

SUPPORTING SIBLINGS

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. 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.





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Ask about

- **Chestnut Tree House** – run activity days allowing siblings to meet other children or teenagers who also have a sick brother or sister. Their therapists can also provide individual support for siblings who are coping with having a very sick brother or sister, or who have been bereaved. For more information go to: www.chestnut-tree-house.org.uk/our-care/families-and-carers, email: cthadmin@stbh.org.uk, or call: **01903 871800**.
- **Disability Living Allowance (DLA)** – your child may qualify for DLA, a state benefit that will help with their care. For further information visit www.gov.uk/disability-living-allowance-children.
- **Reaching Families** – provides training, information & other fact sheets related to this topic. See especially our fact sheet on *Short Breaks and Respite*. We also offer peer-support, benefits advice, a Facebook group & handbook (see below) for parent carers of children & young people with SEND in West Sussex. See www.reachingfamilies.org.uk.
- **Short Breaks for Disabled Children** – fun, leisure and social activities for disabled children and young people outside school. Children who receive middle or high care component of Disability Living Allowance (DLA) automatically qualify. For more information and links to providers, visit: <https://westsussex.local-offer.org/services/82-1-short-breaks>. Tel: **0330 222 2562** or email: SENDCommissioningTeam@westsussex.gov.uk.
- **Super Siblings** – offer monthly support groups with fun activities for siblings. For more information go to: www.supersiblings.org, call: **07503 931691**, or email: info@supersiblings.org.
- **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.
- **West Sussex Children's Services** – support from health and social care. They can assess the needs of the whole family, including siblings, and do a Carer's Needs Assessment for you. If your child is under 18, contact the Integrated Front Door (IFD) for West Sussex Children's Services. Tel: **01403 229900** or email: WSChildrenservices@westsussex.gov.uk. For social care for over 18s call the Adults' CarePoint: **01243 642121**, or email: socialcare@westsussex.gov.uk. Online referral forms for children's &/or adults' social care are available via: www.westsussex.gov.uk/social-care-and-health/social-care-support.
- **WSCC Young Carers** – Support, information and advice for young carers. Call: **01903 270300**, visit: www.westsussex.gov.uk/youngcarers, or email: youngcarers@westsussex.gov.uk

Further information and useful links

- ***Making Sense of it All: From Birth to Adulthood*** – Reaching Families' handbook for parent carers of children and young people with SEND in West Sussex. This provides essential information on money matters, including claiming DLA and PIP, as well as social care, health, leisure, travel, education and employment. Go to: www.reachingfamilies.org.uk/guides.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**.
- **Sibs** – charity for siblings of children and adults with disabilities. Go to: www.sibs.org.uk.
- **Sibling Support** – U.S. website with information and links, as well as useful books to share with your children. Go to: <https://siblingssupport.org> for more information.
- **West Sussex Local Offer** – go to <https://westsussex.local-offer.org> for local services, support and details of *Short Breaks* providers for children & young people aged 0 - 25 years with SEND.
- **Winston's Wish** – charity that supports bereaved children. For details, go to: www.winstonswish.org.uk or call their helpline: **0808 802 0021**.

