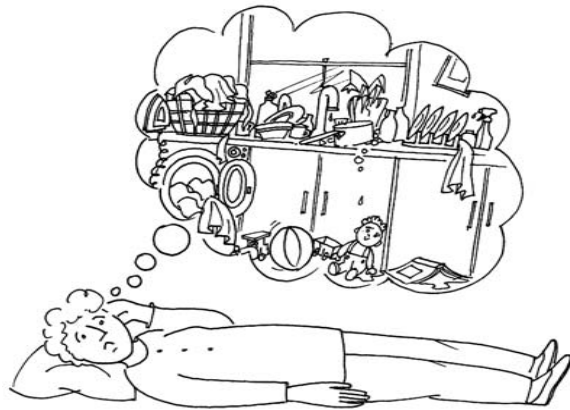


Chapter 6

Help with daily life



Life with a child with any sort of disability or special need can make managing daily living harder in various ways. For many of us, just finding out about the kinds of help available was difficult enough in itself.

In this chapter we tell you about some of the services and types of practical help that are around, how to go about asking for it, as well as suggesting places to look for other information and keep up to date with new developments. The Local Offer on the council's website has information about all the services the council expects to be available in the city for children and young people with SEN and disabilities - visit www.brighton-hove.gov.uk/localoffer. It's good to remember that some services for disabled children are city-wide. However, more

mainstream services may also be useful to you and these are often provided according to which area of the city you live in, so it's worth checking locally.

In Brighton and Hove most of the specialist health and social care services for children and young people are managed by the Integrated Child Development and Disability Service, based at the Seaside View Child Development Centre. You can find their number at the back of this book.

Remember, every household is different and you will need to work out what help is best for you and your child. It may be that you feel you need a regular night off every so often to give some attention to the rest of your kids. Or you need to get your house adapted so your daughter can go to the loo downstairs. Or perhaps you'd just like someone to take your son or daughter out every now and again so they can make friends and you can do the housework.

Whatever you want, don't be afraid to ask. Ask other parents where they got that equipment, how they were able to access that service or simply how they coped. Ask professionals what is available, ask groups and organisations where to find information, ask your friends, relatives and neighbours for a bit of extra support.

If people say to me 'let me know if I can help', I take them up on it - find something they can do! People in my church have been wonderful, providing meals, doing the ironing, giving practical help during the hardest times.

Unfortunately, it's often the case that families only ask for help from social services when they are in crisis or feel that they can't cope anymore. This is natural and very common. However, it's useful to remember that it can take quite a while to get an

assessment of need for a service and even longer for the help you need to be arranged. So, it's worth asking for help with daily life before things get difficult, if at all possible.

HOW TO ACCESS SERVICES

You may have many professionals involved in your child's life or you may only have one or two, but it's handy to figure out who can help you access services that your child may need. Your health visitor is often the first place to start when your child is small - they should be regularly monitoring your child's development and listening to any concerns you may have, and will usually refer your child to a specialist if they think it necessary, or if you ask them to. Health visitors work with Children's Centres, which are another good place to start as they may have early years visitors and others who can help, or you can ask your GP or even a teacher at your child's school. Any of these professionals can refer you for additional specialist support.

When we moved house our new health visitor was brilliant, she arranged a meeting of all the people involved with our son – physio, paediatrician, PRESENS, speech and language therapy, even his nursery teacher – so we could discuss our concerns with everyone and form an action plan for him. We felt reassured that everyone was working together and the health visitor was keeping an eye on everyone!

Family CAFs and referral to additional and specialist services

Family CAFs (Common Assessment Frameworks) are used in the city as a way of pulling together extra help for families who need more than the universal services that are provided for all families and children. They are not specifically for families of disabled children, but you need to have a CAF before you can

be referred for some services. You can ask any education, health or social care professional who knows you to start a Family CAF. Or you may find they suggest this to you. The CAF happens whenever someone who works with a child or family thinks they are going to need extra help that goes beyond a single issue or involvement with just one service or professional. The aim is to coordinate what is planned and avoid you having to have lots of different assessments and meetings. You have to agree to the CAF and be involved from the start. There may be a meeting that draws together a Team Around the Family (TAF) of people from services that may be able to help. These will depend on your particular circumstances and could include schools, health visitors, nurseries, housing, substance misuse services, play and youth work, and services from the community and voluntary sector.

