



For brothers and sisters  
of disabled children and adults

## **Supporting siblings of children and young people with Tourette Syndrome**

### **Introductory workshop for parents**

### **Siblings' experiences**

#### **Positives & opportunities for siblings**

- Having fun with their brother or sister
- Feeling caring, protective, proud
- Developing tolerance and empathy for others
- Opportunities for learning new skills
- Being in touch with other siblings
- Surprise benefits – taking part in special activities!

#### **Difficult issues for siblings**

- Not understanding the link between the condition and their brother or sisters' behaviour/communication/moods
- Feeling that they get less attention
- Resentment and jealousy at different rules/rewards
- Feeling embarrassed by behaviour/tics in public
- Feeling that others don't understand
- Worries about Tourette Syndrome being passed on in families

#### **Challenges for some siblings**

- School work and concentration affected
- Being bullied or teased

- Other people's attitudes
- Getting hurt by their brother or sister
- Being a young carer
- Disrupted sleep
- Not being able to do things as a family
- Not enough time for own activities
- Worry about the future

### **Current research on siblings of children with a range of disabilities**

Siblings of children with intellectual and developmental disability overall have a slightly increased risk for problems with their wellbeing and their educational. Some will have no problems at all and others will find things more difficult. Siblings who are likely to have the most problems are:

- Sibling young carers
- Siblings whose brothers and sisters have behavioural problems

Parents, schools and sibling groups can all help siblings become stronger emotionally. This will help them cope better with the more difficult aspects of their family lives.

#### **Siblings can become emotionally stronger through:**

- 1. Making sense of their experiences**
- 2. Having a sense of control in difficult situations**
- 3. Being connected to their peers & supportive adults**
- 4. Having ways of coping with their emotions**

## **Things that help siblings**

### **Regular attention**

It shows you love them too, reduces jealousy, and helps with sibling behaviour. Make it regular, short and fun.

- 15 minutes one to one daily - with your full focus
- You suggest the activity they really like doing with you; attention jar

- Appreciate siblings for who they are as well as for what they do to help
- Let sibling know you are thinking about them when they are not there - postcards/notes/texts
- Reward positive sibling behaviour
- Know about siblings' lives and what matters to them
- Celebrate siblings' achievements
- **Let them go first sometimes!**

### Helping siblings to self-identify

Reduces feelings of isolation and gives siblings a sense of being part of a bigger network/community

- Show siblings aged 7-17 the youngSibs website
- Check out films, TV programmes and books which feature sibling characters
- Look out for celebrity siblings – Jo Whiley (Sibs Patron), Rag 'n' bone man, Alesha Dixon, Lewis Hamilton all have a disabled brother or sister.
- Follow Sibs on social media for regular media stories featuring siblings.

### Top tips for supporting siblings

- 1. Spend time each day with siblings one to one**
- 2. Talk about disability from an early age**
- 3. Acknowledge the negative feelings as well as the positive ones**
- 4. Teach siblings fun activities they can do with their brother or sister**
- 5. Give siblings choice about spending time with their brother or sister**
- 6. Limit the type and amount of care and support that siblings do**
- 7. Take action on issues that affect your siblings' wellbeing and education**
- 8. Talk to siblings in the teenage years about plans for the future**
- 9. Give siblings permission to enjoy and live their own lives**
- 10. Celebrate siblings' achievements.**

## Concern about a sibling

### Signs that a sibling needs more help

- Shows changes in behaviour after a hospital stay
- Keeps asking questions about their brother or sister that you can't answer
- Gets easily annoyed with their brother or sister
- Always complains or tries to get your attention
- Feels very sad or angry or jealous
- Is reluctant to talk to you
- Avoids spending time with friends
- Finds it hard to get homework done or is falling behind at school
- Is being teased or bullied
- Is doing too much care
- Is getting hurt by their brother or sister

### Where to get more help

- Sibs [www.sibs.org.uk](http://www.sibs.org.uk)
- Health visitor; learning disability nurse
- School - teacher; counsellor; pastoral care; school nurse; SENCO
- GP; CAMHS (Child & Adolescent Mental Health Team)
- Young carers worker; sibling support worker
- Sibs Talk primary school intervention ([www.sibs.org.uk](http://www.sibs.org.uk))
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### About Sibs

Sibs is the UK charity for siblings of disabled people. Sibs supports siblings of all ages who are growing up with or have grown up with a brother or sister who is disabled, has special educational needs or a serious long-term condition.

Parent information **[www.sibs.org.uk](http://www.sibs.org.uk)**

YoungSibs online support **[www.youngsibs.org.uk](http://www.youngsibs.org.uk)**

**Email:** [info@sibs.org.uk](mailto:info@sibs.org.uk)

**Tel: 01535 645453**

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