

CHAPTER 4

Health



Nobody told us so many people could be involved in treating our children. Someone we know counted 22 appointments in two months! Sometimes it can feel like being your child's personal manager, juggling appointments and supervising treatment at home.

Specialists tend to concentrate on just one bit of your child; speech therapists obviously focus on communication, physiotherapists on movement, and so on. This doesn't mean they're not interested in your child as a whole person, but the fact is that parents are the people who know the most about their own children. You see your child every day, you know what treatments he or she is receiving and you know how they affect your child. You are probably the one constant figure in your child's care, and you understand them better than anyone else. With this unique knowledge, you should expect to be treated by professionals as a respected and valued partner in all aspects of your child's care. Amaze has a factsheet called 'Managing meetings and appointments' which has tips for handling healthcare appointments.

In addition to looking at this chapter, you can also find information about health services for children with SEN and disabilities on Brighton & Hove's Local Offer. Visit www.brighton-hove.gov.uk/localoffer.

Every child with Down's syndrome is going to be different from every other; every autistic child is different from every other; how does a professional know exactly where your child's strengths and weaknesses are, or what exactly their comprehension level is? Tell them.

YOUR FIRST HEALTH SERVICE CONTACTS

Some of us knew before our babies were born that they were likely to have some sort of disability, although it may not have been clear quite what impact this would have. It's a time for lots of questions: 'What treatment is there?' 'Will the baby need surgery?' 'Is it life-threatening?' 'Where can I find out more?' Many of these questions will be answered by a consultant who can talk you through what is likely to happen. Or perhaps you will be

referred for extra tests to Guy's or King's College Hospital in London that specialise in, amongst other things, detailed ultrasound scans.

In Brighton and Hove, we are very fortunate to have both a children's hospital and a specialist neo-natal intensive care unit called the Trevor Mann Baby Unit (TMBU). Sometimes our babies started life on the TMBU. The unit cares for premature babies and those who may require specialist medical support when they're born. They have a counsellor attached to the unit, who is there if you need help adjusting to the fact that this baby isn't the one you were expecting. Staff at the unit can offer you advice and support.

Some babies who are known to have very complex medical needs may be born in London-based hospitals, where there is very specialist support immediately available. Counsellors and Outreach Liaison Nurses are attached to the baby units in these hospitals, and are the 'glue' that links your specialist London care with your local ongoing care. The vast majority of us, however, will find that our child's difficulties are first picked up by us with our health visitor, our GP, or our child's school.

Health visitors

Health visitors will often be the first professional you encounter once you've settled your new baby into your home. They visit all parents after the birth of a baby (at 10 to 14 days) and when the baby is six to eight weeks old. They are there for your baby and, importantly, for you too in those early weeks of adjusting to having a new life to care for. They will also contact or visit you when your child is one, and at two/two and a half, or if you move into an area with a child under five. They are usually based at your local Children's Centre where they run drop in information sessions and can offer advice on anything from breast-feeding and weaning, to potty-training and sleep difficulties. Health visitors also work with early years' educators and community nursery nurses to support families where children or parents have additional needs.

It is the health visitor's job to assess the development of children under five. If, during these assessments, they feel that you or your child need additional help or support, then they will plan this with you and see you more often. They call this their enhanced service. They may refer you to other professionals, for example, the Brighton & Hove Inclusion Support Service if your child needs specialist support for their early education. Or the Speech and Language Therapy team if your child has difficulty swallowing or has a delay in their speech or understanding. They will work with the identified professionals to make sure that your child gets the right support and that services are coordinated.

Health visitors are also a great source of general information about local groups, activities and ways of supporting your child's health and development, so try and make use of their local knowledge.

There are also specialist health visitors for children with additional needs, based at the Seaside View Child Development Centre. If you have been referred to Seaside View (read more about this below), they will support you and your family and offer information and liaison with local services.

"My health visitor has been with me from the start and is such a brilliant advocate. She has got everything going with assessments for my little girl. Because we have such a strong relationship, starting from the very beginning when she was born, she has been an emotional lifeline for me through it all."