If a Family CAF goes ahead there are three stages:

1. **Assessment** – you talk to a worker who knows you or your child, they find out more, fill in a CAF form and agree with you whether to go ahead with the CAF.
2. **Action plan** – you, and the workers who can help, discuss how to support you and your child. Usually this will be at a TAF meeting. This is written up as an action plan and a lead professional is picked to follow it through.
3. **Review** – you and everyone involved look at how the plan has worked and what comes next.

If it is clear that your child needs to be assessed at Seaside View you don't have to wait for a CAF before being referred there, although a Family CAF may also be useful. And if you need a highly targeted type of support such as respite you will need to go beyond a CAF and get a social work assessment.

Getting help from a social worker

I think you cope, you don't really ask for help when you're feeling articulate. You usually end up waiting until you're not articulate and everything's gone to pot, and that's when you need these people.

Many of us turned down the offer of a social worker when we first discovered we had a child that was disabled. We couldn't see how it was relevant to our situation. We thought that social workers only dealt with families where there was abuse or neglect, and where children were 'at risk'. We were afraid that social workers would judge how good we were as parents, particularly if we admitted to feelings of anger towards our children or that at times we felt unable to cope.

In fact, although social workers have to put the safety of the child first, they cannot take children into care or put them on the 'at risk' register without parents' knowledge and involvement at every stage, or without trying every alternative course of action first. Instead, social workers feel that if at all possible the best place for a child to be is with their family. But it is recognised that caring for a child with significant additional needs is a challenge at times so identifying a disabled child as a 'child in need' is no criticism of their parents.

As we said earlier, many of us only asked for help when we were desperate. By law, social workers have to put at the top of their list families where children are 'in need' (this includes eligible disabled children), 'at risk' or need protection. So, unless you make it clear just how difficult things are, it's possible you may find your request for help falling to the bottom of the pile with a long wait ahead of you. If you need help now, say so, or try to ask for help before you reach crisis point.

What I realised after I'd asked for help was that my entire life had been out of control for ages. I thought I was coping - I thought I was keeping the lid on the pan.

Before you meet the social worker, try to think about how your life has changed and become more difficult as a result of caring for your child, and what kind of help you think you all need, now and in the future. Social workers have a legal responsibility to consider your needs as a carer of a disabled child.

To get help from a social worker

You need to ask for a social care assessment of your child. The law around social care can be confusing, but essentially the local authority has a duty to assess your child if they may be "in need" and being disabled is one of the defined reasons that a child can be "in need". Even if your child's additional needs do not mean they are seen as disabled, they may still be entitled to an assessment if their health or development will be impaired without extra services. If it looks like your child is entitled to be assessed they have a duty to make an initial assessment within eight working days and, if it is necessary, a more detailed core assessment within 35 days. If you already have a CAF they'll use this as their starting point. Depending on the nature of your child's needs, there are two places to ask for this assessment:

- Contact the social work team at Seaside View if your child has a severe learning and/or a physical difficulty or a moderate learning difficulty with challenging behaviour/mental health issues whose needs can only be met through the input of specialist social work support services.
- If your child doesn't have the kind of disabilities described above, contact MASH (Multi-Agency Safeguarding Hub), the council's new 'front door' for all social care and safeguarding enquiries relating to children and families. If a child is at risk of harm the referral will be dealt with by

MASH. All other social care enquiries will be referred to the new Early Help Hub for assessment. Call MASH on 01273 290400.

What happens when the social worker visits?

On the home visit the social worker (or social work resource officer) will carry out an assessment of your child's and your family's needs. This 'needs assessment' is taken to the service manager and all assessed requests for social care support for disabled children are taken to the resource panel at Seaside View.

As a parent carer of a disabled child you are also entitled to a 'parent carer's needs assessment' if you request one. The assessment that is used by Seaside View social workers is intended as a combined assessment of your child's needs and yours as a carer, but you may want to mention your right to a parent carer's needs assessment to remind them to focus on this too.

If your child needs equipment or adaptations to the home, an occupational therapist will carry out their own specialist assessment.

Getting an assessment does not always mean you end up getting actual services from social care. The assessment can find that your family has a number of needs but not identify all (or indeed any) of them as being needs it is necessary for them to meet by providing or funding a service. They can suggest other sources of support for your family or community resources you could use. Ultimately they will be considering whether your child is at risk of "significant harm" without getting some provision. If they do decide an intervention is required they must set this out in a care plan which should be a realistic plan of action.

