

SUPPORTING SIBLINGS OF DISABLED CHILDREN

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



When a child is diagnosed with a disability, many families feel as if their life has been turned upside down. The focus tends to be on finding out more about the disability and making sure you put in place the right support to meet your child's needs. However, it is also very important to make sure that your other children understand what the diagnosis means and are given lots of support as they adjust to the changes.

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 siblings say that they have a very close bond with their 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. The 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.

There are many 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. Links to some resources are given overleaf. 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 Breaks for disabled children in your area. Our companion fact sheet on Short Breaks tells you what kinds of things are available and how you can get them. See below for details of where to download it.





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And, if you are not eligible for this kind of care, perhaps you can find an inclusive mainstream activity or playscheme 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

- **ASPENS (previously Autism Sussex)** – go to <https://aspens.org.uk> or call: **0345 450 0060**. It runs clubs and siblings clubs as well as support services for families.
- **Choice Team** – works with children and families who access a lower level of support through Personal Budgets or Direct Payments. An identified key worker will act as your point of contact, and review your child's support plan annually to ensure that it continues to meet their needs and those of the family. A new service, eventually it is planned that they will accept direct referrals for support where social work is not needed. For more information, call: **0330 222 2633**, or email: choice@westsussex.gov.uk.
- **Chestnut Tree House** – runs support groups for children with siblings who are cared for by the organisation and those who have been bereaved. For more information email: cthadmin@stbh.org.uk or go to: www.chestnut-tree-house.org.uk/our-care/support-for-families.
- **Short breaks** – available for children and young people aged 0-18 years who live in West Sussex and have a disability and/or additional need. Children who receive middle or high care component of Disability Living Allowance (DLA) automatically qualify. For more information and links to providers go to: <https://westsussex.local-offer.org>.
- **Social care** – can assess the needs of the whole family, including you as a carer and siblings of children with disabilities, call the the Integrated Front Door (IFD) for West Sussex Children Services, tel: **01403 229888**, email: WSChildrenservices@westsussex.gov.uk. For respite care for over 18s call the Adults' CarePoint: **01243 642121**, or email: socialcare@westsussex.gov.uk.
- **Sussex Snowdrop Trust** – volunteers who support families of children with life-threatening or life limiting conditions, in a limited catchment within West Sussex: www.thesussexsnowdroptrust.com.
- **WSCC Young Carers** – go to: www.westsussex.gov.uk/youngcarers, call: **01903 270300** or email: youngcarers@westsussex.gov.uk.

Further information and useful links

- **Making Sense of it All and Making Sense of Adult Life (14+)** – our handbooks for parent carers of children and young people with SEND in West Sussex provide essential information on SEND topics. For further information, visit our website: www.reachingfamilies.org.uk/guides.html.
- **Fact sheets** – see our companion fact sheet: *Short Breaks and Respite*. For more go to: www.reachingfamilies.org.uk/factsheets.html.
- **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.
- **Sibs** – charity for siblings of children and adults with disabilities. Go to: www.sibs.org.uk.
- **Sibling Support** – US website with information and links, as well as useful books to share with your children. Go to: <https://siblingsupport.org> for more information.
- **Winston's Wish** – charity that supports bereaved children. For details, go to: www.winstonswish.org.uk or call their helpline: **0808 802 0021**.

