

# Blue Pages



**Registered Charity 1187356**

## Outline

### The purpose of The Special Lioness

We are a couple of local mams who are parent carers for our children who have profound and multiple disabilities.

We have created the “Blue Pages” to help families navigate the minefield that is the Special Needs world.

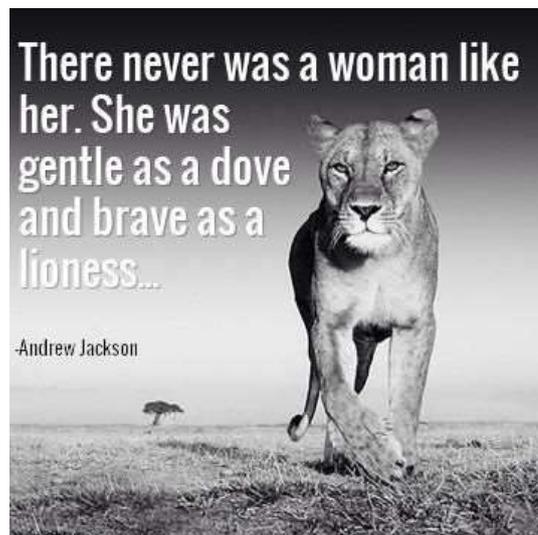
It is a daunting and devastating realisation that your child has a disability or additional special need and you may feel alone, isolated and like you are the only parent going through this, take some comfort in the knowledge that you are not, there is a huge amount of parents out there going through very similar struggles who will be very happy to support and help you along the way – you just need to find them.

#### ***In this journey, Knowledge = Power***

Knowledge is your best friend and can save lots of conversations, dead-end searches and save on lots of sleepless nights. We have created this handbook, almost to replicate the good old Yellow Pages which is a directory of services, shortcuts, procedures, guidance and random helpful things we have discovered along the way.

It may look daunting, but only look at the services that you feel may suit your child right now, or that you have heard come up in conversation, not everything in this handbook will be relevant to your child, but we hope that it will at least help you along the way.

Join as many Special Needs networks as you possibly can, widen your circle of friends to include SEND parents as these are the people who will truly “get it”. Reach out whenever you need to, its okay to not be okay. Challenge what your being told if it doesn’t feel right, and ask those “stupid” questions, as they aren’t stupid to you.



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## A

### Adaptions to your home

Your OT will make an assessment of you, your child, your whole family and what adaptions are required to enable your child to remain safe and to help you to carry out their care without any further complications. They can assess for ramps, hoists, beds, highchairs, lifts, stair lifts, bathing, dressing, etc. See the list of equipment available in the appropriate sections of this book.



### Bathing

When designing an accessible bathroom for a child with a disability, first and foremost we recommend an individual assessment with an occupational therapist as your child may be eligible to receive a disabled facilities grant (DFG) to help towards the cost of the adaptation. The information contained below is not intended as a replacement for a thorough assessment in your home environment.

Information and advice on design issues is available from the Centre for Accessible Environments. The organisation is a leading authority on inclusive design and they provide consultancy, training, research and publications on building design and management to meet all user needs. This organisation keeps a database of architects, surveyors and similar professionals with experience of designing for disabled people, and has a number of useful publications and design sheets.



- The needs and preferences of the child and the parents
- The age of the child - the facilities may need to reflect their changing needs as they grow and their emerging independence and need for privacy
- Other bathroom users
- Access and space
- Structural alterations, and whether a grant is available to help cover costs
- Type of floor, i.e. wooden or concrete
- Sanitary fittings - what is currently being used, assistive devices and the alternative, more specialised fittings e.g. push-button showers, lever taps or wash/dry toilets
- Children who are not able to move around easily may get cold very quickly when undressed. Additional safe heating in the bathroom may be required
- The possible therapeutic benefits of bathing in warm water, e.g. children with tight muscles may find it easier than usual to move in warm water
- If a bath is to be installed, or is to remain in a new bathroom design, consider the size. Can it accommodate supportive bathing equipment now, and as your child grows?
- The storage and cleaning of any equipment required.
- Information and advice on design issues is available from the Centre for Accessible Environments. The organisation is a leading authority on inclusive design and they provide

consultancy, training, research and publications on building design and management to meet all user needs. This organisation keeps a database of architects, surveyors and similar professionals with experience of designing for disabled people, and has a number of useful publications and design sheets.

#### Other factors to consider

- Any additional head support the child may require
- Safety for children with poor sitting balance or head control
- Safety for children with sensory loss
- Children with epilepsy and the risks to them whilst bathing. Children with epilepsy who use a bath chair or hammock may need quick release fastenings on the equipment
- The size of the bath and whether it can accommodate supportive bathing equipment
- Drying and dressing your child once they have bathed; do they need a safe space to sit or lie down during this process?
- Using simple methods of increasing independence such as automatic soap dispensers, lever taps and shower controls that are easy to reach and operate.

N.B. No child should be left unsupervised in the bath even if in a supportive bath chair. Similarly, young brothers and sisters should not be left in charge of a child in a bath seat.

#### Showering

Getting an older child in and out of a bath can be difficult and showering can offer a safer and more manageable alternative. Showering may also make it possible for the child to be more independent. The needs of other family members must be considered, particularly if there is not enough space for separate bath and shower facilities.

It is sometimes possible to build an additional bathroom or adapt an existing space to provide secondary washing facilities, with the help of a Disabled Facilities Grant.

Shower facilities can be provided:

- over an existing bath
- as a separate shower area/cubicle.
- For children who can shower in a supported sitting position
- Shower chairs and stools
- These provide support for children who can sit to shower. Wall mounted options are available (see below). There are a range of styles and models, so check:
  - the size and shape of the seat
  - the level of support it provides
  - whether it allows adequate access for washing.



For more supportive seats see the section below on mobile shower chairs.

Supportive shower chairs can make it difficult to access and wash the areas of the body supported by the backrest, seat, straps and side supports. Many areas have an Equipment Demonstration Centre or similar facility, allowing people to view products before they purchase them, so it may be worth enquiring as to whether they have supportive shower chairs to view. Information about Equipment Demonstration Centres can be found here: [http://www.livingmadeeasy.org.uk/contacts\\_edc.php](http://www.livingmadeeasy.org.uk/contacts_edc.php)

Alternatively, many companies offer a free assessment at your home. This gives parents an opportunity to learn about the product, see it in situ, and consider if it will meet their child's immediate and longer-term needs.

When using a shower chair there needs to be plenty of room around it so that the parent or carer can move around freely, move the chair or help the child, without injuring themselves or getting soaked in the process. Portable half-height shower screens are available to protect the carer from splashes.

### Static shower chairs and stools

These are freestanding, so can be lifted in and out of the shower as required. They are more appropriate for an older, more independent child. Stools tend to have little or no back support; chairs have a higher, more supportive backrest.

Selecting the correct height is important. To support him/herself safely in a sitting position, the child must be able to place both feet flat on the floor. An adjustable height stool/chair can be altered in height as the child grows.

Arm rests can provide additional security and enable a child to stand independently.

Ensure that all toiletries are within reach to encourage independence and reduce the risk of slipping.

### Wall-fixed shower seats

This style of shower seat fixes to the wall, usually via hinged brackets, so that they can be folded up out of the way of other family members who want to use the shower. The seat should be fixed at a height to suit the child's needs. Bear in mind that this will change as they grow. A limited number of adjustable height seats are available which could accommodate growth.

### Mobile shower chairs

A range of wheeled shower chairs are available for those requiring more postural support. These range from simple shells to more complex modular seating including support for the pelvis, chest and head. User-propelled and attendant-propelled versions are available. Larger wheels can make it easier to push the chair in and out of the shower but will take up more space.

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## Shower chairs with a toileting facility

Many mobile shower chairs offer a toileting facility. They can either be positioned over a toilet or used with a commode pan. This type of chair reduces the number of transfers that need to be made between the bed, toilet and shower. Larger children who are physically less able may need to be hoisted into the chair.