What social workers can offer

Social workers can be a source of practical and emotional support for parents and they are able to offer other kinds of help. Between us, we have used them for:

- providing adaptations and special equipment;
- short breaks, which can be with another family, outreach, residential or via Direct Payments;
- help with filling in forms and getting financial help;
- support and advice for all family members.

Tips for working with social workers

Many of us have had lots of contact with social workers over a number of years and we suggest you have a look at Chapter 2, 'Survival Strategies', for some practical tips for working with professionals. Here, we offer you a few extra hints which some of us have found useful:

- If you get a 'no' to your request for help you are fully entitled to make a complaint or representation to a manager. Don't be afraid to ask again as your needs and your child's needs change.
- Find out what services other parents have got, and how they managed it. Inside knowledge can be very useful but bear in mind that each support package is tailored to a family's support needs so families will receive different amounts of support. This can be true even if their child's needs appear to be similar.
- Get other people on your side. Your GP, consultant or health visitor can write letters for you, explaining what you need and how much you need it.
- It's important to build up a good relationship with your GP and social worker as you go along, so that when you are desperate they already know who you are and what you and your child's problems are.

- However, if you're not happy about the way things are going in your contact with social workers, then Chapter 7, 'Making systems work for you', may be of help. Challenging decisions or making complaints can be stressful, but unfortunately it is sometimes necessary. Amaze and other organisations may be able to help.

Keyworking scheme

When families have many professionals involved in providing care for their child a keyworker can act as a main point of contact for all those involved and enable this care to be coordinated. If your child has complex needs or multiple disabilities then this service may be suitable for you. Usually to get a keyworker your child must have four or more specialist agencies involved in providing on-going therapies and services, some of them being from Seaside View. This does not include general services such as your health visitor or GP. There are a couple of designated keyworkers based at Seaside View, but a professional that is already working with you can be your keyworker in addition to their specific role with you. If your family has a named social worker, then they act as the family's keyworker. You can apply to have a keyworker or ask another professional to apply for you.

WHO PAYS AND HOW?

Most kinds of help available for families with a disabled child are free. Parents can't be charged if they are on Income Support, or receiving working tax credit or child tax credit (above the family element). Budgets are almost always very stretched. Many parents are happy with the way their needs have been assessed, but then find there's a waiting list for all those things their assessment says they need, like outreach and short breaks. Direct Payments have been introduced as an alternative way of providing short breaks and other types of support for disabled

children and their families, by passing funds over to families to arrange things themselves.

If your child's disability involves ongoing medical treatment and they are assessed as having significant health needs, then there is a health funding panel which decides whether continuing healthcare funding will be provided to meet your child's needs. All requests for this funding have to come with a health assessment. In practice your child's needs have to be significant to be eligible for this funding.

Over recent years, there has been a move in adult social care towards individual or personal budgets with the aim of allowing people more control over their care and support. The idea is to work out the total amount that might be spent on an individual's care (often using something called a Resource Allocation Scheme or RAS) and then allow them to decide how to use that money to suit their needs. Some of the personal budget might become a Direct Payment, but not necessarily. Personal budgets have spread to children's services, firstly in social care and now education and to some extent health, through Education, Health and Care Plans (see the 'Education' chapter). In Brighton and Hove everyone is still trying to work out how to get individual budgets working well, but Direct Payments are already widely used for social care support.

Using Direct Payments

Direct Payments are a way of giving more choice and control to disabled children and their families about the services they use. Parents can be given money to pay for and arrange services for their child, as an alternative to those their local authority offers. You can use Direct Payments to employ someone to care for your child (usually called a PA or personal assistant), or to buy into a local service, like a day nursery, an after school club, holiday play scheme or even a residential short break unit.

Direct Payments for parents are managed by the Children's Disability Service. If your child is assessed as needing a service, you cannot be refused Direct Payments if this is your choice. Local authorities have a duty to offer Direct Payments: the law says they must tell you about Direct Payments and support you if you wish to take these up.

For more information on Direct Payments see chapter 3, 'Money matters'.

SHORT BREAKS OR RESPITE

We all need a break and that's nothing to feel guilty about. Having a child with special needs puts extra stresses and strains on relationships and family life. Short breaks are all about giving you and the rest of the household that break - allowing someone you trust to look after your child while you go out or spend time with other family members. It can include care in the home, day care away from the home, residential breaks, family link schemes, holidays, after school clubs and holiday play schemes.