Your GP

Your GP may be one of the first people you discuss your child's difficulties with. They may also be the best person to ask if you think your child would benefit from seeing a specialist health professional.

It's important to keep up the relationship with your GP, even if most of your child's subsequent treatment is at a clinic. Support from GPs can be helpful if you're trying to speed up appointments or find respite care (read more about getting a break in our chapter 'Help with daily life'). And of course children with additional needs get ordinary illnesses, just like other children.

It's easy to forget that while specialist doctors work with children with similar conditions to your child's all the time, your own GP may only have a few children with additional needs in the practice. If your child has a very rare condition, this may be the GP's first encounter with it. A good GP will appreciate all the information that you are able to give, and respect the skills and knowledge you are sure to acquire.

Some parents, though, find it useful to have a different GP from their children, believing it gives them a better chance of being seen as an individual rather than as the parent of a disabled child. If your relationship with your GP isn't working, it's worth considering changing to another within the practice or, as a last resort, to another practice altogether. These days the easiest way to find a new GP is via the NHS Choices website (www.nhs.uk). You can use a search facility to find all GPs in your area who are currently accepting new patients. You can also read quite detailed reviews of their service from other patients and see an overall rating they received from patients according to key criteria. If you're not online, you should be able to find a list of local doctors at your library or the Citizen's Advice Bureau.

When Jane was first diagnosed, and we had to go to the GP for medication and stuff, he said 'Right, now this has all been diagnosed, the Seaside View Child Development Centre take care of absolutely everything, you don't need to see me except for medication'. And that was how he treated her. And then, when she was really ill with a chest infection, we called him out and he said 'Children these days don't get chest infections!' Two days later she was in hospital and it was really serious, so we changed GPs - we had to - and we've got a really brilliant one now.

My family GP has known my son since he was a newborn. He made time for me to tell him the birth story and always takes any medical concerns relating to him seriously and I always feel heard and respected. For example, he supported my request for the strongest concentration of diuretics for my son, even though it was a more expensive prescription and meant a special order.

Your child's pre-school or school

You may find that the first you hear about your child having any difficulties is from their nursery worker or class teacher. Perhaps they're having difficulty getting along with other children at nursery or maybe they're having trouble reading or concentrating during lessons. The teacher may invite you to discuss your child's difficulties in more detail with the special educational needs coordinator (SENCO) or Inclusion Manager or suggest they are referred to the Brighton and Hove Inclusion Support Service for further assessment by an educational psychologist. We discuss the special educational needs process in much more detail in the Education chapter. If your child has special educational needs (SEN) to the extent that they are assessed for an Education, Health and Care Plan, this plan should

include any health needs that are related to their SEN. Support for children with medical conditions in school is also covered in the 'Education' chapter.

Another person that you might talk to about your child's difficulties at this point is the school nurse. In mainstream schools, this is usually a visiting Nurse, who is available termly. He or she can check your child's health and development and refer you to other specialist health practitioners. Schools usually notify parents of upcoming visits and this is an opportunity to meet and discuss any health or medical concerns you may have.

SPECIALIST HEALTH SERVICES

Following an initial contact with a professional like your GP or health visitor, your child may then be referred to one or more of the following health service treatment centres for more specialist assessment and support. If it's taking too long to get an appointment or the situation is getting worse, go back to your GP or health visitor and see if they can speed up the process for you.

Seaside View Child Development Centre

Many children will be diagnosed or assessed at the Seaside View Child Development Centre located at the Brighton General Hospital site. Seaside View is the location of the Children's Disability Service for children living locally.

Many different specialists are based at Seaside View, including paediatricians, social workers, health visitors, clinical psychologists, speech and occupational therapists and physiotherapists. They work together to assess children both individually and through group work, and then plan a programme of therapy and treatment.

Some children may be seen at a local child health clinic instead of at Seaside View. For pre-schoolers, an assessment may also take place jointly with staff at Seaside View and BHISS. You can read more about BHISS in the 'Education' Chapter.

