

Children and Young People with Complex Health Needs - A one-stop booklet for families



foundation for
people with
learning disabilities

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Introduction

The aim of this booklet is to offer information and routes to support of a practical nature, which we hope can improve the lives of children and young people with complex health needs. It suggests ways in which your child can be supported to have fun, and gives details of what is available to make the home more comfortable and adapted to your child's needs as they grow up. You'll also find information on your rights and advice on how to start planning for changes and transitions in your child's life.

We developed this booklet from a programme to help families caring for a child with complex health needs. It accompanies a guide written as a result of the first part of the project, which describes some of the unique issues of children with complex needs and/or children who are dependent on medical technology. You can find the first booklet called 'An Ordinary Life', at www.learningdisabilities.org.uk.

We worked with a group of families over 12 months and found that what parents need is really practical information on day-to-day issues, such as how heating bills can be reduced, how their child can be supported to ride a bike or get on an aeroplane when they are unable to bear any weight, and how a parent can get out with a baby and a disabled toddler. We only touch on health, because it was covered in the first guide, and because families often already have extensive expertise in how to support their child's health needs.

As parents do not have masses of time on their hands, and have told us that they do not want to wade through lots of information before they finally find what is useful to them, there is an index at the back so that you can look for something specific and find it easily. The booklet does not cover everything, but we hope you will find some practical ideas and tips on where to go for more detailed information if required.

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Being at home



Your family home

They say that home is where the heart is, and if you spend lots of time there, it is particularly important that it should make you feel relaxed and at ease. Most children with complex health needs will spend more time at home than their non-disabled peers.

There are a number of things to think about to make sure that your home meets your child's needs. It should, for instance, be warm and comfortable, with the right support provided to enable them to continue to live there, and also to ensure that they feel included and welcomed in their local community.

Many children with complex health needs, particularly those with physical impairments, will require adaptations to the home as they grow. Adaptations may include having a tracking hoist to take them to the bathroom from their bedroom and/or lounge; transforming a room downstairs into a bedroom; or making the entrance wider to accommodate a wheelchair.

Each home is individual and families can apply for a range of grants from their local authority to make these adaptations. These include the Home Repair Assistance Grant and the Disabled Facilities Grant (www.gov.uk), both of which are accessible via local authorities. For further information about adaptations to your home, see the 'An Ordinary Life' booklet at www.learningdisabilities.org.uk.

There are many organisations offering advice and information on practical day-to-day living, such as bathing, feeding, drinking and sitting. For examples see the Living Made Easy website (www.livingmadeeasy.org.uk).

Meru (www.meru.org.uk) designs and makes very specific products for your child's individual needs, and the Newlife Foundation (www.newlifeable.co.uk) provides recycled equipment such as specialist seating, manual wheelchairs, buggies, walking frames and assisted living aids like height adjustable tables.

Latif's story

Latif, aged six, has a close relationship with his sister. His sister is at university and when she is away he likes to spend time in her bedroom, which is a loft conversion. Latif is able to climb the stairs to the room, but cannot go down unaided. His parents desperately needed help to find a way for him to get down the stairs by himself.

The request did not fit the criteria for a Disabled Facilities Grant, but a family support worker referred them to Remap (www.remap.org.uk), a charity run by retired engineers who advise on adaptations for disabled people in and out of the home.

The engineer suggested lower rails for Latif to grip on to and his family were then referred to a local charity that would help towards the cost of the materials.

Planning ahead

As young people become adults, they may wish to gain greater independence. They may be able to move into a home of their own, or you could consider building an annexe to your home for them. From the age of 16, young people may be able to claim Housing Benefit if they are renting a self-contained property from a relative. This can be an extension to a parental home, although they must have their own kitchen and bathroom.

For more information about the range of housing options for people with disabilities, see the Housing and Support Alliance website (www.housingandsupport.org.uk) and their factsheet 'Renting Accommodation to Relatives: Can they Claim?'

Inheritance

For some parents, thinking about the future and how to leave their property to their child is a cause of concern. It is worth considering setting up a discretionary trust as part of a will because it can be used to:

- leave an inheritance to your son/daughter
- set up a group of people to manage your assets (money or property) for your son/daughter
- prevent your son/daughter from losing means-tested benefits
- prevent care funding from being stopped.

There are two ways of using a discretionary trust:

- to own, manage and look after a property
- to provide money that your son/daughter can use to pay for things that they could not otherwise afford, such as holidays, equipment and activities, or to pay people to give additional support where this is not covered by statutory funding e.g. to join a club for teenagers or go shopping with a friend.

For more information about leaving your property to your child and making a will and/or setting up a discretionary trust, see the Foundation for People with Learning Disabilities' work on making financial plans in 'Thinking Ahead: a planning guide for families' at www.learningdisabilities.org.uk.

Keeping warm, water bills and council and bedroom tax

Keeping your home warm and comfortable is of paramount importance if you are caring for a child who is unable to keep warm by themselves. An allowance called 'Cold Weather Payments' can be offered if the temperature is, or is forecast to be, 0 degrees Celsius or below over seven consecutive days between 1st November and 31st March. Cold Weather Payments (www.gov.uk) can be claimed if a parent is receiving any of the following:

- Income Support
- Jobseeker's Allowance
- Pension Credit
- Employment and Support Allowance
- Universal Credit.

The Disabled Facilities Grant (www.gov.uk) could be used to install insulation and/or a better heating system, but cannot be used to meet fuel bills. Another useful organisation offering advice on heating is the Home Heat Helpline (www.homeheathelpline.org.uk), which provides specialist information and advice on ways to reduce heating bills, including information for people with disabilities.

