

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** – make a folder in your email account to copy all messages into. 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 your child's SEN support records (sometimes called an Additional Needs Plan or provision map).
- **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 for delays.** If your child is coming to the meeting, bring snacks, drinks and games in case it overruns. Maybe get something easy in for tea afterwards.

At meetings

- **Be on time.** You'll feel less flustered and have time to gather your thoughts



MEETINGS AND PAPERWORK



- **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.
- **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

- **SENDIASS** - Amaze provides the **Special Educational Needs Information, Advice and Support Service** to families with children and young people with SEND in Brighton & Hove and East Sussex. Our advisers can offer impartial advice about anything to do with SEND and help you prepare for meetings. Call **01273 772289** or email sendiass@amazesussex.org.uk
- **Advocacy services** can help disabled children and young people to be heard.

The **Sussex Advocacy Partnership** is an umbrella organisation that provides a range of advocacy services to residents of Brighton & Hove and East Sussex via different organisations. <https://www.sussexadvocacypartnership.co.uk>.

Brighton & Hove's Youth Advocacy Project offers advocacy for children and young people with a disability. Call **0800 0524 280** or go to: www.bhyap.org.uk/your-zone/what-advocacy.

Brighton & Hove Speak Out offers advocacy for young people aged 17+ with a learning disability Call **01273 421921** or visit their website: www.bhspeakout.org.uk.

Asphaleia Care offer advocacy to under 18s who have an East Sussex County Council social worker. Call **01323 324010** or visit their website at asphaleia.co.uk/ivandadvocacy. **SWAN (South East Advocacy Network)** provide advocacy services for children, young people and adults in East Sussex. Call **0800 862 0995** or email eastsussex@swanadvocacy.org.uk. Visit <https://swanadvocacy.org.uk/services-near-you/east-sussex>.

- **My Care passport** - to record information about your child including communication needs, toileting, food, etc. to help improve their experience in different healthcare settings. You can download the passport here <https://www.uhsussex.nhs.uk/resources/this-is-me-my-care-passport/>



MEETINGS AND PAPERWORK



- **Making a complaint** - Always try to resolve your issue directly with the individual or service concerned first. If you are not satisfied, the following can give advice on health care complaints: Healthwatch East Sussex (0333 101 4007) or Healthwatch Brighton & Hove (01273 234040); East Sussex Children's Services Customer relations team via <https://www.eastsussex.gov.uk/children-families/key-policies/feedback> or Brighton & Hove Customer Feedback Team at <https://www.brighton-hove.gov.uk/council-and-democracy/feedback-about-council-services/childrens-services-complaints>. You can also call 01273 291229 or email customerfeedback@brighton-hove.gov.uk.

Further reading and useful links:

- **Amaze's *Involving Young People and Preparing for Adulthood* fact sheets** - Download from <https://amazesussex.org.uk/resources/fact-sheets>
- **Contact** - this national charity supporting families with disabled children has information and resources covering everything from education and health to benefits. Go to contact.org.uk or call their helpline on 0808 808 3555.
- **Independent Parental Special Education Advice (IPSEA)** - for information and advice about SEND including the law, EHC Plans, tribunals and more go to: www.ipsea.org.uk.
- **Local Offer** - Each local authority is required to provide information about local services and support for children and young people aged 0-25 with SEND. Brighton & Hove's Local Offer is at <https://www.brighton-hove.gov.uk/special-educational-needs-and-disabilities> and East Sussex Local Offer is at <https://localoffer.eastsussex.gov.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 <https://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: 0300 302 3731.
- **Special Needs Jungle** - parent-centred information, resources and opinions about SEND, children's health and SEND politics. Visit <https://www.specialneedsjungle.com>