Before choosing a shower chair with a toileting facility consider the following:

- Is wheeled access into and around the toilet/bathroom possible?
- What is the clearance gap over the toilet? The chair must fit easily over the toilet bowl, but too wide a gap means splashing may occur.
- Check the height and position of the toilet cistern and the push handles of the chair to ensure that positioning of the chair is not impeded.
- The size of the seat and aperture. The seat must be supportive but should also allow for the child to clean him/herself or to be assisted with cleaning after he/she has used the toilet.
- If the child is to be hoisted in or out of the equipment, is there enough access to be able to fit and remove the sling? It may be beneficial to use a mesh bathing sling.
- Shower chairs for children generally have a range of supportive accessories including:
  - pommel/splash guard
  - head and trunk supports
  - foot supports
  - safety belts and harnesses.

An assessment with a reputable company rep is recommended to make sure that the chair offers the right level of support.

Larger children or children requiring less support will be able to use an adult shower chair which can be fitted with cushion inserts to reduce the internal seat dimensions. Always make sure that their feet are well supported.

For children who need to be showered in a lying or semi-lying position

## Shower cradle

There is a small range of shower cradles that comprise a mobile chassis onto which a nylon mesh cradle or a hammock-type bath support is fixed. The angle of the mesh cradle is fixed on some models and adjustable on others. The more upright the support, the less space it will occupy. If a cubicle is to be used, check its size as many of these supports are too long for a standard cubicle.

On some cradles the mesh supporting the head can be detached and folded down to make it easier to wash the hair.

Accessories are often available to assist with head and body positioning and safety.

Some tilt-in-space models offer a toileting aperture.

### Tilt-in-space/reclining shower chairs

A range of shower chairs for children have a reclining backrest or a tilt-in-space seat unit so that the child can sit in a semi-reclined or tilted-back position. These also offer a toileting aperture. These chairs could be considered as an alternative to a shower cradle and generally take up less space in the bathroom.

### Shower stretchers

Wall-mounted shower stretchers can also be used as changing tables and fold up against the wall when not in use. They are made of a perforated material and can be used over a bath - folding down to rest on the bath rim - or in a shower area with two supporting legs which rest on the floor.



On some, the angle of the backrest can be adjusted, while the height of others can be adjusted electrically to position them at a comfortable height for the parent.

How the parent will lift the child onto the shower stretcher must be considered. A hoist may be required. Always try to work out a washing and dressing routine that involves the fewest moves from one item of equipment to another as this saves time and effort for the child and parent.

### Shower trolleys

These are mobile showering tables, often with a reservoir to catch the water during a shower. They are large and not often used in the family home because they are difficult to manoeuvre in a restricted space.

## Adapted Shopping Trolleys

In many major supermarkets there are now adapted trolleys suitable for older children to be pushed in. They are not suitable for all children with disabilities however they can be very useful if you have an older child who has outgrown the toddler seat trolleys but still needs to be pushed around a store due to their mobility or behavioural issues.



## Accessibility

Access to local places and facilities can be very difficult and make a journey out and about with the family even more stressful, we have found a very good resource with lots of hints and tips about getting around on Facebook, "AccessAble". Check out their page for some useful guides.



Accessible toilets and changing facilities can make or break a day out, so before you head out, check out the "Changing Places" webpage or Facebook page which will give you all the locations of suitable changing facilities, and the site is updated constantly. (Also, see our section on Changing Places)

## Alan Shearer Centre

The Alan Shearer Centre is a highly specialist, respite, residential and social facility for people with complex disabilities and acute sensory impairments. Situated in its own grounds on the outskirts of Newcastle, the Alan Shearer Centre comprises three specialist facilities on the same site:

### The Alan Shearer Activity Centre

A specialist recreational, sensory and social resource for disabled people of all ages, catering to a wide spectrum of need. Facilities are completely free to use and include a hydrotherapy suite, sensory rooms and cave, a giant ball pool, a music room, seasonal activities and a café. Overhead tracking and hoists are fitted throughout, enabling full accessibility to all areas for those with limited mobility.

To find out how to become a member, or to arrange a tour of the Activity Centre, please ring Amanda Head, our Alan Shearer Centre Manager on 0191 267 8118, or email [amanda.head@stcuthbertscare.org.uk](mailto:amanda.head@stcuthbertscare.org.uk), and she will be delighted to help.

### The Alan Shearer Short Break Centre

Providing highly specialised respite breaks in a safe and specially adapted environment for people with a range of disabilities and behavioural issues, the centre allows parents and carers a well-earned rest. It is the only short break centre in the North East with its own on-site Activity Centre, set within several acres of private and beautifully landscaped grounds.

If you would like to see the facilities, please call the Registered Manager, Jackie Dunn, on 0191 267 8128 or email her at [jackie.dunn@stcuthbertscare.org.uk](mailto:jackie.dunn@stcuthbertscare.org.uk).

## Our Alan Shearer Specialist Residential Home

Also situated within the Alan Shearer Centre, the home offers residential accommodation for adults with profound and multiple disabilities. Here they provide longer term, safe and nurturing care and support. In addition, the disabled residents have full access to the on-site Activity Centre. For more information, or to arrange a visit to see the facilities, please call the Manager, Gareth Bainbridge on 0191 264 8925 or email him at [gareth.bainbridge@stcuthbertscare.org.uk](mailto:gareth.bainbridge@stcuthbertscare.org.uk).

## B

### Bicycles

Information about adapted bikes can be found on the following website, this details the variations between adaptations and what would suit your needs, or you can request a trike/bike through your physiotherapist  
<https://www.cyclinguk.org/article/cycling-guide/guide-to-adapted-cycles>



### Blue Badge

Your local authority offers a Blue Badge scheme for adults and children aged 3+ and in receipt of high rate mobility of DLA/PIP. However, if your child is under 3 you can claim a Blue Badge if your child is required to carry medical (bulky) equipment such as feeding machines, oxygen etc.

If you are not in receipt of high rate mobility you can still apply to your local authority for a Blue Badge. An Occupational Therapist will conduct an assessment to see whether you are eligible for one. There is a small fee charged for the Blue Badge and is renewed every few years. From August 2019, there will be a new eligibility criteria for the issue of Blue Badges. Currently Blue Badges tend to only issued to people who have physical mobility problems however from August 2019, people with mental health difficulties, learning disabilities and dementia can also apply.

### Bins (Home waste)

Your local authority offers a service of having an extra household waste bin and a larger recycle bin for medical waste to enable you to manage your waste better, simply call your local authority and request an additional bin due to medical waste and a bin will be dropped off at your house and both bins will be collected and emptied as usual.

### Beds at home

Your OT will carry out an assessment of your child's needs and will provide your child with an appropriate bed depending upon their needs and requirements. They range from cot style hospital beds to safe spaces.



### Bibs

Standard bibs from shops do not fit children past the age of around 3, but larger bibs are available, they can be obtained by various large companies i.e. Firefly for around £15 for 2, or buy from someone local, usually one of our very talented mums for less than half the price! There is a lovely lady on Facebook who makes bibs in many beautiful patterns and can also be made to match an outfit, see **Unique Bib Boutique**.

## Beach Accessibility

Accessing beaches if you are a wheelchair user can be extremely difficult as it can be a struggle to move the wheelchair across the sand. Beach resorts are beginning to address this problem and many resorts now have improved access, slopes and beach wheelchairs. They can often be hired by the hour for a small fee. You can usually find out if the resort where you are has a wheelchair accessible beach by visiting Tourist Information. They will also be able to tell you whether a beach accessible wheelchair can be hired. If you visit [www.disabilitygrants.org/beach-wheelchairs-for-hire.html](http://www.disabilitygrants.org/beach-wheelchairs-for-hire.html) you can locate which resorts in the UK have a beach wheelchair available for hire. The website also gives you information on the types of chair that can be hired, prices of hire and who to contact in order to make the reservation.