You may be entitled to reductions in water rates if you receive certain benefits and if someone in the household has complex needs and requires higher than normal water usage. Each water company is different so it's best to check with your own supplier to find out if you are eligible for a reduction.

Ben's story

Ben and his mother live with his mother's parents, who own their home. Ben's grandparents wanted to guarantee that Ben and his mother would inherit the house. Having spoken to a solicitor with expertise in wills and trusts, they learned that they need to make a will containing a discretionary trust.

This will ensure that Ben and his mum will still be able to receive means-tested benefits, as any assets held in the trust are protected when they inherit the house.

Ben's grandparents will need to appoint at least two trustees in their will (Ben's mum is not permitted to be one of them).

Ideally, one should be a family member and the second a friend or someone who knows the family; a third trustee could be a professional to keep the legal/technical side of the trust in order.

A disabled 'band reduction' scheme is available to ensure people with disabilities don't pay more council tax if they need a bigger property or need to adapt their home because of their disability. For more information see www.gov.uk.

Housing Benefit rules have recently changed for council or housing association tenants who have more bedrooms than they are considered to need. This is often called the 'bedroom tax'. Children with disabilities are not expected to share a bedroom with a sibling if their condition prevents them from doing so.

At the time of writing legal cases are still pending, but the Government says it will not allow an exemption for an extra room for storing medical equipment or for overnight carers to sleep in under the current Housing Benefit rules. For up-to-date information on the 'bedroom tax', consult the Contact a Family website: www.cafamily.org.uk.

Health at home

Health is a major consideration, particularly if your child needs to use medical technologies. Parents and carers are often very experienced in using equipment such as gastrostomies and oxygen ventilation and spend a great deal of time teaching others (such as personal assistants) how to use it with their child.

The Royal College of Nursing has provided a guide called 'Managing children with health care needs: delegation of clinical procedures, training, accountability and governance'. This resource covers accountability for non-medical staff using a range of medical equipment and drugs in caring for children. Parents may also find it useful: www.rcn.org.uk.

Recognising pain in your child and finding the best way to relieve it is something all parents and carers do on a daily basis. If your child is unable to communicate their pain verbally to you, it can go unrecognised and untreated. Pain recognition tools are available – one example is the Paediatric Pain Profile (www.ppprofile.org.uk). This is a behaviour-rating scale for assessing pain in children with severe physical and learning impairments. The Profile helps you to interpret your child's behaviour to determine whether they are in pain.

The Profile can also be used to measure how your child is feeling on a day when they are not in pain and these measurements can be used to compare 'good' and 'bad' days. This can help your child's personal assistants, school or medical staff understand the level of pain they are in. If your child is able to express when they are in pain, Dr Friedrichsdorf's top 10 apps for pain management may be helpful: www.childrensmn.org.

Children spend on average 3,600 hours a year in bed, so it is vitally important that those with limited mobility are supported to have the best possible postural care, with effective use of therapeutic night positioning and measurement of their body symmetry.

Schools and therapeutic teams spend a great deal of time sourcing equipment, applying therapy in the school setting and teaching parents how to apply it in the home. However, neglecting a child's posture during sleep has serious health consequences. For example, it can result in dislocated hips, chest distortion and scoliosis (curvature of the spine). This can cause internal organs such as the lungs to become squashed, which can lead to breathing and digestive problems or make existing problems worse.

Poor positioning can also cause the child or young person to become disconnected from people and events around them. For example, being unable to hold their head up if they are sitting in a position that is too upright will affect their learning and social interaction.

For more information on postural care see:
www.mencap.org.uk or
www.posturalcareskills.com.

Make sure you ask your child's physiotherapist for specific guidance on how to support them properly when they are in bed.

Relationships



Building social networks

As children get older they want to spend more time with people of their own age rather than their parents. This can be more difficult to arrange for children and young people with complex health needs because of the associated health and transport issues. One way to overcome this is to develop a circle of support (www.learningdisabilities.org.uk).

A circle of support or friends is a group of people who are important to a person. Having a circle of support can help them extend their social networks through their existing contacts and interests. If your child has a personal assistant, they could be asked to get involved in supporting your child to be more engaged with school friends and the local community. Examples of how they can engage include arranging a movie night, organising a nail-painting session or supporting them to go on a shopping trip with their friends.

Circles can meet as infrequently or as often as required. At the heart of the circle is the voice of the person, with those around them supporting them to achieve their goals. See Sophie's story in the 'Having fun' section and read how some of her circle of support are helping her achieve her goal of going to a music festival.

Sexuality

As well as maintaining and extending their social networks, young people will also start discovering their sexuality. For useful reading around sexuality, see 'Growing up, sex and relationships – a booklet to support parents of young disabled people' (www.cafamily.org.uk) and 'Growing up, sex and relationships – a booklet for young people' (www.cafamily.org.uk). Contact a Family also has a podcast for young people (www.podfeed.net).

Brook, the national charity for sexual health for the under-25s (www.brook.org.uk), has a number of titles, including 'Looking ahead' (for young men and young women), and the Family Planning Association has developed resources for parents of children with learning disabilities. For more information see: www.fpa.org.uk.

Social technology

There is a wide range of technology available for children and young people with disabilities. This includes social media platforms such as Facebook and Twitter, 'apps' for tablets or mobile phones, switches, computer programmes and specialist communication systems such as 'Eyegaze' (www.eyegaze.com), which can help them communicate their needs through their eyes and can also give independence by enabling them to control television channels, the internet and lights in their home.