Parents and carers can ask any professional who knows their child to complete a referral form and send it to the team at Seaside View. When the service receives the referral form, this is taken to a team meeting. Within two weeks of this team discussion the family should receive a letter which explains the outcome of the meeting and also how the service may be able to help. They aim that children will begin their assessment within 18 weeks of a referral. Seaside View operates on a 'triage' basis, which means that more urgent cases may be seen more quickly. Parents and carers are also welcome to contact Seaside View direct for more information on 01273 265780. It's always worth checking where your child is on the waiting list.

Seaside View also offers a free Counselling Service for parent carers of children with complex needs and learning disabilities. You can be referred by one of your child's consultants, or you can self-refer by contacting Seaside View direct.

Royal Alexandra Hospital for Sick Children

The Alex, as many people call it, is the local children's hospital where many of our children are diagnosed as having certain medical or clinical conditions. The consultants at the hospital have their own specialist areas, for instance in the treatment of asthma, diabetes and epilepsy, but will hold joint clinics alongside visiting specialists from hospitals such as Great Ormond Street, to get a clearer picture of your child's needs and to plan a programme of treatment. Occasionally, your child might be referred to a hospital

outside this area which specialises in your child's condition, such as the Evelina Children's Hospital in London

The Alex is located in a new building on the site of the Royal Sussex County Hospital. The hospital provides inpatient and outpatient services, including intensive care and a 24 hour Children's Emergency Department. The Alex has leaflets for parents about what to expect if your child has an appointment or a stay in the hospital and its own website, www.theroyalalex.co.uk.

Play Specialist Team

The Alex has an in-house Play Specialist team, who operate within the wards, but who are also available to talk to you in advance of any major planned hospital stays. As well as offering useful advice, they are also able to work with you one-to-one if your child has developed a phobia of being in the hospital. If your child is already in hospital and you are struggling to get a procedure done, you can ask the staff to bleep the on-duty Play Specialist for some distraction therapy.

Specialist beds are available – known as 'safe beds' for older children, if a regular hospital bed isn't appropriate, for that child's safety and wellbeing. It's important to discuss the potential need for a safe bed at your admission appointment as they are limited in number.

Community Nursing Team

Operating out of The Alex, the Community Team are a vital link for families whose child requires home-based support or equipment such as dressing changes after major surgery, or a home oxygen supply. They can also help with the transition from a major hospital stay to getting your child back home. You will be referred to the Community Team via your child's consultant or as part of the discharge planning process.

Paediatric Psychological Support at the Alex

The Paediatric Psychological Support Service (PPSS) at the Royal Alex aims to look after the mental and emotional wellbeing of children with long-term physical health conditions. The team provide advice and consultation to the medical staff on giving better psychological care to both inpatients and outpatients. They also offer some brief direct work with children, young people and their families.

If you think your child might benefit from this kind of psychological support, you can attend the weekly parent drop-in held on Mondays from 10 to 11am on Level 7 at the Royal Alex, or speak to one of the medical staff you see at the hospital for more information.

Special dental services

Brighton and Hove has a special community dental service for anyone who has difficulty accessing general dental services. This might be because of learning or physical disabilities, a phobia or an ongoing health or mental health issue. They also work with children who have very challenging behaviour.

Special dental services are located at Morley Street Clinic in Brighton. The dentists who work there have extensive experience of treating patients with additional needs and are very sympathetic to your child's and your concerns. Appointments are considerably longer than those at other dental practices and they will work at the child or young person's pace – for instance, an initial check-up may just be a chance to sit in the chair and have a chat, if that's what your child needs to make them feel comfortable.

Your family dentist or any other medical practitioner can refer you, or you can call Morley Street for advice on 01273 692549.

Educational Psychology

The Educational Psychology (EP) team is part of Brighton and Hove Inclusion Support Service (BHISS). If your child's difficulties are first picked up at school or pre-school they may be referred to see an EP. If your child is already known to other professionals, they may also make a referral. EPs will assess your child's developmental progress and will give advice on appropriate educational help. They will normally be able to give you a clear idea of your child's difficulties and in some cases will also refer on to other professionals for further assessment. Read more about the role of the educational psychology team in the Education chapter.