## Benefits

The benefits system is an absolute minefield, but we have found the most up to date and HELPFUL information can be found at the Citizens Advice. Please take a look at the guidance on their webpage, you may be surprised as to what you and your child are entitled to. You can also call them or pop in for a chat and they can look at your finances as a whole and guide you in the process.

<https://www.citizensadvice.org.uk/benefits/sick-or-disabled-people-and-carers/benefits-for-people-who-are-sick-or-disabled/>

Contact – the charity for families with disabled children is also another source of useful information around benefits and tax credits. They have extensive information on their website which is <https://contact.org.uk/advice-and-support/benefits-financial-help/benefits-and-tax-credits/>

## C

### Calvert Trust

The Calvert Trust enables disabled adults and children, together with their families and friends, to achieve their potential through the challenge of outdoor adventure in the countryside.

They aim to do this by providing:

- A wide range of adventurous outdoor activities, meaningful challenge and adventure within a framework of safety
- Skilled, qualified and caring staff able to fulfil the needs of visitors
- Accommodation appropriate to the needs of the visitors
- Facilities for families and friends to share the enjoyment and experience

The benefits and enjoyment of the activities will be offered to all, irrespective of ability. These benefits include:

- The enrichment in the life of each individual through adventure and personal achievement
- The chance to enjoy countryside of exceptional natural beauty
- Recreational opportunities that can be transferred into everyday living

Personal development and rehabilitation leading to integration

### Car Seat

Your OT will carry out an assessment of your child's safety whilst travelling and can offer a range of car seats to suit their needs. In turn they will set up a meeting with a car seat rep who will allow you to try various seats until you find the appropriate one. Each time your child grows out of their car seat, you are entitled to a new assessment and a new car seat.



## Carer's Assessment

If you care for someone, you can have an assessment to see what might help make your life easier. This is called a carer's assessment.

It might recommend things like:

- someone to take over caring so you can take a break
- gym membership and exercise classes to relieve stress
- help with taxi fares if you don't drive
- help with gardening and housework
- training how to lift safely
- putting you in touch with local support groups so you have people to talk to
- advice about benefits for carers
- A carer's assessment is free and anyone over 18 can ask for one.

To get a carer's assessment you would need to contact your local 'Children with Disabilities Team'. The number for the Sunderland Team is 0191 5205550 or email [child.disability@togetherforchildren.org.uk](mailto:child.disability@togetherforchildren.org.uk). You could also ask your health visitor, school nurse or your child's paediatrician to put in a referral for you.

## Changing Places

Changing places is an organization who are campaigning to have the appropriate changing facilities to be installed across the country. They are being installed in many shopping centres and supermarkets, so keep a look out for a "Changing Places" sign and this usually means there is a toilet, bathing, hoisting facility for disabled users. A list of changing places can be found on the changing places website: <http://changingplaces.uktoiletmap.org>. You can also download a toilet finder app to your phone if you are on Apple or Android operating systems.

## Changing Tables

These tables provide a surface on which children can be cleaned, changed and dressed and are suitable for babies, infants and larger children. There are wall mounted, free standing and mobile models available.

The adjustable height tables may be operated electronically, mechanically or hydraulically so that the table can be positioned at a comfortable height for the carer. Again, ensure you have a full assessment from your OT.



## Charities

There is a comprehensive list of charities in which you can apply for funding for equipment, this list is updated frequently, please visit our Facebook Page for further details.

## Clothes

Adapted clothes are available from various shops and is ever increasing. M&S are established in providing good quality, affordable adapted clothes ranging from underwear to coats and jackets.



## Community Dentist

The Community Dental Service is different from high street dentists as you have to be referred to them in order to use the service. The Community Dentist cares for people who find it difficult to visit a regular high street dentist due to a disability, learning difficulty or behavioural difficulty or dental anxiety. The Community Dentist in the Sunderland and South Tyneside area has specialist equipment such as wheelchair recliners, hoists and transfer aids. In order to access this service you would need to be referred by a health and social care professional however they will also accept appropriate referrals from any person living in the area. For further information, please visit <https://www.stsft.nhs.uk/services/dental-services>

## Council Tax

If you use one specific room within your home, purely for the child's benefit (other than their bedroom), you can request an assessment by your Local Authority and they will determine whether you are entitled to a Council Tax reduction.

## D

### Disabled facilities Grant (DFG) for Children

A Disabled Facilities Grant is a grant from your local council to help towards the cost of providing adaptations and facilities in your home. These adaptations must be to make caring for your child easier or to increase your child's level of independence at home. The grant is paid if your council considers that the proposed changes are necessary to meet your child's needs, and that the work is both reasonable and practical depending on the age and condition of the property.

This can include major adaptations such as extensions and structural work to accommodate, for example, a ceiling track hoist, stairlift, widened doorways, an external ramp, or a downstairs bathroom.

An occupational therapist will assess your circumstances and home environment before recommending any required adaptation(s).

Any proposed work must have planning permission and fall within building regulations.

Who can apply for a Disabled Facilities Grant?

- You can apply if the answer to the following four statements is yes:
- You or the child living in your property, is disabled.
- You, or the child on whose behalf you are applying, are the owner or tenant of the property. Note: a landlord may apply on behalf of a disabled tenant.
- You are willing to certify that you, or the child on whose behalf you are applying, intend to occupy the property as your/their main or only residence throughout the 5 year grant period.
- You, or the child on whose behalf you are applying, live in England, Wales or Northern Ireland. Note: Scottish residents should contact their local social services department for information on their Home Improvement Grants.

How much money will be awarded?

The maximum grant that can be awarded in England is £ 30,000, less any assessed contribution. The grant will only be paid on work assessed as necessary, and when the council are satisfied that the work has been carried out.

Always check what help is available before starting work on your home to make it suitable for you or your child. Grants will usually not be provided retrospectively.

Who will be means tested?

DFGs are not means tested so long as the grant is provided to meet the needs of a disabled child (under 19 years of age).

Families who need to adapt their home for a person over the age of 19 will have to go through a means test/ financial assessment. When aged 19 or over, the person with the disability is tested. This test (based on a person's ability to pay) is intended to target help towards the most needy, and it looks at income, savings and expenditure. The grant awarded can then vary from 0 to 100% of the cost of the work assessed as necessary.

## E

### **EHCP (Education & Health Care Plan)**

An education, health and care (EHC) plan is for children and young people aged up to 25 who need more support than is available through special educational needs support.

EHC plans identify educational, health and social needs and set out the additional support to meet those needs.

#### Requesting an EHC assessment

You can ask your local authority to carry out an assessment if you think your child needs an EHC plan.

A young person can request an assessment themselves if they're aged 16 to 25.

A request can also be made by anyone else who thinks an assessment may be necessary, including doctors, health visitors, teachers, parents and family friends.

Your Local Authority's website should give information on how to apply for an EHCP. You should always apply in writing and keep a copy. You should also keep a record of the date you posted the letter/sent the email.

If you are unsure what to write you can get a template letter from IPSEA.  
<https://www.ipsea.org.uk/making-a-request-for-an-ehcneeds-assessment>

SOS SEN also provide template letters. [https://www.sossen.org.uk/information\\_sheets.php](https://www.sossen.org.uk/information_sheets.php)

If the local authority decide to carry out an assessment you may be asked for:

- any reports from your child's school, nursery or childminder
- doctors' assessments of your child
- a letter from you about your child's needs
- The local authority will tell you within 16 weeks whether an EHC plan is going to be made for your child.

#### Creating an EHC plan

Your local authority will create a draft EHC plan and send you a copy. You have 15 days to comment, including if you want to ask that your child goes to a specialist needs school or specialist college. Your local authority has 20 weeks from the date of the assessment to give you the final EHC plan.

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## Disagreeing with a decision

You can challenge your local authority about:

- their decision to not carry out an assessment
- their decision to not create an EHC plan
- the special educational support in the EHC plan
- the school named in the EHC plan
- If you can't resolve the problem with your local authority, you can appeal to the Special Educational Needs and Disability (SEND) Tribunal.