Having access to such technology can help the child or young person to feel less isolated, as they can be supported to text, Skype or FaceTime and use Facebook to keep in touch with friends and family.

You can find more information on these technologies from the following resources:

- www.folonghorn.com provides general information on technology use, including suggestions of suitable apps
- www.aidis.org is a charity that specialises in computer technology to help disabled people
- www.netbuddy.org.uk provides information on a range of subjects for parents of children with disabilities (including difficulties with communication)
- www.communicationmatters.org.uk is a one-stop shop for all matters concerning communication and communication systems
- www.appsforaac.net is a free alternative and augmentative communication app that can be used on a tablet that supports people to communicate
- www.multime.com is a networking tool that helps anyone to communicate and plan their lives
- www.learningdisabilities.org.uk has easy read guidance on keeping safe when using social media.

Belonging to your community

As well as living in a comfortable home, feeling at ease and connected with your local community is important for you and your child. It can be more difficult for your child to feel part of the local community if they have complex health needs.

'Community Connecting' is an approach that empowers disabled people to build stronger relationships within their communities, based on shared interests and mutual benefit. It enables them to make an active contribution by helping them to take part in specific activities, matching their skills, talents and interests with the needs of their local community.

The outcomes of connecting will vary according to the aspirations of the person involved, but may include taking on a role in a local organisation or simply finding a circle of friends. The Foundation for People with Learning Disabilities does lots of work in this area for more information see: www.learningdisabilities.org.uk.

Having fun



We all need some fun in our lives, and this is particularly true for children and young people. Being spontaneous or trying new things can be a challenge for those with complex health needs, but with some forward planning it is possible.

Toilets

A big obstacle to taking your child out can be access to appropriate toilets that have a hoist and changing bed. The Changing Places campaign (www.changing-places.org) is devoted to campaigning for more accessible toilets across the UK. Their website has a map where you can find all the accessible toilets and how to go about campaigning for one in your local area.

They also have an app that you can download for use on your mobile/tablet when you are out and about. Knowing where you can find a clean, accessible toilet can reduce the anxiety when planning a day out. A couple of companies also hire out bespoke accessible toilets, including the Bruce Trust (www.brucetrust.org.uk) and Coachbuilt GB (www.coachbuiltgb.co.uk).

The National Key Scheme (NKS), sometimes called the 'Radar key', offers a key and guide that lists the location of the 9,000 disabled toilets fitted with the NKS lock. You can buy one from this site: www.crm.disabilityrights.org.

Getting out and about

If you have a child with complex health needs it is likely that you will require a car and a wheelchair to take them out and about. If your child receives the higher mobility component rate of Disability Living Allowance (DLA) or if they are over 16 years old and receive the enhanced rate of the mobility component of the Personal Independence Payment (PIP), you are entitled to lease a car through the Motability scheme (www.motability.co.uk) and a Blue Badge. The Blue Badge entitles you to parking concessions so you can park closer to where you want to go. You can get

one from your local council department (www.gov.uk). The scheme does not, however, operate in some central London boroughs. Further details are available from the Department for Transport website (www.dft.gov.uk) or by calling 020 7944 2914.

Wheelchairs

A wide range of wheelchairs are available and the NHS wheelchair service offers assessments and equipment to suit individual needs on their website. For tips on choosing a wheelchair see: www.nhs.uk. A number of organisations and charities offer advice and grants to children who require something more bespoke.

- **Better Mobility** (www.bettermobility.co.uk) sells a range of electric wheelchairs and scooters.
- **Chunc** (www.chunc.com) manufactures posture and wheelchair solutions for children and young people.
- **Convaid** (www.convaid.com) produces lightweight wheelchairs and strollers for children with special needs.
- **Newlife Foundation** (www.newlifecharity.org.uk) can offer advice and grants towards equipment such as wheelchairs.
- **Whizz-Kidz** (www.whizz-kidz.org.uk) provides wheelchairs and other mobility equipment needed to lead an active and fun childhood.
- **Go Kids Go!** (www.go-kids-go.org.uk) provides wheelchair skills training.
- **Midshires Group** (www.midshiresgroup.co.uk) offers advice on finding the best wheelchair and mould and have preferred supplier status with Newlife Foundation.

For information on making sure your child is in the most appropriate seating position in their wheelchair the following leaflet by Consolor and Postural Care CIC, 'Making the Most of my seating Assessment' is of great use:
www.consolor.co.uk.

Some young people may consider driving as an option and can learn from the age of 16 providing they are claiming the DLA mobility component at the higher level. At the time of writing the disability benefits system is being overhauled, so options and entitlements may change. Motability (**www.motability.co.uk**) provides grants and financial help for young people with disabilities to learn to drive.

Young people can apply for their provisional licence three months before their 16th birthday by completing an online application at **www.gov.uk** or a D1 application form from the Post Office.

The Queen Elizabeth Foundation is a charity working with people with physical and learning disabilities or acquired brain injuries to help them gain new skills and increase independence for life. They have a mobility service that includes a driving school (**www.gef.org.uk**) where they run young driver information days. There are schools of driving across the country that have adapted cars to suit the needs of people with physical impairments.

Holidays

Going on holiday usually takes a great deal of planning because the accommodation has to fulfil the needs of the whole family. How to get there can be a challenge too. There are a number of organisations that produce annual guides on holidays, such as Contact a Family (**www.cafamily.org.uk**) and hft (**www.hft.org.uk**).

