

MEETINGS AND PAPERWORK

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



When you have a child with additional needs, just managing their medical appointments, school meetings and disability benefits can seem like a full time job and a very stressful one at that. Here are some tips to help you keep on top of managing your child's support and hopefully make the process less stressful and more effective for you and your family.

Good habits to develop

- **Keep a 'contacts' diary** – note down the names of any professionals you've had contact with and the department they work in. Make a brief note of any conversations so you can refresh your memory if need be.
- **Keep copies of everything you send** and ask for copies of any paperwork made by others.
- **Keep all paperwork about your child in one place** – buy a box file (or a set of box files) and as soon as you get any paperwork store it in there.
- **Always be polite to receptionists and secretaries** – they are the gatekeepers and can smooth contacts or speed up waiting times.
- **Make sure you meet deadlines:** it's in your interest to complete forms and attend appointments on time. And if you can't, or you do miss them, contact people as soon as possible.

Before meetings

- **Try and arrange appointments that suit you and your child.** For example, if they're really tired in the afternoons and will struggle to wait, try to book a morning appointment.
- **Gather relevant paperwork together so you can go through it beforehand.** For example, before an Annual Review, make sure you've read over your child's Education, Health and Care Plan. Or ask to see copies of SEN Support records.
- **Think about what you want to get out of the meeting.** Perhaps you want speech and language therapy or extra support in the classroom. This will help you to keep focused if the meeting seems to drift.
- **Prepare a list of questions you want to ask.** That way if you get stuck, you'll have something to jog your memory.
- **If English isn't your first language, ask for an interpreter.**
- **Ask a friend to go with you.** Show them your list of questions and tell them what you want out of the meeting. Apart from moral support, they can prompt you on things you've forgotten.
- **Be prepared food-wise.** If your child is coming to the meeting, bring snacks, drinks and games in case it overruns. And get something easy in for tea afterwards.

At meetings

- **Be on time.** You'll feel less flustered and have time to gather your thoughts.
- **Be positive** – most professionals want to do the very best for your child and if you keep this in mind the meeting is likely to go more positively.





MEETINGS AND PAPERWORK

- **Ask for the names and roles** of all the people at the meeting and write them down.
- **Ask if you don't understand anything and keep asking!** It's your child and it's OK to ask for clarification.
- **Don't allow yourself to be rushed** – take time to think and try not to rush the professionals; they're human too and will be able to explain things better with time to do so.
- **If your child is with you, explain how the other people at the meeting can communicate with them.** Make sure your son or daughter is included in discussions as much as possible.
- **At the end of the meeting, summarise what has been discussed and agree what happens next** - what interventions have been agreed and when will they be reviewed.
- **Ask for any notes** or minutes to be sent to you.

After meetings

- **Talk over what happened with your friend** in case you missed anything and don't be afraid to go back to professionals with further queries.
- **Follow up the meeting with a call or email** to the professionals involved and chase up paperwork if necessary.
- **If you're not happy with how a meeting went or what was agreed, complain.** Health, education and social care all have complaints procedures and your concerns will be taken seriously.

Ask About

- **Healthwatch** – is the local independent statutory body helping people to have their say and get the information and advice they need about health and social care. They can advise you on what to do if things go wrong and gather information to help improve standards of care. Go to: www.healthwatchwestsussex.co.uk, email: helpdesk@healthwatchwestsussex.co.uk, or call: **0300 012 0122**.
- **Hospital passport** – an information form that you can fill in and give to staff telling them about your child or young person's needs. Give a copy to staff at the pre-admission appointment, or on admission. Other West Sussex community services can also receive this Hospital Passport about your child if you wish. Find out more and download a copy from: www.sussexcommunity.nhs.uk/services/servicedetails.htm?directoryID=16352.
- **Mind in Brighton & Hove (Advocacy services)** – for young people with mental health challenges, MIND have advocacy workers who can provide support to young people aged 11 to 18 in West Sussex. For details, go to: www.mindcharity.co.uk or call: **01273 666950**.
- **Reaching Families** – provides training, information & other fact sheets related to this topic. See especially our workshop on *Making Sense of Meetings and Paperwork*, and our fact sheets on *Involving Young People* and *Preparing for Adulthood*. 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.
- **West Sussex Advocacy Service** – can help disabled children or young people who receive help from a social worker or any child or young person wishing to make a complaint about West Sussex Children's Services. For more information email: AdvocacyService@westsussex.gov.uk, go to: www.westsussex.gov.uk/education-children-and-families/your-space/life/advocacy, or call: **0330 222 8686**.





MEETINGS AND PAPERWORK

- **West Sussex Children's Services** – support from health and social 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**. The IFD is also an entry point for the Children with Disabilities (social care) service for children & young people with severe and/or complex disabilities. Eligibility criteria apply – See: **<https://westsussex.local-offer.org/services/265>**. For over 18s call the Adults' CarePoint: **01243 642121**, or email: **socialcare@westsussex.gov.uk**.
- **West Sussex SEND Information, Advice and Support (SENDIAS) Service** – contact them for advice and support. They also have Young People Advisers, who can support young people up to the age of 25 to help them to think through their options. Go to: **<https://westsussexsendias.org>**, call: **0330 222 8555**, or email: **send.ias@westsussex.gov.uk** (parent carers) or: **cyp.sendias@westsussex.gov.uk** (children and young people).

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**.
- **Contact** – a national charity for families who have a child/young person with a disability. As well as information and resources, it also runs a helpline. Go to: **<https://contact.org.uk>** or call: **0808 808 3555**.
- **Independent Parental Special Education Advice (IPSEA)** – for information and advice about SEND law, EHC Plans, and tribunals, as well as template letters and an advice line, go to: **www.ipsea.org.uk**.
- **SEND Code of Practice** - Government guidance on the legal duties of education providers in relation to SEND provision for children and young people aged 0 to 25. See: **www.gov.uk/government/publications/send-code-of-practice-0-to-25**.
- **SOS SEN** – information and advice about SEND law. Runs workshops and events and a telephone helpline for parents. Go to **<https://sossen.org.uk>** or call: **0208 538 3731**.
- **Special Needs Jungle** – parent-centred information, resources and opinions about SEN, disability, children's health and SEN politics. Visit: **www.specialneedsjungle.com**.
- **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.