It's a big thing at any time, isn't it, putting your child in someone else's care... You feel better about having admitted that things are too much at times. I phoned up Susie's link family and I said, 'Look, we really are having a crisis, would you be able to have her for a whole day', and they said 'Yes, fine, we'll have her'. It was so good because then she knew how I felt...

The other benefit of a short break is that it can be a great confidence booster, for you as the carer and for your child. You find out that it is possible to let your child go, and your child finds out that he or she can enjoy life away from the family. Some of us have found that this really pays dividends in the long term, because our children have learned to adapt to new

situations and experiences much better than they might have done otherwise.

Sometimes it's not easy to admit you need a break. You struggle so hard to keep going, the thought of having to make any extra arrangements for your child's care seems hardly worth the effort. But once you get over the hard work, most of us have found any good short break a life-saver, and well worth the effort spent on getting it right. Direct Payments are a really useful way of putting aside some money to pay for an occasional short break, too. Amaze produces fact sheets on short breaks and childcare questions, so contact us for copies.

With our short break, the first person who was recommended to us, we actually turned down. I gave it three mornings' trial with this person and she was a brilliant carer, but she didn't have enough oomph for Jane, and I could see it wasn't going to work. So I explained, and we were given another one and she's been with us two years, and is absolutely brilliant.

Getting a short break

A word of warning: a short break can be hard to get! First you need to recognise you need it and deal with all the difficult emotions that may bring up; then you need to start asking for it. It may begin with just a few hours, but can then lead to longer periods that will give you a wonderful break. Here are a few tips:

- Getting a break or respite usually means asking a social worker for an assessment. Put it in writing and keep a copy.
- Explain how the demands of caring for your child are taking their toll and make it clear that things are difficult.
- Ask other professionals to support your request by writing to your social worker as well.

- What's right for one family may not be right for yours so think about what would work.
- If you are offered a family-based short break, meet with the family first and spend time agreeing how best to trial things.
- If you are offered a residential short break, go and visit first when other children are there and ask questions. If you want to, feel free to ask your social worker if they can visit with you.
- Write down a list of questions beforehand and take this with you to visits or meetings about short break arrangements.
- Keep an open mind as sometimes first visits don't go well and often it takes time for children to settle in with new people.
- If you want something more flexible, think about asking for Direct Payments. We explain about this in the 'Money matters' chapter.

What kind of short breaks are available?

Realistically, most short breaks will only be provided for more severely disabled children. So unless your child has severe learning difficulties or complex needs and behavioural difficulties or physical disabilities, you are unlikely to get any respite care from the council. If your child is more able, you could think about short breaks in terms of childcare, after school clubs, or leisure activities where you can leave your children for a while. See the sections on 'Childcare' and 'After school clubs and holiday play schemes' further on in this chapter for more detailed information.

Parents who do get more traditional types of respite will find that they are usually given a pick and mix of different types of short break, such as one night's respite, one day a week at an inclusive play scheme in the holidays, and a befriender once a

week. Let's take a closer look at the various types of short break available.

Short breaks that require an assessment by a social worker

Outreach service

The outreach service is for children and young people aged 2 to 18 with moderate to severe disabilities. It supports them to access activities and events in their local community, on an individual or group basis after school, at weekends and also during school holidays. Outreach also provides essential crisis intervention support to families who may be close to breakdown, or where there may be child protection and safeguarding issues. The service is accessed via a social work assessment.

There are two women that come. They're very different but they're both great with her. It's hard work at the beginning but it's fine now, and they're quite adaptable - it's very much geared around what you want, and you dictate what happens.

Residential services

Drove Road provides short breaks and residential care for young people aged 8 to 18 who have a learning disability and may also have challenging behaviour. Young people have an allocated number of nights that are planned ahead and this can take place during term time, holidays and weekends.

Tudor House provides short breaks and residential care. It's open to young people aged 10 to 18 with a learning disability who may also have a physical disability or more complex needs. The homes provide a range of opportunities and experiences within the local community so young people can enjoy their breaks as much as possible. These units are both run by the Child Development and Disability Service.

It was difficult to let Zoe go. Although I knew that she needed that time at Tudor House as much as we did, it felt strange to think that someone else could give her all that she needed as well as we could.

Link Plus

Barnardo's Link Plus is a service for disabled children which provides family based care ranging from a few hours or an occasional overnight stay to full-time foster care. The aim of this service is to 'link' families who require care with other local families who will share the care of the child. Care usually takes place in the carer's home. Some children have regular overnight stays throughout the year, others have occasional weekends away from home plus extra care during the school holidays. Some children and families prefer to have day care sessions only.