For those who like to holiday in the UK or Europe, one option is to use an accessible motorhome. Motorhomes provide transport and shelter in one vehicle and can be rented or bought. Alternatively, some families enjoy using adapted narrow boats and barges for a relaxing holiday on the water. For more information on these options, see our 'Leisure' factsheet **www.fpld.org.uk**.

Sophie's story

Sophie and her family like camping and attending music festivals. Now that she is approaching adulthood, her family are aware that she wants to do this with friends her own age rather than go with her parents and siblings.

At her last person-centred planning meeting she said that one of her goals was to attend a music festival with people her own age. Sophie has a team of personal assistants who support her, and three of them who are not much older than her offered to go with her, along with another school friend. They did research on motorhomes and found one that had an electric hoist and wet room.

The motorhome had room for four people; they decided to take an awning and tent so that there was extra space available. They also researched the most accessibility-friendly festivals and booked tickets.

With all the research undertaken and the motorhome and tickets booked, Sophie and her friends cannot wait to go to the festival.

If you like more of an adventure holiday, the Calvert Trust (www.calvert-trust.org.uk) has centres at three locations in England and offers a variety of outdoor activities. Families of children with complex health needs have also found holiday parks such as Center Parcs (www.centerparcs.co.uk) a good place to go on holiday, as they can cater for the needs of the whole family. Phab (www.phab.org.uk) runs holiday clubs and provides opportunities for group activities if you want to join up with other families or young people on supported holidays.

If you want to fly, it is important to find out what support is available at the airport and on the actual aeroplane to ensure your child can get on and off safely and be seated comfortably during the flight. Airports have staff called 'service providers' who can assist with handling people and lifting them and their equipment on and off aeroplanes, because you cannot take a wheelchair on board. When booking a flight ask the company to alert the service providers at the given airport so they have advance notice.

Some airlines have a range of travel systems suitable for people with mobility impairments, such as the Burnett body support and the Meru TravelChair. The Burnett body support is moulded to the shape of the person's body and can be used in conjunction with a three- or five-point Crelling harness. The Meru TravelChair is suitable for children up to the age of 12 and is used by a variety of airlines. For very small children some airlines can lend you child seats. For example, British Airways can provide seats for infants weighing up to 12.5 kg.

Try b4u fly (www.tryb4ufly.co.uk) is a Surrey-based service that provides children, young people and adults with disabilities with the unique opportunity to try out specially designed aircraft seating support. They also have a hire service so you can try out the systems and practise using them if the airline you are using does not hold them in stock. Contact your airline well ahead of the flight to check how they can assist you. For more information about flying see our Flying Factsheet at www.fpld.org.uk.

Jack's story

Jack is unable to support his upper body and had only flown once as a small child. He and his family were worried about how he would be able to fly in the future, as he can no longer be carried onto an aeroplane.

In order to find a solution, he visited the Virgin Atlantic Airways rig near Gatwick Airport and met the airline's Passenger Accessibility Manager, who let him try out the travel systems available. Jack was positioned in the aeroplane seat by a Burnett body support and a Crelling harness, which made him feel safe and comfortable.

He also learned really useful information about when to contact airlines about your needs (as soon as possible) and that it is essential to make contact with the airport special assistance team as soon as you reach the airport, because they have service providers who assist with lifting and handling people and equipment on board.

Jack left with much more confidence, happy that his dream of flying could now be a reality.

Other activities

There are ways to have fun closer to home too. Those with smaller children may be able to use trikes, specialised buggies or other adapted equipment to get outdoors. There are trikes that can be attached to a bike if your child is able to support themselves but unable to steer.

For those who enjoy walking, robust buggies such as the Delta All-Terrain buggy by Delichion can be used on beaches and woodland paths.

Living Made Easy (www.livingmadeeasy.org.uk) publishes a list of all the charities and funds that may help to pay for equipment for children and young people with limited mobility.

Guides to accessible walking routes are also available, such as those described by the Disabled Ramblers (www.disabledramblers.co.uk) and on the Rough Guide to Accessible Britain website (www.accessibleguide.co.uk).

For more information on these leisure opportunities see our Leisure Factsheet at www.fpld.org.uk.

George's story

Fiona and John love the outdoors and before becoming parents spent much of their time walking and cycling in the countryside.

Their son George is not able to walk far and is very unsteady on his feet. When he was younger they wrote to grant-giving charities and raised enough money to buy an all-weather terrain buggy so that they could take George out for walks.

They also joined the Disabled Ramblers (www.disabledramblers.co.uk) and used the Rough Guide to Accessible Britain website and guide (www.accessibleguide.co.uk), which has a 'family days out' section. Now that George is older, Fiona is looking into attaching a trike to her bike so that they can go out cycling together safely.

Your rights



As a parent it is important to know your rights when you are advocating for your child. Under the Human Rights Act (1998), people with disabilities and their family carers have rights with respect to the way they are treated by public bodies.

In addition, as a result of the Disability Discrimination Acts (1995) and (2005) (www.legislation.gov.uk), and the Equality Act (2010) (www.gov.uk), disabled people have rights with regard to education, employment, access to goods, facilities and services (including large private clubs and transport) and owning or renting property. For more information on these acts see: www.equalityhumanrights.com.

The Citizens Advice Bureau can advise you on your rights. To find out where your local branch is, look on their website (www.citizensadvice.org.uk). Also, in every area in England, you will find parent forums or Parent Partnership Services (PPS) who offer advice and support to parents and carers of children with special educational needs (SEN). You can find out where your local service is via their website (www.parentpartnership.org.uk).

