

## SUPPORTING SIBLINGS OF DISABLED CHILDREN

This fact sheet has been written by parent carers for parent carers



Looking after a disabled child can mean that their brothers and sisters get less attention and, when you add to that the extra caring responsibilities that can come with having a disabled sibling, it's easy to see just how important it is to make sure that siblings get the advice and support they need, too.

### Helping siblings to understand a diagnosis

Being honest with your children about their sibling's diagnosis is vital. If you try to hide things from them they can feel very worried about what is going on. When you explain things to them, keep it age appropriate, but answer any questions they have honestly. Remember that children tend to be very matter of fact about things that adults find difficult to talk about. For younger children, you could start by sharing a picture book about the relevant disability. With older children, you could search for information together online. You may find you have to explain the condition to your children several times and they may want to ask you questions.

### Life-limiting illnesses

If your child has a life-threatening or life-limiting illness, try to take some time to find information about their condition so you can explain it simply to their siblings. It is very important that you tell them yourselves – it will be far more distressing for them if they overhear you discussing it with someone else, or hear from another person. Although it is very painful having to discuss these things with your other children, being open with them is important in helping them to come to terms with it.

### Support from others

Long-term, many children and adults say that they have a very close bond with their disabled sibling and that dealing with their disability has taught them to be more tolerant and understanding. Even so, your other children will still need support to help them cope with the situation. They may have very mixed emotions, ranging from feeling like they have to be 'really good' for their parents, to feeling isolated, resentful, or depressed. Try to make sure they have a good support network around them. This could be other relatives or family friends that they can talk to. And if you can, try to find a local support group or a group online where your child can talk to other children in similar situations.

There are books available that deal with what it is like to have a disabled sibling and these can often be a great way to open up a conversation with your child about how they feel. National charity, Sibs, has lots of useful resources for parent carers as well as a dedicated Young Sibs website that's just for siblings themselves. Visit [www.youngsibs.org.uk](http://www.youngsibs.org.uk).

If your other children are at school it's a good idea to make their teacher aware they have a disabled sibling, so that they can keep an eye on them and provide another listening ear if needed.

### Time together

Your other children will also need time alone with you. even if it is just ten minutes to chat, or do an activity, it is important to give them your undivided attention. You may want to find out about short

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breaks for disabled children in your area. Our companion fact sheet on **Short Breaks and Respite** tells you what kind of things are available and how you can get them. And, if you are not eligible for this kind of care, perhaps you can find an inclusive mainstream activity or play scheme that gives you the chance to spend some time with your other children. If you have a social worker, you could also speak to them about using Direct Payments to fund the type of care that suits your family best.

### Ask about

- **Amaze** – the **Special Educational Needs and Disability Information, Advice and Support Service (SENDIASS)** offers impartial, confidential advice on anything to do with special educational needs and disabilities for 0 to 25 year olds. Parents, carers, children and young people under 25 with SEND living in Brighton & Hove or East Sussex can use the service. Email [sendiass@amazesussex.org.uk](mailto:sendiass@amazesussex.org.uk), call **01273 772289** or visit our website at <https://amazesussex.org.uk>
- **Brighton Pebbles** – the parent-run social group for children with SEND aged 4 to 14 also runs regular events for siblings. email: [brightonpebbles1@gmail.com](mailto:brightonpebbles1@gmail.com), call **07506 105265** or visit: [www.brightonpebbles.org.uk](http://www.brightonpebbles.org.uk).
- **Chestnut Tree House** – runs support groups for children with siblings who are cared for by the organisation and those who have been bereaved. Go to: [www.chestnut-tree-house.org.uk/our-care/support-for-families/](http://www.chestnut-tree-house.org.uk/our-care/support-for-families/) or email: [cthadmin@stbh.org.uk](mailto:cthadmin@stbh.org.uk).
- **Young Carers** – The Carers Centre offer support and social activities for young carers under 18 including siblings of disabled children. Call: **01273 746222** or email: [info@thecarerscentre.org](mailto:info@thecarerscentre.org).
- **Young Carer's Card** – siblings aged 8 to 25 of Compass Card holders living in Brighton & Hove can apply for a Young Carer's Card, which offers discounts across the city. Call the Carer's Hub on **01273 977000**, email [info@carershub.co.uk](mailto:info@carershub.co.uk) or apply online at [new.brighton-hove.gov.uk/adult-social-care/care-and-support-adults/apply-carers-card](http://new.brighton-hove.gov.uk/adult-social-care/care-and-support-adults/apply-carers-card).

### Further information and useful links

- **Amaze's Short breaks and Respite fact sheet** - Download from <https://amazesussex.org.uk/resources/fact-sheets>
- **The Carer's Trust** – online support for all young carers, including those who have siblings with disabilities. For more information go to: <https://carers.org>.
- **Contact** – has information and resources, including a section about supporting siblings. Go to: <https://contact.org.uk>. Also runs a helpline. Call: **0808 808 3555**.
- **Direct payments** – information on how to apply for direct payments. Go to: [www.gov.uk/apply-direct-payments](http://www.gov.uk/apply-direct-payments).
- **Local Offer** – the local authority's online listing of all the services and support that are available to families with children with SEND in the area. Visit [new.brighton-hove.gov.uk/special-educational-needs-and-disabilities](http://new.brighton-hove.gov.uk/special-educational-needs-and-disabilities)
- **Sibs** – charity for siblings of children and adults with disabilities. Go to: [www.sibs.org.uk](http://www.sibs.org.uk)
- **Sibling Support** – US website with information and links, as well as useful books to share with your children. Go to: [www.siblingsupport.org](http://www.siblingsupport.org) for more information.
- **Winston's Wish** – charity that supports bereaved children. For details, go to: [www.winstonswish.org.uk](http://www.winstonswish.org.uk) or call their helpline: **0808 802 0021**.