The Home Support Service provides support to a parent of a disabled child, either within their own home or out in the community, including siblings. The home support workers are carefully matched to each family. Link Plus also operates a Contract Carer's scheme. A Contract Carer is a self-employed carer offering regular short breaks for children and young people with autism and/or challenging behaviour in the carer's home following assessment and approval.

I get two nights a week 5.30 - 8pm. They take her out, give her tea and get her ready for bed. They take her swimming and it's just lovely, she's doing normal things after school. I can't take her otherwise, because of the other children.

Foster care

The Brighton & Hove mainstream fostering service can provide overnight or longer-term care for children and young people with special needs, where the children are cared for in the foster family's home. All carers go through a rigorous fostering assessment and care is taken to match suitable families.

Crossroads

Crossroads Care is a charity that provides respite care in your own home, on a regular basis, to give you a break as a carer. Crossroads care workers can come and play with your child for a few hours a week or month, and can visit after school, at evenings or weekends. Contact them direct or get referred by a professional like your GP, health visitor or social worker.

I did have two people from Crossroads who came and stayed in the house and played with her. These women who came in loved children, and they were brilliant. They were all mums and they brought an enjoyment to the house when I couldn't, when I was struggling.

Short breaks without an assessment

These short breaks (funded partly or fully by the local authority) are suitable for children with disabilities but you don't need a social work assessment to get them. Often you will have to pay towards the cost of these and families that get Direct Payments might use them for this:

BHIP (Brighton and Hove Inclusion Project) offers an inclusive after school club for children aged 4 to 12, as well as a youth club for the over 11s and a holiday playscheme.

Cherish is run by Brighton & Hove City Council. It provides two specialist term-time youth clubs for young people aged 13 to 18 with a wide range of learning disabilities based in specific venues, as well as Easter and summer holiday schemes based within the community. All are staffed at a ratio of one to one. They also run a Specialist Young Adults service during holidays and term time for young people with learning disabilities aged 19 to 25.

Extratime provides inclusive after school, Easter and summer holiday play schemes for children at Hillside School, St Lukes

School and Ash Cottage next to Downs View School. They run holiday youth schemes for disabled young people up to 19 in partnership with Sussex YMCA and The Crew Club. They also support disabled young people to use mainstream youth activities through the Access 2 Youth scheme.

The Compass Card is a leisure card which provides discounts and special offers for leisure activities across the city, such as swimming, cinema, bowling, and more. There are also regular Compass Card Activities with specially trained instructors. To be eligible for a Compass Card, children need to be aged 0 to 19 (soon to be 0-24), with a special need or disability that has a significant effect on their daily life and living in or going to school in Brighton and Hove. In general, children on the Compass either have a Statement of SEN or an EHCP, or are in receipt of Disability Living Allowance. There is more about The Compass in the chapter, 'Social and Leisure Activities'.

All-Terrain Beach Wheelchairs can be hired for use on our beaches. They can be booked in advance from the Seafront Office. They are free to use with a refundable deposit.

Forest View Holiday Lodge is a fully accessible static caravan in the New Forest which is available to use at a much discounted rate. The caravan was bought using Aiming High funding to provide an affordable, suitable holiday venue for families and children with special or additional needs. For more information call 01273 295530.

Health-related short breaks

Chailey Heritage

Chailey Heritage runs a short break service for children who have complex physical disabilities and/or medical needs. Children are usually referred by social workers or health professionals. Chailey Heritage can provide residential short

breaks where each child has a keyworker, a named nurse and a care plan to ensure that the break is enjoyable, useful and medical needs are met. They also have a service where nurses and carers provide short breaks at home.

I've got Chailey, and it's tailored to what Christina needs, and they have her for six hours a week in one block.

Chestnut Tree House

Children with life limiting or life threatening conditions can have short breaks at Chestnut Tree House near Arundel. Sometimes your child may stay there while you have time away perhaps with your other children, and sometimes you might stay with them but enjoy having others take over their care so you can rest and relax a bit. They can offer some great support to families who use them, including counselling and activities for siblings, so this is more than just a break. A health professional can refer you to Chestnut Tree House or you can contact them direct to see if your child may be able to use what they offer.