Carers' centres also provide information, advice and support to people who care for a disabled relative. This may include advice on what benefits are available, through to finding out about local support groups. For more information contact the Carers Trust (www.carers.org) who can inform you about your local centre.

Law and policy

At the time of writing the Government is in the process of transforming the system in England for children and young people with SEN, including those who are disabled, so that services consistently support the best outcomes for them. These changes will be included in the new Children and Families Act, which will come into force in September 2014. The Act takes forward the reform programme by:

- replacing the current Statementing system with a new Education, Health and Care Plan (EHCP) for children. Those young people with more complex needs will have the legal protection of an EHCP extended until they are 25 years old as long as they remain in education
- offering personal budgets covering education, health and social care
- improving cooperation between all the services that support children and their families, in particular requiring local authorities and health services to work together
- considering the views of parents and carers and young people themselves and putting them at the heart of cooperation between services.

All local authorities will have to set out a 'local offer' for families of children with a SEN or disability. This is likely to be in the form of a comprehensive website where everything you need to know or want to find out about in your local area will be in one place. This could be information on how a specific service works, or the range of inclusive activities at a school or all the inclusive leisure activities in an area. Accessibility to the local offer will be very important, so local authorities must make sure information is clear and easy to read, and that there are systems in place to help you find out what you'd like to know.

As all the local offers will be cross-referenced, you will be able to find out about things in neighbouring counties and across the country. For more information see: **www.education.gov.uk**. If your son/daughter is aged 14 or over you may be interested to find out about the 'Preparing for Adulthood' programme (**www.preparingforadulthood.org.uk**). It provides information and support to all local authorities and their partners for young people moving into adulthood.

Financial help

When bringing up a child with disabilities, it's important to make sure you're getting all the financial help you're entitled to. Some benefits are based on your child's needs and you

will be eligible to receive them regardless of your income. Others depend on your income and savings. Don't be afraid to ask for help when completing the forms for these allowances, as some of them can be quite complex and time-consuming.

Your health visitor, staff from the child development centre or organisations such as the Citizens Advice Bureau, the local Scope, Mencap or Carers UK branches can give support.

Benefits you might be eligible for include:

- Disability Living Allowance (DLA). This is currently changing; for example, in future when a young person reaches 16 they will have to apply for the new Personal Independence Payment (PIP). For more information see **www.gov.uk**.
- Carer's Allowance
- Jobseeker's Allowance: the Disabled Child Premium and the Carer Premium
- Transport costs to hospital for treatment
- Community Care Grant or Loan
- Tax credits
- Family Fund
- Road Tax Exemption (Vehicle Excise Duty).

For more information about these see our 'Financial help' factsheet at **www.fpld.org.uk**.

The benefits system is complicated and changes frequently, so always get advice about claiming if you are unsure. The following organisations and resources can help:

- **Disability Benefits Centre** – for advice on DLA, PIP and other benefits. Various helpline numbers are listed on their website **www.gov.uk**.
- **The Department for Works and Pensions** does not provide a general helpline so if you wish to speak to someone, call the Disability Benefits Centre above **www.dwp.gov.uk**

Contact a Family factsheet 'Benefits, Tax Credits and other financial assistance' at www.cafamily.org.uk and helpline on **0808 808 3555**

- **Citizens Advice Bureau** – regional numbers can be found at www.citizensadvice.org.uk
- **Local welfare rights adviser** – ask your local council to put you in touch.

Getting the right support for your child and yourself

To get an idea of the support on offer, you can start by looking at the 'Raising Our Sights' guides and DVD clips from Mencap and the PMLD Network at www.mencap.org.uk. There are ten guides that outline what good services and support for people with very complex needs look like. Topics include communication, housing, advocacy, clinical procedures and wheelchairs. There is a section on how families can campaign if they are not getting the right support.

Having a child with complex health needs may mean you need extra help in and out of the home. Some children and young people who have complex health needs and/or who use medical technology receive support from their local Clinical Commissioning Group and/or local authority, usually in the form of nursing or support workers provided by an agency, the NHS or local authority.

More recently there has been a big push from the Government for people with long-term conditions to receive more individualised support. They call this 'personalisation'. Personalisation means that every person who is eligible for support should be empowered to shape their own lives and the services they receive. This starts with planning that puts the person and their family at the centre. See the 'Planning for now and changes in the future' section for more information on this.

The Children and Families Act introduces personal budgets, which can bring together individualised funding from education, health and social care to spend on support agreed in the child's EHCP.

Oliver's story

Oliver was born with a heart condition that meant he required intensive medical intervention when he was a baby. His health improved as he grew and by the age of 18 months his parents felt that they could both go back to work.

They required support on two days per week when neither they nor a grandparent was available to babysit. They were advised not to send Oliver to a nursery during the winter months because he was very susceptible to catching a chest infection. In light of this, the family were awarded a personal budget. Then they discovered that a nanny who cared for a child in their street was looking for more work.

The nanny now cares for Oliver and the other child at the same time (for two days per week). This means that he can enjoy the company of another child and the cost of paying the nanny is shared with another family, so it is affordable for his parents.

There is a specific tool for determining the amount of money your family could receive and a social care worker will help your family to plan how to use your personal budget to get the right choice and control for your family. There are different options for administering your budget: some families look after their budget themselves and some have a broker or let the local authority administer it for them. The organisations In Control (www.in-control.org.uk) and KIDS (www.ritdns.com) have produced useful information for parents.