Mental health services for children and young people

Children who need help with their mental health and emotional wellbeing may get this through school, through the Brighton and Hove Community Wellbeing Service, or through specialist CAMHS (Child and Adolescent Mental Health Service).

Some children with mainly emotional and behavioural problems may be referred to **specialist CAMHS** for diagnosis and assessment. This includes children with conditions like ADHD, as well as issues like anxiety and depression, eating disorders and self-harming. CAMHS has a team who specialise in children's mental health including child psychiatrists, family therapists, counsellors, and play and art therapists.

Schools in the city have a named **primary mental health worker as part of the Schools Wellbeing Service**. All secondary schools have a worker in place who can support school staff to work with children's mental health and wellbeing and do some direct work, such as running groups. At the time of writing, how this will work in primary schools is still taking shape.

Brighton and Hove Community Wellbeing Service provides a range of community-based short term therapeutic interventions for children and young people who are experiencing emotional or mental health problems that do not meet the threshold for Specialist CAMHS.

The service is available to children and young people who would benefit from some planned treatment of their mental health but whose needs are not severe enough to meet the criteria for specialist CAMHS. Short term interventions may include face to face counselling (including specialist BME and LGBTQ counsellors), online counselling, therapy based activities, EMDR (Eye movement desensitization and reprocessing) and Cognitive Behavioural Therapy, support groups to help with issues such as worry and anxiety, mindfulness, brief interventions offering support and advice and family intervention where appropriate.

It provides an alternative pathway for children and young people who are unable to or do not want to access the service that is available through their school via a primary mental health worker. There will be close working links between the two services, as well as specialist CAMHS, to ensure a smooth transition from one service to the other should this be in the child or young person's interest.

Referrals

Talk to your child's school about getting support from the primary mental health workers linked to school.

For anything other than an urgent crisis, there is a single point of access for all mental health referrals (including specialist CAMHS) through the Community Wellbeing Service. Referrals to the Community Wellbeing Service can come via your GP or a trusted professional. Or you can refer yourself directly on 0300 002 0060 or by visiting www.brightonandhovevowellbeing.org.

Dealing with a crisis

In the event of an urgent crisis, you should contact your GP or named CAMHS clinician. And if you have an urgent physical and mental health crisis you should attend the children's A&E department at the Royal Alex. Or call 999 for an ambulance or help from the police.

CAMHS Learning Disability Team

This is a specialist team shared between CAMHS and Seaside View which gives additional support to families of children who have a learning disability when there is concern about their emotional wellbeing or mental health, or there is difficulty managing their behaviour. The team includes a consultant child and adolescent psychiatrist, clinical psychologists, nurses and learning disability practitioners, counsellors for parents, and a social worker/family therapist. They will develop an individual plan for your child and work closely with you.

OTHER SPECIALIST HEALTH SERVICES

Audiology

The Children's Audiology Service is responsible for testing and monitoring children's hearing. If your child needs hearing aids, they will be referred to the Royal Sussex. Any healthcare professional or school SENCO can refer a child to Audiology if there's a concern about their hearing. Issues may also be picked up during routine hearing checks in primary schools. Children with a significant hearing impairment will also be referred to the Sensory Needs Team at BHISS for support at nursery or school.

Paediatric ophthalmology or optometry

If your child has a significant problem with their vision, this will usually be picked up during routine developmental checks carried out by a health visitor or GP; they will then refer them to the paediatric ophthalmology teams at the Sussex Eye Hospital for assessment and support. Children with significant visual impairments will also be referred to the Sensory Needs team within BHISS for specialist support with their education.

If you suspect your child has some more common issues with their vision, you can have a free sight test at any high street optician. Otherwise, previously unidentified visual problems may be discovered during routine sight tests for all children during primary school. In both cases, they will be referred to the paediatric team at the Sussex Eye Hospital for further assessment.