Childcare

For parents of more able children, paying for some childcare may be the best option for giving you a break. The Family Information Service (FIS) keeps up to date lists of childminders, nurseries, pre-schools, nannies, parent toddler groups, after-school and holiday clubs. They can also offer extra support to families of children with additional needs to find the right childcare. This might include making appointments for you or linking with professionals who can provide appropriate training to the childcare provider.

FIS produce a booklet called 'Childcare Choices' which has a section about children with special needs and explanations of all the types of childcare and financial support available. This

includes Childcare Inclusion Funding which can help make sure your child can take up a childcare place by paying towards extra staffing, special equipment or adaptations to the premises. For under fives there is also the funding for early years education which in practice overlaps with childcare as it is often provided by the same play groups and nurseries. Children are entitled to free part-time early education (15 hours a week over 38 weeks of the year) from the term after their third birthday until the term in which they turn five.

Some children are entitled to free early education/childcare from age two, for example if they get Disability Living Allowance or if you are on Income Support. The Family Information Service can tell you more and help you apply. Call FIS on 01273 293545 or visit their website at www.brighton-hove.gov.uk/fis. Amaze also produces two fact sheets, 'Childcare Questions' and 'Choosing Childcare', with lots more information about what's out there. Call our helpline for copies of either.

If you prefer your child to be cared for in your own home, FIS also runs the At Home Childcare Service, which matches Ofsted registered childcarers with families who may find it difficult to use traditional childcare. The At Home Childcarers are self-employed so rates will vary but the FIS matching service is free. You should also talk to your health visitor as they can advise you on what should be in place for your child to attend a particular setting, particularly if they have medical or physical needs.

After school clubs and holiday play schemes

If your child is at school, you may need an after-school club or play scheme for the school holidays. Many schools have their own after-school clubs, while some are run by private companies or charities – ask your child's school or contact FIS for details of suitable schemes. All schemes should be ready and

willing to include disabled children. Some are especially welcoming to disabled children and young people. We have mentioned Extratime, BHIP and Cherish already. Honeycroft in Conway Court is another really inclusive one, whilst Whoopsadaisy runs holiday schemes for children up to 12 with cerebral palsy and similar physical needs.

If you need help with finding the right after school or holiday scheme for your child you can ask for FIS' Extra Support Service. You may also be able to apply for Childcare Inclusion Funding as explained above, if your child needs additional support to make their placement viable.

For summer schemes, FIS' 'Summer Fun' booklet lists every holiday play scheme provider as well as other activities and events – look for it in local libraries or on the council's website.

Private care

If you've exhausted offers of help from your family and the forms of short breaks we've described above, there are some private short break agencies, though these are usually expensive. You could pay for them with your Direct Payments as it is not usually possible to get funding for them. You will need to find out about the agencies yourself, for example, by doing an internet search.

DAILY LIVING EQUIPMENT

If your child has severe physical difficulties which make it hard to manage everyday things such as meal times, going to the toilet or getting around, you may be able to get special equipment or adaptations in your home to make life easier.

You can get some things to help with looking after your child at home through a loan scheme run by social care and the health

service. Non-slip mats, toilet seats, bath aids, ramps and other equipment might be available if you ask your health visitor, social worker, occupational therapist or the Children's Disability Team.

There are constant changes and developments in the kind of equipment and gadgets that are available, and it's sometimes useful to be able to see what's on offer and try things out. Some of us have found it helpful to visit independent living exhibitions or centres. The Daily Living Centre at Montague House in east Brighton gives carers and young people an opportunity to test out different equipment. The centre doesn't sell the equipment but they will tell you the cost and suppliers' details. The Red Cross run a short term mobility equipment loan service in Hove. The Disabled Living Foundation in London is also a good place to visit if you can get there. They have a telephone helpline and their website (www.livingmadeeasy.com) has a huge database of equipment.

The biggest annual exhibitions of equipment and useful gadgets are Naidex and the Mobility Roadshow (which also has dozens of exhibitors of products not just to do with cars/vehicles and wheelchairs). The dates and venues for these are advertised in the online news site Disability Now or on the Amaze website. Disability Now carries adverts for second hand equipment, or you can try the Disability Equipment Register as well.

If looking after your child involves a lot of lifting, the Back Care Support Service offers advice and training to carers (see below).

Specialist equipment

The Royal Alexandra Children's Hospital and Seaside View currently share a store of equipment designed to make everyday tasks easier for you and your child. Occupational therapists and physiotherapists will assess each child

individually for the suitability of such equipment, which may then be available on short term loan.