The most common forms of support are:

- short-term breaks
- direct payments
- personal budgets
- personal health budgets.

For more information on all of these, see pages 15-16 of the 'An Ordinary Life' booklet at www.learningdisabilities.org.uk.

The following websites may also be of use if you are interested in setting up a personal health budget:

- People Hub www.peoplehub.org.uk
- Personal health budgets and NHS Continuing Healthcare www.dh.gov.uk

Carers' assessments

Carers' assessments are available to those providing regular and substantial care to another person. Any parent providing substantial care to their disabled child is entitled to request one. To find out more see: www.nhs.uk.

Nasrat's story

Nasrat is 11 and has muscular dystrophy type 2. She attends a mainstream secondary school and receives a personal budget that includes health funding, because her needs at school are health-based.

A personal assistant comes to her home and helps get her ready for school, accompanies her in the taxi to school and remains with her all day, going home with her in the afternoon. Before she had the personal budget, Nasrat had no support at home and was falling behind on her school work when she was unwell.

Now she has support to keep up with her studies even when she isn't at school.

Education

In September 2014 a new duty in the Children and Families Act will of come into force regarding schools. Governing bodies will be obliged to make arrangements to support pupils with medical conditions so that they can play a full and active role in school life, including access to school trips and physical education, remain healthy and achieve their academic potential.

Schools are also required under law to provide suitable full-time or part-time education to children who cannot attend school (including special schools) due to health problems. For more information see: www.education.gov.uk.

Your child may be too unwell to attend school full-time. One new option for supporting their continuing participation is to use their personal budget (bringing together funding from education, health and social care) to employ a personal assistant. The assistant can go to school with your child and also stay at home with them if they are unwell. It means that your child can keep up to date with their schoolwork and keep in touch with their friends. Some areas have developed protocols for when children spend time away from the classroom, so that everyone has an understanding of what the child is entitled to.

For more practical information about supporting your child at school, in particular relating to transition to secondary school, see page 17 of the 'An Ordinary Life' booklet at **www.learningdisabilities.org.uk**.

For further information regarding the law and your rights, have a look at:

- The [Equality and Human Rights Commission's](http://www.equalityhumanrights.com) website: **www.equalityhumanrights.com**
- [Independent Parental Secondary Education Advice](http://www.ipsea.org.uk) has particularly for education rights **www.ipsea.org.uk**
- The [National Family Carer Network's](http://www.familycarers.org.uk) factsheet 'When things go wrong': **www.familycarers.org.uk**
- [Contact a Family's](http://www.cafamily.org.uk) factsheet 'The NHS and caring for your disabled child': **www.cafamily.org.uk**
- 'Disabled children: a legal handbook' by Steve Broach, Luke Clements and Janet Read. To download chapters of the book for free go to: **www.councilfordisabledchildren.org.uk**
- 'Cemented to the floor by law', a paper about using the law to fight cuts to disabled people's services by emphasising the legal duties of public bodies to disabled children: **www.councilfordisabledchildren.org.uk**

Planning for now and changes in the future

NOW	WHO CAN HELP	ACTIONS
<p>School Prom Talk to Boat people about making it accessible - Bring the party and dancing to stay on the boat</p>	<p>Grainne (James)</p>	<p>Talking Negotiating Write letters to Boat people By Xmas Sleep Over with Geli + Cameron</p>
<p>Lasting friendships + making new friends</p>	<p>Geli + Cameron in Next year. Hannah + Tina, Alison + Amy</p>	<p>(on my ipad) Skype Facebook Telephone Movie Nights</p>
<p>Movie Nights</p>	<p>Hannah + friends</p>	<p>3 events by 2014 Ice Skating (Spectrum)</p>
<p>Accessibility Champion - Start local</p>	<p>School Mrs Nell Anna, Yvonne Hannah</p>	<p>Article in Village Trust - New Writing a blog Go to a Music Festival</p>
<p>Summer 2014</p>	<p>Jill Fundraising Church Training Community Geli + Hannah Sports</p>	<p>Feb 20th Song - Festival 1 - Bronze Trust Competition - Research with Amy - Research school - Organise it. Start + Travel to London - Research with Amy By Christmas holidays Options by April 2014</p>
<p>Getting out + connect + local community</p>	<p>Mrs Caroline Newell Hannah</p>	
<p>Sleep Overs at</p>		
<p>Find something fun to Study at school</p>		

Keeping things ‘joined up’

Having a child with complex health care needs means you are linked to many different organisations and professionals. Examples include the local wheelchair service, school, paediatrician and hospital, to name just a few. Having the right information about which services join up (and which don't) can help you plan for and support your child to have a better experience from services. It is well known that the services do not always link up as well as they should do; this means that you as parents need to be especially aware and proactive about ‘joining the dots’. The Council for Disabled Children's publication ‘Dignity and Inclusion: making it work for children with complex health needs’, illustrates how agencies can work together to ensure needs are met (www.councilfordisabledchildren.org.uk).

If your child is frequently admitted to hospital, preparing a short document about their health needs can reduce the time spent answering questions when you arrive. Some people have this information in a health action plan or hospital passport (see page 17 of the ‘An Ordinary Life Booklet’ for more on these). In addition, some local health services have their own document, which includes a brief but informative summary of the person and their health issues that you can take to hospital to show staff. See, for example, the document used in Gloucestershire, which is based on the ‘traffic light’ system: www.2gether.nhs.uk.