Chailey Heritage Clinical Services

Parents who have children with complex physical and neurological disabilities are sometimes referred to Chailey Heritage, near Lewes. Chailey Heritage is made up of two organisations: one is part of Sussex Community NHS Trust; the other is Chailey Heritage School. Chailey Heritage Clinical Services offers a range of services for children and young people. These include medical, clinical and therapy services, flexible overnight care and outreach, and rehabilitation engineering. Chailey is a highly specialised centre and will only assess children whose needs are very complex and can't be met elsewhere.

Rehabilitation

Based at Brighton General Hospital, the Sussex Rehabilitation Centre provides and adapts aids and equipment for disabled children. This service provides prosthetics, wheelchairs and therapy to match the child's needs. The engineers and therapists can make home visits, if necessary. You would normally be referred to the Sussex Rehab Centre by an occupational therapist or physiotherapist at Seaside View. Once you are registered with the wheelchair service, you can contact them directly on 01273 242160 ext.3828. More complex problems are referred on to the Rehabilitation Engineering Unit at Chailey Heritage Clinical Services.

Hospices

Children who have life-limiting or life threatening conditions and need nursing care, or have complex physical and medical needs, may spend time in a hospice, an environment in which they can feel safe and where the care is specialist. Hospices are bright sunny places. Parents often find the support offered is invaluable. There are two children's hospices used by local children and their families, Chestnut Tree House and Demelza House. Referrals for hospice care will usually be made by a consultant or medical professional with permission from the family but both hospices also welcome requests for help directly from families. Only children with a very high level of need are likely to be eligible for specialist hospice care, and children receiving end of life care are given priority.

THERAPIES

Children who have more complex needs and difficulties may require extra help to learn the skills we all need to manage everyday life.

Speech and Language Therapy

Speech and Language Therapists (SLTs) diagnose and treat problems with communicating, speaking clearly and understanding what other people say. Other SLTs specialise in difficulties with chewing and swallowing.

If you think your child has these kinds of difficulties or someone working with your child suggests that they do, you should be referred to the SLT service. The SLT service will provide assessment, diagnosis and management of your child's difficulties. After an initial assessment, your child may get a block of direct sessions with a speech and language therapist on an individual basis or in a group. Or someone already working with your child, for example a TA at their school or their nursery worker, may get a programme of exercises or activities to use with your child. To make the best progress, your child will need you to do the same at home too.

In either case, the therapeutic programme will always be reviewed by the speech and language therapy service. Be aware that therapy is unlikely to go on forever and may be put in place for a specific period of time.

Part of the SLT service focuses on children with more complex needs. This service is based at the Seaside View Child Development Centre. Again, help provided by the complex needs team will be given in association with your child's nursery or school, and with your help at home. For further information you can contact the Speech and Language Therapy team on 01273 242079.

Children with more complex issues around swallowing and eating, such as a serious reflux condition, are likely to be treated by dysphagia specialists at the Royal Alex, working in conjunction with respiratory and gastro specialists.

Occupational Therapy

Occupational Therapists (OTs) help children develop everyday skills, such as feeding themselves, getting dressed and playing, if these are affected by physical, developmental, sensory disabilities or sensory processing issues.

OTs will assess and treat children at home, at school or pre-school or at the Seaside View Child Development Centre.

After assessment, an OT will write a report that identifies any areas where your child needs help. This might also include advice on exercises, adapting tasks to your child's ability or equipment. There will be activities you can do at home with your child as well as in school.

Anyone can refer a child to the OT service, but the majority of referrals come from paediatricians or SENCOs in schools. All referrals go to the Seaside View Referrals Panel.

A word about the other kinds of OT

There's another kind of OT, called a community occupational therapist, who is employed by social services to carry out assessments for families who need equipment and adaptations at home. Be aware that these won't be the same OTs you meet through the health service. Read more about these OTs in the 'Help with Daily Life' chapter in relation to home adaptations.