For specialised equipment, Chailey Heritage has a rehabilitation engineering unit, which will custom-make or specially adapt existing aids to suit your requirements. REMAP and MERU are other organisations who will try to make equipment to suit your child's individual needs, which you may not be able to get anywhere else.

For buggies or wheelchairs, you will have to go to the Sussex Rehabilitation Centre at Brighton General Hospital. Referral is usually by an occupational therapist or a physiotherapist and you should get an appointment fairly quickly. However the choice of wheelchairs for children is very limited. A wheelchair voucher scheme enables people to have a 'voucher' equal to the cost of an NHS wheelchair, leaving them free to pay the additional cost to an agreed supplier for a more expensive chair.

Whizz-Kidz is a charity which provides mobility equipment for children (wheelchairs, trikes, buggies). They may be able to help if the equipment you feel your child needs is not available from the Sussex Rehabilitation Centre, for example if you'd like your child to have a better wheelchair than can be provided on the NHS.

If your child needs specialist equipment at school, you should discuss the situation with your child's school. Hillside outreach and inclusion service can provide additional advice and support to mainstream schools in relation to children with physical and/or medical needs.

ADAPTATIONS TO YOUR HOME

Getting major adaptations to your home can be a very slow process. Just getting a ramp or stair lift in your home can take a

year or more, and alterations like an extension will take at least 12 to 18 months.

Start by contacting Seaside View or your social worker, if you already have one. They will arrange for an occupational therapist(OT) to visit you at home to discuss what you need and assess to see if you are eligible for support. Recent changes in the rules for grants mean that if there are long waiting lists to see an OT, Children's Services can ask someone else (eg your GP) to carry out the assessment.

There are various ways of paying for these works. Council tenants are usually funded from budgets held by council departments. Owner-occupiers and people in rented accommodation can be assisted to apply for money the council call Disabled Facilities Grants. The maximum amount for this grant is £30,000. For adults this grant is means tested but this is not the case if the work is for a child under 19. In exceptional circumstances Children's Services may also be able to assist with costs if they are above £30,000.

The OT will continue to supervise any work you are having done. Only works recommended by the therapist will be paid for and these have to be considered essential and not just desirable. However, the Disabled Facilities Grant now has an element concerning making the home 'safe' - this was added specifically with the needs of children with challenging behaviour in mind.

The Adaptations Service have helpful booklets that explain more about how this all works.

Moving home

It may be that your present home isn't suitable and can't be adapted to meet your child's future needs. If you are a council

or housing association tenant you should speak to your housing officer about transferring to a more suitable home. Although it's often a long wait, sometimes, if you need specially adapted accommodation, you will have a better chance of being able to move, or your name can be put forward to another housing association that has appropriate flats and houses.

If you rent your home from a private landlord it can be even more difficult to make it suitable for your child's changing needs. The council's Housing Options Service in Bartholomew Square in Brighton can give you information about getting onto the council or housing association waiting lists.

The Housing Options Service may also know about any local estate agents who keep information about adapted and accessible properties for sale in the area. Although it's a national website it's also worth looking at Disability Now as many people advertise there when they are selling property suitable for households with a disabled person (or you could place a 'wanted' advert). There's also a property website dealing exclusively with accessible homes for sale and rent - 'The Accessible Property Register'. See the Daily Life contacts at the back of this book for details.

OTHER KINDS OF PRACTICAL HELP

This section includes a range of other schemes which can help with day to day living. For information about the schemes which primarily offer financial help, such as Motability and the Family Fund, see Chapter 3, 'Money matters'.

Help with health issues

Sometimes the help you are giving your child may cause you physical pain, particularly if you are having to do a lot of heavy lifting. Brighton and Hove's Back Care Support Service is a free

service for carers who are experiencing or worried about back pain. The service gives practical advice and training on safer ways of lifting and handling, back care and helpful equipment. You can refer yourself or ask your GP or social worker.

There are courses to support and encourage you to look after your health and wellbeing as you care for your child. The Sussex Community NHS Trust Expert Patients Programme (EPP) offers Caring with Confidence which is a free programme of flexible sessions offering support to carers. Amaze runs Looking After You courses that combine a chance to talk with learning relaxation techniques and bite-size Pilates.

There are a number of organisations offering complementary therapies and treatments, some free or at reduced prices for parent carers or children with additional needs. Contact Amaze or the Carers Centre for more information. The Carers' Card also offers a range of discounts designed to look after your health and wellbeing – see page 189 for more details.