A number of hospitals have learning disability liaison nurses, who support people with learning disabilities before and during their time in hospital. Some of these nurses work with children and adults, some with adults only; so check with your local community team for people with learning disabilities to find out whether the hospitals you attend provide this support.

A communication passport is another resource for sharing information about your child. Many schools develop these with the child and family, and they are kept on the child at all times (usually in their school bag).

We have developed a communication plan, A Book About Me, that includes essential information for when a medical or social care emergency arises and you can download it from our website: www.learningdisabilities.org.uk.

Technology such as that used in the Multi-Me programme (www.multime.com) is another good way of encouraging joined-up working. Some areas have bought the Multi-Me system so that information can be shared with several agencies through their electronic platform.

The move from primary to secondary school can unnerve the most confident of children; if the child has a disability, the transition can be much more challenging and require joined-up working. Not only do they have to cope with a change to a much bigger school, but they also have to adapt to having a new set of teachers, moving around the school for each class, new rules and new fellow pupils.

The 'Moving on to Secondary School' guides (www.learningdisabilities.org.uk) include practical tips to help children, parents and teaching staff prepare for the move.

Person-centred planning

Person-centred planning is an effective way of planning for all aspects of your child's life. Your child is at the centre of the planning, and with support they decide how they want to make their plans, who they would like to help them, how they want to record the plans and who they need help from to make the plans happen. Person-centred plans need to be revisited regularly as a person's life changes over time.

Person-centred planning is widely used across the UK, including during the person-centred reviews held for all students with a Statement of SEN in schools. It is important to involve others (including your child's circle of support – see 'Relationships' for more details), keeping the child or young person at the centre. The way people communicate should always be respected.

For those who do not communicate verbally, support to prepare what is important to them is vital, via DVD clips or photographs or using objects of reference ahead of the planning session.

Some parents prepare a summary of the plan, known as a one-page profile, in which the key information about their child is on one page so that they can give them out at meetings. This profile reminds other people that the child is

an individual with personal preferences and needs. For an example of a completed one-page profile and a template, see www.learningdisabilities.org.uk.

To find out more about person-centred planning and circles of support, see pages 11-12 in the 'An Ordinary Life' booklet at www.learningdisabilities.org.uk.

If you would like to develop a more detailed plan that incorporates your child's health needs see www.learningdisabilities.org.uk.

Planning for change in services

Moving on to adult services is often called 'the transition', and you need to know that services change when young people turn 18. Everyone wants their son/daughter to have a fulfilling life as an adult, but sometimes finding out how to achieve this and what is available can be hard. The future may seem uncertain to a young person after the familiarity of school or college.

Over the years, there has been a big shift in the way things work. In the past, following an assessment, the young person might have been offered a day service placement; now it is agreed that young people's futures should be based on individual needs and preferences.

Ideally, person-centred planning should be at the heart of the planning process during transition to adult life. In England, Year 9 pupils with a Statement of SEN (to be replaced with an EHCP from September 2014) have a review organised by the school (which should be a person-centred review). It should involve family, friends and staff across different agencies that are supporting the young person and should include a discussion on how to address health needs too. The review is carried out annually until the young person leaves full-time education, and contributes to the transition plan.

At 16, at the last review before the end of compulsory education (being raised to 18 in 2015), the young person should have an assessment, which gives them an opportunity to clarify their further education and training needs. This is currently called a 'Section 139a Assessment' and should fit in with the young person's overall planning

for the future. In the autumn of 2014 the Section 139a Assessment will be replaced by the EHCP.

The 'Preparing for Adulthood' programme, referred to in the 'Your Rights' section, supports young people with SEN and disabilities to have better outcomes as they move into adulthood. Those outcomes include finding paid work, independent living, good health and community inclusion. See www.preparingforadulthood.org.uk for more information about this.

Social care needs and the transition

If the young person already has support from social services, a representative should attend the Year 9 review. Otherwise, social services must be informed if the young person is likely to need support from them when they reach the age of 18. The kinds of support could be help with personal care, activities, short breaks or getting support into work.

The young person will need a community care assessment and a plan, if they meet the eligibility criteria for their local authority. At the time of writing the Care Bill is going through Parliament and this is expected to introduce eligibility criteria that will be the same wherever you live in England.

Health needs and the transition

Your child's health needs are an important consideration during the transition to adulthood. There should be a health transition plan or health action plan to support them, and to complement other plans that they are being supported to make during the transition stage. Up until the age of 18, your son/daughter will probably be under the care of a community paediatrician or child development team, who coordinate care between various other health professionals.

When a young person reaches 18, this no longer happens and it can be difficult to find a health professional who will continue to coordinate care, although the GP will provide some continuity. GPs are currently expected to carry out annual health checks on adults with learning disabilities who are known to social services; from April 2014 this is being extended to young people from the age of 14.

Research around the transition to adulthood for young people with life-limiting conditions has been carried out at the University of York, through the STEPP project. For details on their findings see: www.york.ac.uk. You may find it useful to inform your child's health professionals about the good practice guides produced by the project.

An important change in NHS funding for support also takes place when your son/daughter reaches 18. For children and young people under 18, continuing care for children funding from the NHS may be part of a combined package that includes social care and education funding. At 18, however, they may be assessed for 'NHS Continuing Healthcare'. This is a complete package of health and social care funding for people whose 'primary need' is regarded as a health need. It is important for families to be fully informed and involved in this assessment and planning.

For more detailed information see our booklet 'What do I need to know about NHS Continuing Healthcare? Information for families of people with learning disabilities at www.learningdisabilities.org.uk.