IPSEA have some excellent resources on their website for challenging decisions including letter templates. Their website is [www.ipsea.org.uk](http://www.ipsea.org.uk)

You can also find some really useful information, including flowcharts of the EHCP process at <https://www.specialneedsjungle.com/flow-chart/>

## Personal budgets

You may be able to get a personal budget for your child if they have an EHC plan or have been told that they need one. It allows you to have a say in how to spend the money on support for your child.

There are 3 ways you can use your personal budget. You can have:

- direct payments made into your account - you buy and manage services yourself
- an arrangement with your local authority or school where they hold the money for you but you still decide how to spend it (sometimes called 'notional arrangements')
- third-party arrangements - you choose someone else to manage the money for you
- You can have a combination of all 3 options.

## Independent support for children of all ages

Independent supporters can help you and your child through the new SEN assessment process, including:

- replacing a statement of special educational needs with a new EHC plan
- moving a child from a learning difficulty assessment (LDA) to an EHC plan

You can find out how to get local support through:

- Council for Disabled Children
- Information, Advice and Support Service Network
- your local authority website and search for 'Local Offer'

## Equipment

Feed pumps  
Suction Machines  
SATs monitor  
Oxygen machines  
Supportive seating  
Highchairs  
Shower/bathing chairs  
PPods  
Hoists  
Lifts  
Stair Lift  
Hospital beds  
Safe Space  
Wetrooms  
High-Low Bath  
Changing Table  
Supportive pushchairs  
Wheelchairs  
Slings  
Ramps  
Paediatric shoes/ boots  
Walking Frames  
Standing Frames  
WAV (Wheelchair Accessible Vehicle)

## Emergency Care Plan

This is a document produced by your child's leading consultant which holds all their medical needs and instructions to Emergency Health Care professionals. This document is held in a yellow envelope and should be carried with the child at all times. All persons/settings caring for your child should be aware of this document. This can make Emergencies slightly easier to deal with as this document (providing it is kept up to date) can be handed over to paramedics or emergency health care providers on their arrival and this can inform them of history and instructions for emergency care.

## F

### **Fire assessment in the home**

You can contact your local fire station and request an assessment of your home to ensure you have the correct smoke detectors, if you have someone in your home who is visually or hearing impaired there are various types of smoke detectors which can be installed appropriately and you will also be placed on a priority list, so should the worst ever happen, the fire service are already aware that you have a child/person in your home with a disability, making their job easier by them being fully prepared and informed of your situation.

## G

### Gas and Electric

The Priority Services Register (PSR) is a free service provided by suppliers and network operators to customers in need. Each energy supplier and network operator maintains its own register. To be eligible for inclusion on the register you or someone living in your household must be of pensionable age, disabled or chronically sick, have a long-term medical condition, have a hearing or visual impairment or additional communication needs or are in a vulnerable situation. As a priority customer you would get advance notice of any planned power cuts, receive priority support in an emergency as well as other services that could help. For further information on this scheme, please visit <https://www.ofgem.gov.uk/consumers/household-gas-and-electricity-guide/extra-help-energy-services/priority-services-register-people-need>

### Grace House

Grace House is a local short breaks and respite centre in Sunderland. They offer breaks for children ages 5-18 years old and offer some wonderfully support and opportunities for the wider family.

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## H

### Hearing impairment

Hearing loss sometimes gets better on its own, or may be treated with medicine or a simple procedure. For example, earwax can be sucked out, or softened with eardrops.

But other types – such as gradual hearing loss, which often happens as you get older – may be permanent. In these cases, treatment can help make the most of the remaining hearing. This may involve using:

- hearing aids – several different types are available on the NHS or privately
- implants – devices that are attached to your skull or placed deep inside your ear, if hearing aids aren't suitable
- different ways of communicating – such as sign language/ Makaton or lip reading – See our section detailed “SALT – Speech and Language Team”

### Healthcare Professionals

If your child has a disability, it is likely that they will meet a variety of healthcare professionals. This page attempts to list a range of them and explain what they do. It also has information on how to find out if your health professional is registered.

- Audiologist
- Dietitian
- Occupational therapist (OT)
- Orthotist
- Physiotherapist
- Consultant
- Social worker (from the Children with Disabilities Team)
- Speech & language therapist (SALT)

#### Audiologist

Audiology is an area of speciality dealing with the assessment and rehabilitation of patients with hearing and balance disorders. It covers a wide age range starting with new born hearing screening for infants and progressing through to hearing screening at schools and all the way up to age related hearing and balance disorders. A typical day for an Audiologist working in the Community involves assessments of hearing loss, fitting of hearing aids and follow ups.

Conducting an assessment of hearing loss is the first step in the patient pathway which involves determining if a patient referred by the GP has any underlying hearing problems. The results are then discussed with the patient before agreeing a treatment plan that suits their needs.

## Dietitian

Dietitians are qualified health professionals that assess, diagnose and treat diet and nutrition problems at an individual and wider public health level. Uniquely, dietitians use the most up to date public health and scientific research on food, health and disease, which they translate into practical guidance to enable people to make appropriate lifestyle and food choices.

Dietitians work in the NHS, private practice, industry, education, research, sport, media, public relations, publishing, NGOs and government. Their advice influences food and health policy across the spectrum from government, local communities and individuals.

Most people will be able to see a Registered Dietitian within the NHS after being referred by an NHS GP, doctor, health visitor or other medical staff. You can also self-refer.

## Occupational therapist (OT)

Occupational therapists work with people who have a physical disability, a medical condition, a mental health difficulty or a learning disability. They help individuals who have difficulties with everyday tasks, such as preparing a meal, taking a bath, going up stairs or lifting their legs into bed.



The aim of occupational therapy is to enable individuals to live as independently as possible, whether at home, at work or at school/college. The occupational therapist can help individuals to adapt to changes in their everyday life and to overcome practical problems.

They may do this by providing advice, recommending ways an everyday task can be done differently or recommending equipment or alterations for an individuals home. Occupational therapists work in health, social care or private practice and work closely with health, housing and educational services.

If you qualify for a Disabled Facilities Grant towards the cost of adapting your home then an occupational therapist is involved in the assessment process.

To enquire about an assessment with an occupational therapist contact your local social services. You can obtain their contact details by entering your postcode on the directgov website.

Alternatively, if you wish to obtain private assessment or advice then you can search for a private occupational therapist on the College of Occupational Therapy's online directory of independent occupational therapists.

## Orthotist

Orthotists provide a range of splints, braces and special footwear to aid movement, correct deformity and relieve discomfort. They work collaboratively with other health-care professionals to provide integrated treatment.

Orthotists provide orthotic management for people with a wide range of conditions such as rheumatoid arthritis, cerebral palsy, diabetes, and strokes.

Orthotists assess the patient's needs, diagnose the problem and treat the patient by prescribing the most suitable orthosis (a device to support or control part of the body) to meet these requirements. They work alongside Physiotherapists to ensure all needs are met around equipment in the home and School.



## Physiotherapist

Physiotherapists have specialist skills in the physical treatment and rehabilitation of people. Physiotherapy helps restore movement and function to as near normal as possible when someone is affected by injury, illness or by developmental or other disability.

Physiotherapists use a number of different techniques including manipulation and mobilisation, massage, hydrotherapy, exercise programmes, electrotherapy (e.g. ultrasound) and in some cases acupuncture.



Chartered physiotherapists work in a variety of settings including hospitals, health centres, GP practices, schools, work places, private clinics and also by visiting people at home.

## Social worker

Social workers are professionally qualified staff who assess the needs of service users and plan the individual packages of care and support that best help them. Social workers form partnerships with people: helping them to assess and interpret the problems they face, and supporting them in finding solutions. They have to know how the law works and be fully up to speed with the social welfare system.

Social workers liaise regularly with other professionals - teachers, doctors, nurses, police, lawyers - acting on behalf of the people they are working with.