You can find contact details for all the organisations mentioned here at the back of the book.

Carers Emergency Alert Card

This is a small card you can carry with you with a message saying 'Someone depends on me. In an emergency please telephone ...' That number will alert the Care Link Centre, which will respond by carrying out the instructions on an enrolment form previously filled in by you, the carer, with details of people who may be able to provide care in your place. If you do not have family or friends who would be able to assist at short notice then back-up services may be provided by the council. Call the Emergency Back-Up Scheme for Carers via Access Point on 01273 295555 for information.

Free nappies

If your child gets to four years old and still needs nappies throughout the day because of his or her special needs, you should be able to get them free from your health visitor. School-age children can get them via the school nurse and six products per day is the usual maximum number of items allowed. The Continence Adviser at the Children's and Young Persons Continence Service may also be able to help. You can contact them through your health visitor, school nurse or district nurse.

GETTING OUT AND ABOUT

Those of us who have children with complex physical needs have to plan outings, even simple everyday ones, with care. Even a trip to a supermarket can present problems if your child uses a wheelchair or large buggy. The local council and access groups produce sets of leaflets about access, which can be a useful starting point. They have details of a wide range of accessible places locally, including disabled toilets. They are also useful if, for instance, you want to find out which branch of your bank or building society has a ramp.

If you use the internet, the Fed Centre for Independent Living's website contains an Accessible City Guide giving information on accessible accommodation, transport, restaurants, bars, clubs, shops or attractions in Brighton and Hove, as well as information on accessible parking in the city. Disabled Go is a website with access information for many other towns around the country. Also you may be able to get a RADAR key to open accessible public toilets - contact the council or Disability Rights UK.

It is always worth checking with the place you are going to because information does get out of date, and sometimes the level of access described in leaflets can be misleading.

Enjoying the local beach and parks

There's now an accessible walkway for wheelchairs in front of the lifeguard station near King Alfred Leisure Centre car park. You can also book special beach wheelchairs from the Seafront Office on 01273 292716. The council website also has lots of information on accessibility in public facilities like parks – visit www.brighton-hove.gov.uk and follow the 'Leisure and libraries' link on the home page.

Blue Badge scheme

The Blue Badge scheme entitles the holder to parking concessions to make it easier to park closer to your destination. You can use it in anybody's car, but it belongs to the child and is there to help them rather than the rest of the family. It is usually valid for three years.

Brighton & Hove City Council administers the scheme and applies strict criteria. Children are unlikely to get a Blue Badge if they are under two unless they have a medical condition that means they need to travel with bulky medical equipment or be close to a vehicle for emergency medical treatment. For children over two, it will depend on the degree of their disability. They will normally qualify if they are receiving the higher rate of the mobility part of Disability Living Allowance or are registered blind. Contact the Parking Officer at the council to apply (see Blue Badges in our contact details). There is more about Blue Badges in the 'Money matters' chapter in the section on the mobility component of DLA.

Disabled parking bay scheme

If your child has problems with getting around and has a blue badge, you may be entitled to a disabled parking bay outside your house as long as you do not already have off-street parking. Ask for a form from the Highways department at

Brighton & Hove City Council. It's important to note that, although it will be outside your house, the parking bay is available for use by anyone who has a Blue Badge.

Free Bus Pass

Children over five who get DLA at the higher rate for mobility may be eligible for a free bus pass. To check your child's eligibility, visit the Brighton & Hove website or call 01273 291924.

WHO'S WHO IN SOCIAL CARE

Children's Centres	City-wide centres where parents and children can get services and support, advice and information
Community Family Worker	Works in the home alongside the parents, offering practical and emotional support
Duty Officer	A social worker on the 'duty desk' taking new referrals and dealing with emergencies
Early Years Visitor	Work alongside health visitors as part of the Children's Centre teams
Family Link Workers	Also known as Linx workers or Parent Support Advisors, they provide support to families and are a link between home and school
Health visitor	Visit children in their homes from birth until they go to school, checking their health and development
Key worker	Acts as a main point of contact for everyone involved in the care of your child and enables this care to be coordinated
Occupational Therapist	Carry out specialised assessments for families who need equipment and adaptations to the home

Outreach workers

Provide programmes of activities for children, either in their own home or by taking them out. Outreach workers are part of the Children's Disability Team

Social workers

Offer ongoing emotional advice and practical support to families in need. Responsible for needs assessments. Some SWs have special expertise in services for children with disabilities