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 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 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.
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 SEN and disabilities in Brighton & Hove and East Sussex. Our helpline advisers can offer impartial advice about anything to do with SEND and help you prepare for important meetings. Call 01273 772289, email sendiass@amazesussex.org.uk or visit amazesussex.org.uk. Amaze also has information on how to prepare young people to take an active part in meetings and decisions - see ‘Further reading’ below.

- **Advocacy services** - can help disabled children and young people to be heard. POHwER East Sussex (0300 456 2370 or pohwer.net/east-sussex) provide advocacy for children and young people with learning disabilities and Speak Out! (0300 303 9649 or changegrowlive.org/young-people/speak-out) provide advocacy support for looked after children and young people or those getting support from East Sussex Children’s Services.

- **Hospital passport** - a document where you can record lots of information about your child including communication needs, toileting, food, etc. to help improve their experience in different health care settings. Download East Sussex Healthcare Passport for children and young people with additional needs: www.esht.nhs.uk/leaflet/this-is-my-hospital(passport

- **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 complaints: Healthwatch East Sussex (0333 101 4007); East Sussex Children’s Services Customer relations team via www.eastsussex.gov.uk/CSFeedback or 0345 60 80 192.
Further reading and useful links:

- **Involving Young People and Preparing for Adulthood** fact sheets - these Amaze fact sheets offer specific advice on preparing young people to take part in meetings about their lives. Visit amazesussex.org.uk/resources/fact-sheets
- **Local Offer** - The local authority's online listing of all the services and support that are available to families with children with SEND in the area. Visit www.eastsussex.gov.uk/childrenandfamilies/specialneeds/
- **Contact** - have a national SEN advice service that you can reach on 0808 808 3555 and lots of advice and resources at contact.org.uk
- **IPSEA** - independent advice and support on special education. Visit ipsea.org.uk
- **Special needs jungle** - parent-centred information, resources and opinions about SEN, disability, children's health and SEN politics. Visit specialneedsjungle.com