Roles include providing assistance and advice to keep families together; working in children's homes; managing adoption and foster care processes; providing support to younger people leaving care or who are at risk or in trouble with the law; or helping children who have problems at school or are facing difficulties brought on by illness in the family.

Most social workers are employed by a local government social services department. But they also work for local education authorities, hospital trusts, and charities. You may be asked early in your child's life whether you would like access to a Social Worker, this will be assigned by the 'Children with Disabilities Team' and is not your typical Social Worker, they are assigned to help assist you care for your child safely at home so they can assess the child's movements around the home and whether they require adaptations to the home and to give you a 'carers assessment' to ensure you are not forgotten in your role as a parent carer and if you have any underlying medical conditions, they can assess whether you need further assistance at home and can offer PA/carers support for you.

### Speech & language therapist (SALT)

The role of a speech and language therapist (SALT) is to assess and treat speech, language and communication problems in people of all ages to enable them to communicate to the best of their ability. They may also work with people who have eating and swallowing problems.

SALTs assist children and adults who have the following types of problems: difficulty producing and using speech; difficulty understanding language; difficulty using language; difficulty with feeding, chewing or swallowing; a stammer; a voice problem.

SALTs work in a variety of settings, these include: hospitals (both inpatients and outpatients); community health centres; mainstream and special schools; assessment units and day centres; clients homes.

Most speech and language therapists work for the NHS. If you think you or your child needs to see a speech and language therapist ask your GP, district nurse, health visitor, or your child's nursery staff or teacher for a referral. You can also refer yourself to your local speech and language therapy service. You do not have to wait for someone else to refer you.

## Home Education

Home education, also known as elective home education is where parents choose to remove their child from school and take full responsibility for their learning. Any parent can choose to home educate their child and they do not have to follow the national curriculum, enter them into any exams or even have a teaching qualification.

It is a simple process to deregister a child from school and some parents choose to do so if they feel that the school is not meeting the needs of their child. As home educating a child is a big responsibility that requires a lot of time, patience and energy it's always best that you contact your child's school prior to deregistering them to see if they can offer support and to try and iron out any difficulties that

you feel they may be having. If you still feel that deregistering your child is the best option then in order to deregister you would need to do the following:

If your child does not have an EHCP you would need to write to your child's school explaining that you intend to deregister them and the date you wish for this to be effective from. The school will then remove the child from the roll and make the local authority aware of the change.

If your child has an EHCP, the rules around deregistering are slightly different as the local authority need to be in agreement with the deregistration as they have a legal duty to ensure the plan can be met outside of the school environment. Someone will usually meet with you from your local authorities home education department to discuss the EHCP and how you intend to meet the objectives in the plan. The LA then produce a report that is sent to the SEN team.

## Home to School Transport

All local authorities have a legal duty to provide free, suitable home to school transport for eligible children aged up to the age of 16 to their nearest suitable school. Children who have SEN, mobility problems or a disability are classed as eligible in Schedule 35B of the Education Act. In the transport guidance there is a walking distance criteria however for children with SEND it is not applicable. The Education Act 1996 states that children with SEND cannot be reasonably be expected to walk to school. In section 1.3 of the home to school transport and travel guidance, it also states within the SEN/Disability or mobility problems eligibility: "Usual transport requirements that is the statutory walking distances, should not be considered when assessing the transport needs of children due to SEN and/or disability.

To apply for school transport you will need to complete an application form. This can be found online at

[https://www.sunderlandinformationpoint.co.uk/kb5/sunderland/directory/service.page?id=c\\_HBpO\\_A\\_ZHY&localofferchannel=2\\_11](https://www.sunderlandinformationpoint.co.uk/kb5/sunderland/directory/service.page?id=c_HBpO_A_ZHY&localofferchannel=2_11). The Sunderland LA's travel and transport policy can also be found here. You may be asked to provide a letter from your child's consultant to state that your child has SEND in support of the transport application.

It is important to ensure that drivers and escorts are suitably trained and that this training is kept up to date. The local authority will take responsibility for this. Local authorities should also ensure that all drivers and escorts have been DBS checked. Children in primary schools should ideally not travel each way for longer than 45 minutes and in secondary 75 minutes as children should be arriving to school ready for the day ahead and a journey time that is longer than this could impact on that.

## Hospital Parking

If you have Blue Badge this can be used at Sunderland Royal, Sunderland Eye Infirmary and Durham Road Children's Centre by registering the badge at parking services for up to 2 cars to park free of charge at anytime and can be parked anywhere in the hospital other than in reserved areas or staff parking areas. Please remember to keep your details up to date.

## Hydrotherapy

Hydrotherapy involves stimulation and gentle exercise in warm water at a constant temperature of 32 degrees Celsius. Hydrotherapy pools tend to be purpose-built with a constant or very gradual water depth of around 1 metre. Pools usually incorporate multi-sensory equipment such as lighting and sound to stimulate the senses.

Hydrotherapy offers tangible benefits to the health and wellbeing of children and young people with a range of disabilities and health conditions:



- The warmth of the water has an effect on the individual neuro-muscular junctions which results in decreased muscle tone and decreased spasticity.
- Buoyancy of the water is used to assist movement of joints - which is either more difficult or painful on dry land.
- Movement in the water and water pressure helps to reduce residual lung capacity for children and young people with chest problems. This enables more efficient lung function and reduces the risk of chest infections developing.
- Creating turbulence around an extremity (i.e. arm or leg) can increase their awareness of the limb and help with mobility - both in the water and later on dry land.
- Multi-sensory environment helps stimulate the senses whilst calming children with sensory and learning difficulties.

Hydrotherapy is suitable for care and therapies to children and young people with complex needs and vision impairment. Additional needs support include physical disabilities, multi-sensory impairment, significant learning difficulties and disabilities, autistic spectrum disorders, additional medical and health needs (including long-term ventilation or life-threatening or life-limiting conditions) and emotional and behavioural difficulties.

All children and young people who are using the hydrotherapy pool have benefitted:

- Young people who are normally in their seating systems in their wheelchair for a lot of the day can experience freedom of movement in the pool.
- Others who don't move much on dry land become active and really enjoy moving round the pool.
- Young people who have very limited movement and struggle to communicate when on dry land are able to vocalise or move their arms to indicate preferences whilst in the water.
- Passive physiotherapy programmes can be difficult to tolerate on dry land but in the water the young people with tight muscles and joints are much happier when their muscle stretches are incorporated into a fun or relaxing time in the pool.

## Hoists

It is strongly advised that you contact your local social services and seek advice from a professional such as an Occupational Therapist, as they should be able to undertake a full assessment, and provide and maintain the appropriate equipment, as well as providing the carer with all the training required.

One common complaint raised against hoists is that they take too long to use. Carers often say they instead prefer just to lift the person themselves. This can often be because the person using the hoist is unfamiliar with the equipment or because it is unsuitable for the task. This can normally be easily addressed by the provision of the right equipment and thorough training and support in its use. Ultimately the aim of using any manual handling equipment should be to reduce the risk of an injury to the lowest level possible. We have a helpful series of questions to ask before choosing handling equipment here

### Ceiling track hoists

Traditional ceiling hoists run along permanently fixed tracks, so they offer less flexibility in use than a mobile system. On the other hand, they do not occupy floor space as a mobile hoist does, and they may be operated by the user independently – which is not possible with any floor standing system.



They are generally less arduous for a carer to operate than a mobile hoist, and are the more suitable for longer distance transfers.

In selecting a system, thought also needs to be given to structural considerations: ceiling joists may need to be reinforced, and doorways altered, to accommodate the track.

Many ceiling track systems are powered by mains electricity for the transfer, with either a manual or powered raising and lowering mechanism. There will either be a battery back-up for emergencies, or a manual wind-down facility, to enable the client to be lowered to a flat surface. Alternatively, the system may be powered by rechargeable batteries – which is useful in that it is independent of the power supply, and also removes the need for a cable running along the track to provide power to the hoist from the mains. The disadvantage is that the batteries need to be kept well charged up, by returning them to their charging point at the end of the track – and it is quite easy to forget to do this.

