negative feelings
- set time aside just for them
- be conscious of their needs
- be open about difficulties
- let them have a life apart from disability
- if possible try not to split the family up too much
- don't make promises you can't fulfil
- plan ahead – 'in one month's time we'll...'
- don't be afraid of respite – be prepared to let go a bit
- link up with other families
- don't be afraid to seek outside help when things start to get tough

Parents are already short of time and energy and mustn't feel that they have to handle everything alone. TAG has hundreds of member families and different ways in which it can help link them up: an email list; a national newsletter; some regional and a national meeting each year. Also, any of the agencies a family is in touch with can play their part in supporting siblings, whether health, social services, education or the voluntary sector.

Helping siblings to develop self esteem

"Self esteem is the ability to see oneself as capable, competent, loveable and loving, unique and valuable"

Siblings should...

- be allowed to take the lead
- encouraged to talk to others about their strengths
- allowed to talk about their caring role to others outside the family
- have their skills acknowledged
- feel valued when they have done something well
- encouraged to join a club or group that doesn't involve their brother or sister
- have time at home to themselves
- be allowed to make mistakes

The following may contribute to lower self-esteem in siblings:

- feeling different to other children
- parents arguing in front of them
- being laughed at
- being talked about outside the family
- feeling their needs are not important
- not having time or opportunity to make friendships and build relationships

- not being given time to talk about their feelings
- not having opportunities to learn new skills or to become competent at something outside the family
- being seen only as a carer
- worrying about being blamed when things go wrong
- being isolated and feeling ignored
- being taken for granted
- feeling responsible

The higher the self-esteem, the more resilient the sibling will be. The lower the self-esteem, the more vulnerable the sibling will be...

Help siblings learn to:

- build and sustain friendships
- manage their own emotions
- recognise their strengths and weaknesses
- understand the value of co-operation and sharing
- be assertive without being aggressive
- take responsibilities for their own actions
- manage new situations and experiences
- not feel threatened
- feel valued

Bullying and teasing – help your child to cope by:

- encouraging them to talk
- making a list of what to say when bullied or teased
- using role play
- saying 'no' in the mirror
- practising confident body gestures
- drawing and writing about feelings
- eliminating obvious causes for bullying
- building up self-esteem

Twins

Where the sibling is the twin of a child with Arthrogyposis, there may be even more issues to address. As with many non-twin siblings, the sibling is likely to feel guilt about not having the condition. However, on learning that, whilst in the womb, he or she may have been the 'dominant' twin and that this may have caused or contributed to the brother or sister's Arthrogyposis, his or her feelings of guilt could be even stronger.

If the twins are 'identical', the sibling of the child with Arthrogyposis is likely to become conscious of the fact that he or she is what his brother or sister 'should have been'. "If he/she didn't have Arthrogyposis he/she would look like me... He/she should look like me." The affected twin may make a comparison between their physical appearances too. Similarly, it will probably occur to the sibling that he/she can do many things that the affected brother/sister can't.

This in itself may heighten the feeling of guilt. Realising that the affected twin is also aware of this, and perhaps jealous, can add further to a sibling's emotional unrest.

Support from Professionals:

Increased awareness by professionals of the other children in a family, and recognition of their particular situation, can help siblings to feel that they are part of what's going on. Some of the ways in which this might happen include:

- professionals speaking directly to siblings to provide information and advice
- listening to the sibling's point of view – their ideas may be different to those of their parents
- trying to understand the particular rewards and difficulties they encounter and how these may affect their daily lives
- offering someone outside the family to talk things over with in confidence
- providing support that is flexible enough to accommodate the needs of siblings as well as the disabled child and their parents

Sibling Groups

One of the ways of supporting siblings is group work. Many groups are started by local professionals working together with the support of parents. Sometimes siblings who live with a brother or sister with a disability are described as young carers and can access support at their local Young Carers' Project.

Princess Royal Trust for Carers

Tel: 020 7480 7788
www.youngcarers.net

Has a website dedicated to siblings/young carers including discussion boards and chat rooms (moderated by adults who have been police-checked), an "Agony Aunt" page for young people's questions plus information on young carers projects around the UK.

The Children's Society

Tel: 0845 300 1128
www.youngcarer.com

Has a website for siblings/young carers with information and advice, links to useful organisations, together with local projects information around the UK.

Sibs

Tel: 01535 645 453 - Sibs Information Line
www.sibs.org.uk

Runs workshops, training and conferences on siblings issues around the UK. Gives support, advice and information for siblings, their parents and professionals, including factsheets for younger siblings.

Siblinks

PO Box 2561 Coulsdon CR5 2YA
www.siblinks.org

National website for teenage siblings of children with cancer, including a moderated website forum for young people.

Sibling Support Project

www.siblingsupport.org

An American-based siblings information website with the opportunity for siblings to make contact with each other. It has useful books and resources for professionals and siblings applicable to the UK.



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