Making decisions

The law regarding decision-making changes for your son/daughter when they reach 16. Some young people with learning disabilities may lack capacity to make some decisions for themselves. The Mental Capacity Act (2005) was designed to set out what should happen in England and Wales to assess capacity and support decision-making if a person is unable to make a decision by themselves.

Hft, in partnership with the Foundation for People with Learning Disabilities and the National Family Carer Network, developed guidelines to help families understand how the Mental Capacity Act applies to them. There is a section in the guidelines about the transition to adulthood. To download a copy and watch DVD clips go to: www.hft.org.uk.

Planning for life beyond school

Having a disability should not be an obstacle if a young person wishes to go on to further or higher education, but your son/daughter may need support to assert their rights. In practice the options for young people with learning disabilities may be more limited than those for young people with physical disabilities.

Universities and colleges are expected under the law to offer various forms of support to students with a disability, to enable them to have the same opportunities as people without disabilities, such as making sure that buildings and facilities are accessible, providing course materials in Braille and other formats, and ensuring that extra support is provided during exams, additional time given to complete courses, and flexible and accessible teaching methods used. Universities can provide other kinds of practical assistance such as arranging for a sign language interpreter or a note taker to support the student in class.

When your son/daughter arrives at university it is a good idea for them to contact the student disability support office to find out what support is on offer. To see an example of the type of support available, watch the following video: Widening participation in Higher Education (www.youtube.com). The Disability Rights UK website (www.disabilityrightsuk.org.uk) has a range of factsheets

for young people with disabilities who are interested in further education.

We should never assume that a person will never be able to work because they have complex needs. Schools, parents and young people should aim high, and there are plenty of examples of people who require a high level of support who have found work, for instance as a still life model, a greeter in a supermarket, or delivering the local paper on their mobility scooter. Many young people with complex needs will say their goal is to have a job, and parents and schools need to support them to find one.

The good thing about having a personal budget is that it can enable a person to hire a skilled job coach in place of or in addition to a personal assistant. Job coaches work to define a person's skills and personal interests and help them to find organisations or jobs where they can use them. The job coach can help the person to settle into the job and match their skills to the jobs required and then gradually reduce their support.

Some people may find they do not fit in with more traditional jobs and may want to develop their own businesses. The Foundation for People with Learning Disabilities has developed a guide on how to set up a business (www.learningdisabilities.org.uk/inbusiness) in addition to a booklet about employment for parents of children with learning disabilities (www.learningdisabilities.org.uk/gettingajob).

Your son/daughter may be eligible for funding through the government's 'Access To Work' programme (www.gov.uk). Access To Work can pay for additional support, such as adaptations to the workplace, a job coach or assistive technology.

BASE is an umbrella organisation for all supported employment providers, who offer expertise and support for disabled people wanting to find employment. To find out where your local branch is see: www.base-uk.org.

Useful addresses



Contact a Family

www.cafamily.org.uk

Telephone: 020 7608 8700

Freephone helpline 0808 808 3555

Contact a Family is a UK charity for families with disabled children. They offer information on specific conditions and rare disorders.

Council for Disabled Children

www.councilfordisabledchildren.org.uk

Telephone: 0207 843 1900

CDC aims to make a difference to the lives of disabled children and children with special educational needs by influencing Government policy, working with local agencies to translate policy into practice and producing guidance on issues affecting the lives of disabled children.

Foundation for People with Learning Disabilities

www.learningdisabilities.org.uk

Telephone: 020 7803 1100

The Foundation is a UK-wide charity that aims to influence government and local authority policies and services through their work so that they better meet the needs of people with learning disabilities, their families and carers.

KIDS

www.kids.org.uk

Telephone: 020 7359 3635 (London)

KIDS is the national charity working with disabled children, young people and their families across England.

Newlife Foundation

www.newlifecharity.co.uk

Telephone: 01543 462 777

Newlife exists to respond to children who may face both short-term and enduring disability and those with their life expectancy limited through providing informed support to their families and carers. The needs of children with special needs and those of their families and carers, their health and voices are all central to the work of the charity.

Mencap

www.mencap.org.uk

Telephone: 0808 808 1111

Mencap is the voice of learning disability.

PMLD Network

www.pmlidnetwork.org

The PMLD Network is a group of people committed to improving the lives of people with profound and multiple learning disabilities (PMLD).

Phab

www.phab.org.uk

Telephone: 020 8667 9443

Phab's aim is to promote and encourage people of all abilities to come together on equal terms, to achieve complete inclusion within the wider community.

Scope

www.scope.org.uk

Telephone: 020 7619 7100

Scope works with disabled people, of all ages, and their families, across England and Wales, offering practical, everyday support and delivering campaigns that can change lives.

The Children's Trust Tadworth

www.thechildrenstrust.org.uk

Telephone: 01737 365 000

The Children's Trust provides care, education, therapy and rehabilitation to children with multiple disabilities, complex health needs and acquired brain injury.

Together for Short Lives

www.togetherforshortlives.org.uk

Telephone: 0117 989 7820

National helpline 0845 108 2201

Together for Short Lives are the voice for children and young people who are not expected to live to adulthood and their families.

WellChild

www.wellchild.org.uk

Telephone: 0845 458 8171

Wellchild helps seriously ill children, young people and their families throughout the UK through their programmes of care, support and research.

Whizz-Kidz

www.whizz-kidz.org.uk

Telephone: 020 7233 6600

Whizz-Kidz provides disabled children and young people with vital mobility equipment, opportunities to meet and have fun, and training to help them gain skills and look forward to a bright future.

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