## Mobile hoists

Being self-contained units, mobile hoists don't require any track installation, so offer more flexibility of use. They do, however, demand more of the carer, and are really not designed for moving people long distances: a wheelchair or showerchair is better for this, or a ceiling track hoist (above).



In selecting a mobile hoist, thought needs to be given to the environment where it will be used: whether there is enough room to manoeuvre it into the right position; if the legs of the hoist will fit under or around any furniture, such as bed, bath or chair; whether the floor surface is smooth enough to allow it to operate easily: thick carpet or threshold strips are difficult to move over.

It is also important to check that they have sufficient operating range to lift the person clear of any surface, and perhaps also to pick them up from floor level in an emergency.

They also need to be stored when not in use, preferably in an area where they are out of the way, and with a charging point for their battery.

There are smaller mobile hoists with narrower bases which are easier to move in more confined areas. These have a maximum load of perhaps 20 stone (100 kg) or a bit more, and are useful in the domestic environment.

## Harnesses

If your child requires a chest harness to ensure their safety or postural position with a chair/wheelchair these are supplied with the equipment but can become very unsightly after a period of time due to wear, spillages, etc. There are various businesses who make custom harness covers which make the child look much smarter, they can be personalised with their favourite character or name, check out “DAB Hand Harness Covers” for their personalised service.



I

## Intensive Interaction

Intensive interaction is an approach that can help people who are in the early stages of communication development. This approach can be used to support those who have autism and people who have severe, profound or complex learning difficulties. The approach can be used if someone is reluctant to, or disinterested in, interacting with other people. Techniques such as turn taking, mirroring, rhythm and repetition, and sharing personal space can be used to support communication exchange that is initiated and led by the person, and in turn promotes a positive interaction.

J

K

## L

### Lifts / Stair Lift

#### Through floor lifts

Vertical, or through floor lifts, enable an individual to move from one floor to another within their home. Although versions are available that carry a seated or standing passenger, most are designed for wheelchair users. They enable wheelchair users to travel between floors in their wheelchair, avoiding the need to transfer from the wheelchair and onto, for example, a stairlift.



However, vertical lifts need more space than a stairlift and it is sometimes necessary to make structural alterations to the property. Vertical lifts without a shaft are commonly used in home environments as they require less structural alterations than lifts with a shaft. Again, consult your OT for a full assessment.

#### Stair Lift

There are stairlifts which have specialised seats suitable for children with disabilities.

The stairlifts may be either controlled by your child or by you, if a parental control is supplied. They are available for both curved and straight staircases.

Again, consult your OT for a full assessment. Note a stairlift will not be offered if your child cannot self transfer from a chair/wheelchair and need hoisting, this causes a huge safety risk and therefore you would be offered a through floor lift.

### Local Offer

The SEND local offer is a local authority's publication of all the provision that they expect to be available across education, health and social care. It is there to support children and young people from the age of 0-25 with SEN and disabilities whether they have an EHCP or not. The local offer should provide clear, comprehensive, accessible and up to date information about the available provision and how to access it & it should make the provision responsive to local needs and aspirations by directly involving disabled children and those with SEN and their parents. If you live in Sunderland Local Authority you can access their local offer by visiting the webpage as follows <https://www.sunderlandinformationpoint.co.uk/kb5/sunderland/directory/home.page> and clicking on 'local offer'. Here you will find comprehensive information on education, health and things to do, amongst many other topics. You will also find related SEND advice and policies on a variety of subjects. You can also sign the disabled children's register here and apply for a Max Card (see Max Card section for further information).

## M

### Makaton

Makaton is a language programme using signs and symbols to help people to communicate. It is designed to support spoken language and the signs and symbols are used with speech, in spoken word order.

With Makaton, children and adults can communicate straight away using signs and symbols. Many people then drop the signs or symbols naturally at their own pace, as they develop speech. Makaton symbols can be purchased directly from the Makaton website [www.makaton.org](http://www.makaton.org). They also have a selection of books and dvds as well as a free resources section.

If you shop at ASDA stores you can ask at their customer service desk for a Makaton shopping list. The shopping list gives the user the opportunity to add the symbols of items they plan to buy and then tick them off once they have been put into the trolley.

### Max Card

If you live in the Sunderland area or another participating local authority, you can sign the disabled children's register and become eligible for a Max Card. These cards can be used in many different places and enable the card holder to receive discounts on activities and days out. The scheme also enables card holders to register with the Dine Club for discounts on dining out. To sign the disabled children's register in Sunderland you need to visit the following website: [www.togetherforchildren.org.uk/disabled-children-register](http://www.togetherforchildren.org.uk/disabled-children-register) For more information on the Max Card, including where it can be used you will need to visit <https://mymaxcard.co.uk>

### Mobility

It is very important that the occupational therapist and/or the physiotherapist working with your child are involved in the choice of mobility, and standing equipment for your child. It is important that the equipment is right for your child, and suits the skills they have. Also, to ensure appropriate equipment is selected, it is important that your child's lifestyle and home environment is professionally reviewed.

## Medication

Hacks, tips and videos.

If your child is on tablet medication and this needs to be crushed or dissolved in water, there is a quick and easy way to do this in a syringe to save time and waste. Place the tablet into an empty syringe and place the plunger in, draw up the water into the syringe and remove the air from the syringe. Place your finger over the end of the syringe (creating a seal) and pull back on the plunger this will create a vacuum and cause the tablet to disperse and dissolve into the water. This may sound complicated so here is a link to a video which may be easier to follow:-  
[https://m.facebook.com/story.php?story\\_fbid=697769147271826&id=147110465887286](https://m.facebook.com/story.php?story_fbid=697769147271826&id=147110465887286)

## Minor Ailments Medication Scheme

Boots offer a minor medication scheme, whereby certain medication is available free of charge over the counter, you just sign a quick form and the medication is given, e.g. calpol, creams, etc

## N

### Nappies

Nappies can be provided by the NHS from the age of 5, however if your child is outgrowing shop bought nappies prior to this age speak to your child's Health Visitor or Consultant who can make a referral to continence services for an assessment. Junior nappies can now be purchased from Tesco. These nappies are larger than the standard infant/toddler nappies usually available.

## O

### Occupational Therapy (OT)

There is a community OT and usually a school OT, both of which assess the needs and safety of your child and their environment. They can supply information and equipment relating to:

- Seating
- Bathing
- Home adaptations
- Suitable beds
- Safe spaces
- Lifting and handling / hoisting
- Sensory needs (school OT)
- Some behavioral needs (school OT)

## P

### PECS

PECS stands for Picture Exchange Communication System and is classed as an augmentative communication system. PECS consists of six phases and begins by teaching an individual to give a single picture of a desired item or action to a “communicative partner” who immediately honours the exchange as a request. The system goes on to teach discrimination of pictures and how to put them together in sentences. In the more advanced phases, individuals are taught to use modifiers, answer questions and comment. The goal of PECS is to teach functional communication and users will sometimes go on to communicate verbally or use a speech generating device. To find out more information on the system visit <https://pecs-uk.com/pecs/>.

### Physio

Physiotherapists have specialist skills in the physical treatment and rehabilitation of people. Physiotherapy helps restore movement and function to as near normal as possible when someone is affected by injury, illness or by developmental or other disability.

Physiotherapists use a number of different techniques including manipulation and mobilisation, massage, hydrotherapy, exercise programmes, electrotherapy (e.g. ultrasound) and in some cases acupuncture.

Chartered physiotherapists work in a variety of settings including hospitals, health centres, GP practices, schools, work places, private clinics and also by visiting people at home.

### PEG / Button / NG Tube

If your child is having difficulty swallowing, chewing or processing food, after tests carried out by SALT they may be fitted with an NG Tube (Nasal Gastric Tube), which is a small tube inserted into the nose passing into the stomach to help the safe travel of liquids.