Physiotherapy

Physiotherapists help with movement skills and physical mobility. There are two paediatric physiotherapy services covering Brighton and Hove: one is based at Seaside View Child Development Centre and is generally responsible for treating children with complex needs and/or developmental difficulties; the other is based at the Royal Alexandra Children's Hospital and provides in-patient care, and out-patient care of respiratory, musculo-skeletal and rheumatological conditions, amongst others.

Treatment is always based on an individual assessment and may include an individual treatment programme, advice, provision of orthotics, or a combination of these.

At Seaside View, the physiotherapists treat a wide range of conditions, including:

- Developmental delay
- Neurological or neuromuscular disorders such as Cerebral Palsy, Muscular Dystrophy
- Congenital syndromes and metabolic diseases such as Down Syndrome, Rett Syndrome
- Co-ordination difficulties
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Though based at Seaside View, the child development and disability physiotherapy service may also visit community settings such as schools, nurseries or homes.

Children can be referred to the Seaside View service by any professional working with their child, often their GP or health visitor. Referrals to the service at the Alex should come from hospital doctors, community paediatricians, GPs and health visitors.

Psychological therapies

If your child has mental health, behavioural or emotional difficulties they may benefit from activities like play therapy, cognitive behavioural therapy or counselling. These kinds of therapies will be provided either through school counsellors, the school wellbeing team that's part of BHISS or specialist Child and Adolescent Mental Health (CAMHS) practitioners.

The kinds of therapies the school wellbeing team offer might include cognitive behavioural therapy (CBT), solution-focused therapy, systemic family therapy, motivational interviewing and narrative therapy. They also provide consultation for school staff, professionals and parents including some drop-in sessions. Specialist CAMHS may provide more intensive or long-term therapeutic interventions through mental health practitioners such as child psychiatrists.

See the section on CAMHS above for how to go get a referral.

Other therapies

Whoopsadaisy

This is a local charity that provides conductive education for children with cerebral palsy and other physical needs that affect their mobility. Conductive education is a specialist teaching programme based on physical activity which aims to promote children's independence. Whoopsadaisy organises groups according to the child's ability and age and then devise a therapy programme for each group. It's a free service, though they also run holiday play schemes for which you will need to pay. Find their contact details at the back of this book.

Music Therapy

Your child may be assessed as needing or benefiting from music therapy but this is rarely offered. Your child's school or another service would have to choose to buy this in. You may be referred to The Belltree Music Therapy Centre, based at Ash Cottage, Woodingdean (www.belltree.org.uk). Or you could pay for some music therapy yourself privately, if you can afford it. Creative Note Music Therapy is another local provider (www.creativenotemusictherapy.com).

Therapies in private practice

If you feel your child would benefit from a particular therapy and you are in a position to pay for this privately, there are speech and language therapists, occupational therapists, counsellors and psychologists who work in private practice. We cannot recommend any specific people here, but if you call our helpline, we may be able to give you details of independent therapists or professionals that other parents have used. To find out what's out there and what's working well, check the Amaze and PaCC Facebook groups for tips and recommendations from other parents.

Complementary therapies

Complementary medicine includes treatments such as osteopathy, acupuncture, homeopathy, massage and aromatherapy. Some parents have found some of these treatments useful for themselves or their child. It can be difficult, though, to find out whether the practitioners have proper qualifications - often other parents are the best source of information, although some GPs have an interest in this area of medicine. Many of the established forms of complementary medicine have their own governing body or college, which can advise about finding a well-qualified practitioner.

Occasionally, some form of complementary medicine may be available under the NHS but more usually it has to be paid for privately or using Direct Payments (see the 'Help with Daily Life' chapter for more about this).

The Dolphin House Children's Clinic is a registered charity in Brighton, which offers a variety of natural therapies with a sliding scale of fees (www.dolphinhouseclinic.com). You could also contact the Carers Centre to find out about any treatments that are currently available to carers or read about the Carers' Card in our 'Leisure' chapter – there are often discounts for complementary therapies when you have a Carers' Card.

Making the most of therapies

However good your child's assessment and therapy sessions are, they'll make little difference unless you put in regular work at home too. Here's our tips for making sure your child really benefits from therapeutic input.

