

SHORT BREAKS AND RESPITE

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



All parents need a break and sometimes this is not easy to admit without feeling guilty. Having a child with additional needs can put extra stresses and strains on relationships and family life, which make having a break even more important. It's all about giving you and the rest of the household that break from caring while you recharge your batteries. It can also be about new experiences for your child.

Having a short break can help you discover that it is possible to let your child go. It's a chance for your child to find out they can enjoy life away from the family. It can also help them learn to adapt to new situations and experiences.

What is a short break?

When we talk about short breaks we mean any organised activity or care (outside of school) that gives your child a chance to have fun and socialise, and you a chance to take a break from your caring responsibilities. A short break might be an inclusive after school or holiday club, a social group for children with similar disabilities; a few hours care in your own home. It may also be an overnight or residential stay if your child has more complex needs.

Day time short breaks can be accessed by any child under 18 years old with a disability and/or additional need. Families in receipt of middle or higher rate Disability Living Allowance or PIP qualify automatically. Short breaks providers have a simple self-assessment for families whose children do not receive DLA or PIP but have similar needs. Overnight short breaks will require your child to undergo a social care assessment of need.

Your local authority has a duty to tell you about their range of short breaks available, their eligibility criteria and how to apply. Find out what is available in your area by visiting your local authority's Local Offer online. It's also worth asking other parents or local disability organisations for schemes they might have used.

How do you get a short break?

You can organise day time short breaks and short-term individual one-to-one support yourself directly by contacting the short break provider. You should not expect to pay more for your child to attend than any other child.

If you want your child to access overnight short breaks, you will need to contact your local children's social care team for an assessment of need. Social care will use a resource allocation system (RAS) to ensure that assessments and funds are allocated fairly.

See the 'Ask about' section at the end of this fact sheet for the relevant contact details for your area.

Bear in mind that more specialist short breaks can be hard to get. There is always a heavy demand. You will have to jump hurdles and will probably have to wait. But it's well worth the effort. Good respite care can make a huge difference to your ability to cope.

If your child meets the assessment criteria and is considered eligible for overnight short breaks, social care workers will work with you to draw up a care plan that sets out the kinds of support they will get. This plan (which may be part of their Education, Health and Care Plan) will be reviewed regularly.





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Tips for getting a short break

- **Don't wait till you're desperate to ask for help.** It can take a long time to get an assessment and organise care and funding so be brave and ask for support before you're going under.
- **Explain how the demands of caring for your child are taking their toll** and make it clear that things are difficult. Much of the social services funded respite focuses on your child's level of impairment rather than your family's needs. You may need to challenge this.
- **Get other people on your side** – ask your health visitor, GP or other professional to write to social services to back up your need for support.

Funding for short breaks

If your child has been assessed as being eligible for social care, they may be allocated a personal budget which is the amount of money the local authority has decided is necessary to arrange your child's care and support. A personal budget can be allocated to you directly as a 'Direct Payment' so that you can organise and pay for things like short breaks yourself. Or the local authority can hold onto the money and arrange support on your child's behalf. Or you can have a mixture of both. Ask your social worker or short breaks assessor about direct payments and personal budgets once you've been assessed as needing a service.

Making short breaks work for you

- **If your child is assessed as eligible for short break services, get involved in planning their care with the social work team.** This will help make sure that the arrangements are successful and any difficulties are dealt with as you would wish.
- **Don't feel you have to accept what you've been offered** if it's not working out.
- **Write down a list of questions and key things** about your child and take this with you to visits or meetings about respite arrangements.
- **Visit short break providers.** Talk to your child or show them pictures before you take them to visit. Spend time there together and observe what happens. Find out what other parents and other children say about the care provider and ask questions.
- **Spend time agreeing how best to introduce and trial any short break arrangements.**
- **Keep an open mind as sometimes initial visits don't go well.** Often it takes time for children to settle with new people and it's hard to get everything right immediately, so be careful not to miss out on an opportunity because it needs working at for a while.
- **Be prepared for things to go wrong.** There are bound to be hiccups, even in longstanding short breaks arrangements. If there are problems, speak to your short breaks provider first, and then your social care worker or care manager. You should have discussed what might happen in a crisis during the care planning process and have alternative arrangements in place, if necessary.

Ask about

- **Children's Hospices** – Chestnut Tree House (West Sussex), Naomi House & Jackspace (Hampshire), Demelza (Kent & East Sussex) and Shooting Star Chase (Surrey & London) may offer respite breaks to families of children and young people with life-limited or life-threatening conditions who meet their criteria for support. There is some overlap in regions, so we recommend checking which is most suitable for you.





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- **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. For more information, call: **0330 222 2633**, or email: **choice@westsussex.gov.uk**.
- **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**.
- **Family Fund** – you may be able to get help to pay for activities and short breaks. Go to: **www.familyfund.org.uk** or call: **01904 550055**.
- **Independent Lives** – information, care and support services designed to enable people with care needs to be independent, includes information on personal assistants, how to find one and how to manage Direct Payments. For more go to: **www.independentlives.org**, call: **01903 219482** or email: **info@independentlives.org**.
- **Reaching Families** – provides training, information & other fact sheets related to this topic. See especially our fact sheets on *Leisure* and *Survival Strategies*. We also offer benefits advice, peer support, a Facebook group & handbook (see below) for parent carers of children & young people with SEND in West Sussex. See: **www.reachingfamilies.org.uk**.
- **Respite care** – facilities in West Sussex include: Chailey Heritage Residential; Cissbury Lodge, Worthing (currently closed); High Trees, Crawley and Horsham; Orchard House, Cuckfield; and The Finches, Burgess Hill (currently closed). Ask your child or young person's social worker for more information (see West Sussex Children's Services below for contact details).
- **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**.
- **West Sussex Children's Services** – support from health and social care who can help to arrange short breaks and respite care. 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 respite care for over 18s call the Adults' CarePoint: **01243 642121**, or email: **socialcare@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**.
- **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.