If this is a suitable method for feeding, you may be offered a PEG/Button/Mickey (they are all feeding tubes just slight different sizes/shapes and given different names) which is a more permanent feeding tube which is surgically inserted into the stomach through the stomach wall. These are more discreet and private and are much easier to use and manage. To keep the area, we can recommend tube pads are available to buy which should be made from bamboo fabric which has antiseptic qualities and help to keep the area dry and clean and free from bacteria, again these can be found at DAB Hand Harness Covers.



## Portage (National Portage Service)

Portage is a home based service for pre-school children with significant additional needs. Children can be referred to the service by a professional working with the child or by the parent themselves. Multi-agency professionals consider the requests for the service against the agreed guidance and referrers and parents are informed of the decision.

An initial visit is made by the Lead Portage Teacher to explain the service and arrange for a Portage Visitor to visit the home at a mutually convenient time. Portage Visitors assess the needs of the child and work in partnership with their parents to build on their abilities and develop new skills. Portage Visitors and parents discuss and agree long term goals. The Portage Visitor then outlines carefully structured activities to enable parents to support and encourage effective learning for their child.

Sunderland Portage also run community playgroups for preschool children with additional needs, this is a great opportunity to meet other families and for our children to make new friends in a safe and friendly learning environment.

Q

## R

### Radar Key

The National Key Scheme offers disabled people independent access to locked public toilets around the country. Toilets fitted with the National Key Scheme can be found in shopping centres, pubs, cafes, bus and train stations and many other locations across the country. You can purchase a radar key online from several websites for a small fee to enable access to these toilets or apply to your Local Authority for one.



### Rebound Therapy

Rebound therapy is the phrase that describes a specific model of trampoline therapy, exercise therapy which uses a full sized trampoline to provide opportunities for movement, therapeutic exercise and recreation for people across virtually the whole spectrum of special needs.



## S

### School

Your child does not need to have a confirmed diagnosis in order to have a learning difficulty which is classed as a special educational need or for special educational provision to be provided. If they have a special educational need or disability (SEND) then they should be on the school's SEND register for SEND Support. The type of support provided can vary quite a lot from school to school and even though a need is identified it does not necessarily mean that the provision will be good. This is even the case for children who have an EHCP.



Special educational provision for a child over the age of two means educational or training provision that is additional to, or different from, that made generally for others of the same age in—

- a) mainstream schools in England,
- b) maintained nursery schools in England,
- c) mainstream post-16 institutions in England, or
- d) places in England at which relevant early years education is provided.

The SEND Code of Practice provides statutory guidance to all maintained schools, academies, PRUs, early years providers, independent schools and special schools, including non-maintained special schools. These schools must provide support to children inline with the guidance.

If your child needs a high level of support at school they may be entitled to an Education, Health Care Plan (EHCP). The EHCP replaced the original Statement of Special Educational Needs several years ago. Please see the EHCP section for further information.

If your child has an EHCP then the school that is named on the plan has a duty to admit the child. The school can only refuse this under the following circumstances:

- a) the school or other institution requested is unsuitable for the age, ability, aptitude or special educational needs of the child or young person concerned, or,
- b) the attendance of the child or young person at the requested school or other institution would be incompatible with; the provision of efficient education for others or the efficient use of resources.

All schools are required to identify and address the needs of the children that they support. They must ensure that the children get the required support by doing the best that they can to meet the child's needs. They must also ensure that there is a named SENDCO, that SEN children engage in activities alongside children who do not have SEN and that parents/carers are informed when special educational provision is being made for the child.

When it has been identified that a child has a SEN. The school should implement an Assess, Plan, Do, Review system. As part of the assessment, the child's class teacher and the SENDCO should assess the child's needs, they should also take into account any parental concerns. This should be recorded and compared with the analysis completed by the school. When the assessment of the child is complete and it has been decided that the child will be provided with SEN support, the parents should be notified. The school should then agree, in consultation with the parents, what support and adjustments are going to be put into place to help the child. The expected impact on progress and a date for review should be documented and revisited regularly. All teachers and support staff working with the child should be aware of the provision put in place and what they need to do in order to support the child. They should also be aware of any teaching or behaviour management strategies they need to employ and what the expected outcomes for the child are:

The class teacher has overall responsibility for the progress of the child and how the adjustments are put into practice. It is important that the class teacher works closely in conjunction with any support staff so they are clear on what is expected and so they can assess how the interventions are working and whether any further adjustments are necessary.

The support and interventions should be reviewed regularly and at the agreed time. It is important that the impact and quality of the support and interventions are clearly evaluated and this should feedback into the assessment of the pupil's needs. It is also important that the views of the child and of the parents are taken into account. The class teacher and SENDCO should then revise and adapt the initial plan to show how they intend for the child to progress and also outline what support and interventions will be provided. Parents and pupils should then be consulted with and any changes decided together. It is important that parents are included to help the school plan the next steps.

## School Exclusions

Children with SEN account for approximately 60% of all fixed term exclusions and 70% of all permanent exclusions. A fixed term exclusion can last from 0.5 up to 10 school days and the child will return to school after the specified length of the exclusion. A permanent exclusion means that a child has permanently been excluded from their school and they are unable to return. If a child is permanently excluded then the local authority has a duty to find another school placement for them. This is often in a Pupil Referral Unit (PRU) which is a specialist provision set up specifically to teach children with behavioural difficulties. The child may be on roll there for a temporary period until another mainstream school is found or they may remain there until the end of their formal education career. They may also be placed in a school specifically for children with SEND.

In order to exclude, headteachers have to follow certain guidelines and regulations. When making the decision to exclude the exclusion must be in line with the law and it must be fair, proportionate, rational and reasonable. The headteacher must also ensure they comply with the SEND Code of Practice. If a child is exhibiting disruptive behaviour then this could be due to an unmet need. The headteacher must therefore ensure that the exclusion is fair when dealing with a child who has SEND and should provide intervention at the earliest opportunity to assess and address the cause of the disruptive behaviour.

If the provision that is in place for the child is not appropriate then the school should look to see what else it can do to support the child's needs to prevent a reoccurrence of the undesirable behaviour. It is against the law for a school to exclude a child for anything other than discipline. Therefore a school should never exclude a child if they are unable to support their SEND or of the parent is at fault, e.g. not providing the child with the correct uniform.

Some schools will 'unofficially' exclude children by contacting home to ask the parent to collect the child so they can cool off or if there is an issue at a certain time of the school day and asking the parents to collect the child early to prevent the issue from occurring. These informal exclusions are unlawful, even with the parent's agreement and the school should either formally exclude the child or they should look for ways to prevent the issue or similar issues from occurring again.

A child can only be excluded for a maximum of 45 days or 90 half days in any academic year. Once this amount has been reached a school may look to permanently exclude the child.

All exclusions must be formally recorded no matter how short they may be. The headteacher must also report back every exclusion made to the governing body of the school and local authority once per term. The headteacher must also report back to the governing body and local authority any time a child reaches 5 full days or 10 half days of exclusions in a term.

Where there are concerns over the behaviour of a child with SEND the headteacher, in partnership with others such as the SENDCO should consider whether the support the school is providing the child is enough and whether they are still able to meet that child's needs. If it is found that the school are no longer able to meet the child's needs then an alternative placement should be sought.

The headteacher should avoid permanently excluding any child with an EHCP plan unless they are left with no other option. The headteacher should work in partnership with parents and other school staff to support the behaviour of children with additional needs to try to avoid a situation where a child may be at risk of permanent exclusion.

If a child has a learning disability or autism then they may have a 'tendency to physical abuse'. There has been a recent case which was taken to tribunal that found that children who have a learning disability or autism may be aggressive but this type of behaviour is not a choice. Before this case, schools were able to exclude children who displayed aggressive behaviour even if the school had not done anything to support the child's needs. Since the case, schools must justify that the exclusion was reasonable and proportionate to the behaviour displayed by the child and that they have made reasonable adjustments for that child to manage their behaviour.