AT THERAPY SESSIONS

- **Include your child as much as you can:** if possible, encourage them to explain in their own words how they feel. You might be surprised about what's most important to them and what they would like to be able to do or change.
- **Ask questions:** whether you are worried that it takes your child longer to pick up new skills or that they are socially awkward, it will help you both to make sense of the problem.
- **If you don't understand, your child won't either so keep asking:** explanations need to be simple and strategies must be straightforward.
- **Find out what you can both do at home between appointments.** Check that you understand what you will be doing and why. If the advice sounds counter intuitive, ask why it will work. It's much harder to take a different approach and embrace new ideas if it doesn't make sense.
- **Ask your therapist to give real examples,** and show you what they mean
- **Get them to rehearse with you** and practise until you feel confident
- **Make sure you will get a written copy of the recommendations**
- **Ask for help getting hold of resources or equipment** if it might prove tricky
- **Get details of useful websites and online resources**
- **If trialling a new treatment, be sure you both agree how to report unexpected side effects**
- **Check how your child's school or nursery can play their part** and how you'll both be kept in the loop.

AT HOME

- **Build any exercises or strategies into your daily routine:** often you can harness and adapt everyday activities to embrace and practise these new approaches.
- **Enjoy yourselves:** if you can make it fun somehow, the therapies will be more enjoyable and more effective.
- **Take it easy sometimes:** remember, not every moment needs to be filled with purposeful activity. Give your child time to relax and play.
- **Be realistic:** it's what happens day in day out that matters most. Until it feels like second nature, doing things and thinking differently can feel like hard work. Any new approaches need practice - lots and lots of it - so don't expect to see big changes quickly.
- **Be kind to yourself.** Take a longer view: quiet optimism and patience will make a difference. With practice, we can all be our child's best therapist

HOSPITAL TREATMENT

Health Passports

If your child has a condition that means they have to visit hospital or health clinics quite often, or their additional needs mean they need extra help to communicate, or they find it stressful to be in a situation that is different for them, you may find it a real help to create a Health Passport for your child. The Specialist Nursing team at Seaside View have developed this with parent carers. The passport includes details such as 'How do I show pain and how can you support me?', 'What makes me anxious' and 'How am I usually' (vital for our young people whose 'usual' may differ from that of other children) as well as information about medication, toileting, feeding and communication. It reflects the very unique nature of our children and will give health staff an instant snapshot of your child and a better understanding of their individual needs. Staff at The Alex tell us they find the children's Health Passports immensely helpful, so it's worth reviewing it regularly and keeping it really up to date.

You can download the Health Passport from the Amaze website or call Seaside View for a paper copy. Simply fill it in and hand it to health care staff when you arrive for a planned or unplanned visit to hospital or other health care setting. You can also ask for help from The Alex in filling in the form if you are unsure.

The Alex operates a text reminder service for appointments, and sometimes letters do go astray in the post, so making sure that your contact details are up to date is really important. Also to say that if appointments are missed more than once, there is a danger that the child is taken off the list and you may need to go back through the referral service via your GP.

Trips to A&E

Accidents and emergencies might happen to anyone at any time. The main high-tech A&E department for this area is at the Sussex County. The Alex has a 24 hour Children's Emergency department for children referred by GPs or arriving via A&E.

The Royal Alex has worked hard to create a welcoming environment for children: there's a sensory garden and sensory equipment in one of the assessment rooms in A&E, as well as a new SEA LIFE-themed sensory room.

You can't take it for granted that other A&E departments will always have qualified paediatric nurses on duty, and also, if you are away in another part of the country, your child's medical records will not be readily available. Obviously, in this situation, parents have a crucial role to play in helping staff to help their child who they won't have met before. Savvy parents tell us they always take their child's Red Health Book and their Hospital Passport with them, if they are away.

I think you can help the health service to be more useful to you. We were up at the A&E department at the County three weeks running one time, and I always find if you're in a place like that where you might have to wait a long time, it's no use just sitting there waiting and hoping your child won't have a massive tantrum. You've got to be upfront and you've got to tell them exactly why your child's got to be seen next, and they were always absolutely brilliant and got her in there really fast.

In-patient treatment

In our area, most children who need hospital treatment go to the Alex. Sometimes children are sent to Great Ormond Street or to other very specialised centres, where they may spend some time before returning to the Alex for their on-going care.

Children who are treated at the Alex may already have been seen by specialists at Seaside View. Staff from the two sites have plenty of contact with each other, and many of the nurses have years of experience of the conditions treated at Seaside View. However, everything you can do to share your own knowledge and help communications will make things easier for your child. Amaze produces a factsheet, 'Admissions to hospital', so call us for a copy. You should be able to stay with your child at the Alex in a bed next to theirs or in the parents' accommodation.

You have to be very specific and say, 'Look, she really is like this', and 'No, she can't do this', and 'If you're calm, she'll be calm', or whatever. Be up front so that they know the problems - spell it out!

TIPS FOR ADMISSIONS TO HOSPITAL

- **Get a Health Passport** (see above for details).
- If your child has communication difficulties, **write out a guide to help the staff understand** what he or she is saying. For example, if they use signing, how do they indicate for 'toilet' or 'ouch, that hurts'?
- **Tape important messages that you want everybody to be aware of above the bed** or on the locker.
- **Talk to everyone, whenever you can**, to ensure that as many people as possible understand your child's needs.
- **Make sure you are 100 per cent clear what is happening.** Ask questions, and ask again, if you still don't understand. To feel safe, your child needs to feel that you know what's going on.
- **Ask for cover to go for a comfort break or get a cup of tea.** Depending on your child's additional needs, they may need one-to-one supervision at all times to keep them safe. Explain this to staff and see if they can help. There are individual rooms at the Alex which seem appealing, but may make it harder for you as a parent to get support. Friends and family come into their own at times like this.
- **Don't forget non-medical staff on the ward:** they may see the children more often than doctors and can be very good at making children feel secure.
- **Don't assume that every member of staff knows everything about your child's condition.** The information you gave the person in ENT won't necessarily have got through to the X-ray department by the time you will see them. Be happy to tell it again.
- **Explain to other children in the ward about your child's additional needs** and find out what your child would like them to know (and also NOT to know)
- **Ask for the Play Specialist** to visit

It is your child, it is not the doctor's child, and if you don't like the way they're bandaging him or they're doing something that you know will upset your child - even though all the other children with that syndrome are bandaged in that way - you say so, you negotiate.

If you're not happy with your child's treatment or care, speak to the Ward Manager in the first instance; if you're still unhappy then take your concern to Matron or the head of nursing at the hospital. If you can't resolve the issue directly with the hospital team you can contact Healthwatch (see below).

FURTHER INFORMATION ABOUT HEALTH

In these days of access to home PCs and smart phones, many of us will spend hours Googling our child's condition on the internet. This can be enormously helpful by reminding us we're not alone and that there are families dealing with many of the same issues as us. However, it can also be time-consuming and unreliable. It's important to remember that search engines rank for relevance to your query only, they don't operate any kind of quality control, so you may find that many of the sites you are led to are old, American or trying to sell you something!

We wouldn't deter you from researching your child's condition or looking for solutions online, but we would advise you to exercise a bit of caution and common sense. If a website belongs to a large national charity or comes from a government department you can usually rely on the quality of its content and its impartiality. If you are trawling some of the smaller, more independent sites, use your common sense and take things they say with a pinch of salt.

Two safe places to start are NHS Choices (www.nhs.uk) and Contact a Family (www.cafamily.org.uk). You can rely on the fact that their information is up to date and thoroughly checked. Many of the larger charities or hospitals also run Facebook groups or forums for parents which can be a great way of reaching out and finding out what to expect.

For further information about local NHS services, you should contact Healthwatch Brighton and Hove. If they don't have the information you need, they'll do their best to find it for you. They can also guide you through the system and help you to sort out problems or make a formal complaint if it comes to that. Read more about making complaints in the chapter called 'Making Systems Work for You'.