If you are concerned about your child's behaviour in school then the best thing to do is to contact your child's class teacher, their head of year or the SENDCO to discuss a strategy to help your child. The school may implement a positive behaviour plan which lists your child's trigger points, strategies for de-escalation and the procedure to follow if your child is struggling to manage their behaviour in school.

If you feel that your child has been excluded from school unfairly and has been discriminated against because of their disability or SEND then you are within your rights to appeal against the exclusion. The discrimination that you feel occurred could be direct, indirect or failure to make reasonable adjustments. Whenever a child is excluded from school you should receive a letter to advise the reason for exclusion, the length of exclusion and details of a reintegration to school meeting. The letter should also clearly detail the appeals process and who you need to contact to initiate this.

## SENDIASS

Special Educational Needs and Disabilities Information Advice and Support Service or SENDIASS provides free, impartial, confidential and accurate information, advice and support about education, health and social care for children, young people and their parents on matters relating to special educational needs and disability. They should offer information on subjects including local policy and practice, the local offer, personalisation, personal budgets, the law on SEN and disability, health and social care. They should also have links to local parent support groups, provide support in resolving disagreements, mediation and tribunals, support on school exclusions and support through the EHCP assessment and planning process.

As it is a statutory service there has to be one in every local authority however each SENDIASS service may vary from one authority to another due to their size, staffing and resources. To find your local SENDIASS visit <https://cyp.iassnetwork.org.uk/in-your-area/>

## Sensory Processing and Regulation

Many children with a disability or additional needs will have some sort of sensory processing difficulty. Sensory processing is where the nervous system receives messages and turns them message into a response. People who have sensory processing difficulties have trouble processing these messages causing the brain to get mixed up and provide an inappropriate response to the message received.

There are eight different sensory systems. These are visual, auditory, tactile, olfactory, vestibular, proprioception, interoception and gustatory:

- Visual is what you see
- Auditory is what you hear
- Tactile is what you touch
- Olfactory is what you smell
- Vestibular is your sense of head movement in a space
- Proprioception is your sensations from the muscles and joints in your body
- Interoception is a sense of how our internal organs are feeling, for example, feeling hungry or thirsty
- Gustatory is what you taste

Children may be oversensitive to sensory input, undersensitive or both. Sensory processing issues can have a big input on learning and everyday life. If a child is oversensitive to sensory input, they may find noise or lights overwhelming and they will do what they can do avoid this sensory stimulus. If they are unable to avoid it then they may experience distress which then causes them to have a meltdown and their sensory system needs to be regulated before they feel like they are back to normal.

Meltdowns can often be confused with tantrums as there are some similarities but they are in fact very different. A meltdown is a complete loss of behaviour control. The child's brain is unable to cope with a situation and goes into overload therefore they go into meltdown. It is not a choice they are able to make and they cannot prevent this from happening. It can often be quite distressing to see a child have a meltdown and it can be very difficult to stop it once it has started. A tantrum is a chosen behaviour in response to something that a child may want but cannot have and they can choose when to stop the tantrum. A tantrum often occurs when the child is looking for a reaction, with a meltdown, the child does not care who is reacting or watching. During a tantrum the child is also aware of their environment and personal safety. When a child melts down they have lost all control and awareness. Children who go into meltdown cannot stop it from occurring but it will eventually pass. For more in depth information, help and guidance regarding meltdowns visit this <https://www.ambitiousaboutautism.org.uk/understanding-autism/behaviour/meltdowns>

Children who are undersensitive to sensory input will seek out experiences to provide themselves with more sensory stimulation, for example, they may chew or bite on different objects or may want to touch things or feel pressure. Often children who are undersensitive may have a high tolerance for pain. They may prefer to engage in rough play and not understand that this might cause others pain as the action they are using may not cause them pain. Children who are undersensitive to sensory input are often called sensory seekers as they will actively seek out sensory experiences in order to regulate themselves. They often do this with little awareness of danger and may gravitate towards water or climb on furniture as they enjoy the sensations these activities produce rather than consider the dangers of doing the activity.

Some shops and leisure venues have recently started to introduce quiet hours for people who are oversensitive to sound, lights and other sensory stimulus. They tend to choose hours of the day that are already quiet and will ensure that music is not played, lights are dimmed and that there are no tannoy announcements. Some places such as the intu group who manage shopping centres such as the Metrocentre and Eldon Square have a sensory backpack that you can hire out. These backpacks include items such as ear defenders and fidget toys and are designed to make the shopping experience more enjoyable for those with sensory issues. It is always worth checking out a venue's website to see what they can do to make visiting more accessible. Some facilities offer personal shoppers, Makaton sign boards, wheelchairs and Changing Place toilets.

## Sleep System

Weighted blankets can be beneficial to some children who struggle to fall asleep. Lucy's Weighted Blankets group on Facebook is a recommended place to buy a blanket for your child if you feel that this would help with their sleep. You can also be prescribed a "Sleep System" by your Physio, a sleep system is an adaption to the child's bed, whereby they will be assessed as to their needs and a tailored system will be installed which can help with positioning, reduction of bedsores, a temperature controlled bedding.



## SALT (Speech and Language Therapy)

The role of a speech and language therapist (SALT) is to assess and treat speech, language and communication problems in people of all ages to enable them to communicate to the best of their ability. They may also work with people who have eating and swallowing problems.

SALTs assist children and adults who have the following types of problems: difficulty producing and using speech; difficulty understanding language; difficulty using language; difficulty with feeding, chewing or swallowing; a stammer; a voice problem.

SALTs work in a variety of settings, these include: hospitals (both inpatients and outpatients); community health centres; mainstream and special schools; assessment units and day centres; clients homes.

Most speech and language therapists work for the NHS. If you think you or your child needs to see a speech and language therapist ask your GP, district nurse, health visitor, or your child's nursery staff or teacher for a referral. You can also refer yourself to your local speech and language therapy service. You do not have to wait for someone else to refer you.

## Swimming

Bubblejets in Hebburn

Fulwell Day Centre in Sunderland have a hydrotherapy pool. This pool needs to be booked in advance and there are often waiting lists.

If your child is not yet continent and has grown out of the disposable swim nappies, reusable ones can be purchased online from a variety of stores.

## Shoes

Your physiotherapist can help with sourcing the correct shoes for your child, whether these need to be supportive for the ankle, corrective for any misaligned feet or ankles or whether its to fit around a splint. They will refer you to the Orthotics service.

## T

### Teeth Cleaning

There are a range of products you can buy to help make teeth cleaning easier. There are specialist toothbrushes such as the Collis Curve and Dr Barman's brush which are designed to clean all three sides of the tooth at once therefore making teeth cleaning quicker to do. You can also buy flavourless, non-foaming toothpaste called Ora Nurse. This can be useful for children who do not like the strong taste of mint and also for children who have an unsafe swallow. There are also dental finger shields that you can buy that you can use to help keep your child's mouth open wide enough in order to get their teeth cleaned whilst keeping your finger safe. These are useful for children who bite down on their toothbrush. These are available to buy from Ebay, you may also be able to get one from your dentist.

### Travel and Tourism

#### Airports

Many airports are now adopting a scheme to support people who have disabilities, including hidden disabilities. For example, at Newcastle airport you can pick up a lanyard from the Passenger Assistance desk. This lanyard discreetly lets airport staff know that the person wearing it may need a little more time or assistance to travel through the airport. A hidden disabilities/autism passport can also be downloaded from their website. Once this is completed and then validated at the airport it can be used to fast track through security so you don't need to wait in a queue. This is at the discretion of security staff however as the airport does not actually manage the queues. Once through security you can also use the passport to access a quieter waiting area within the terminal. There is also a social story, travel advice and an activity book that can be downloaded to help support people on the autistic spectrum. If you are travelling from a different airport it is worth logging onto their website before you travel to see what assistance they may be able to offer.

### TV Licence

If you or your child/someone you live with is registered blind or severely visually impaired you can claim for a 50% discount on your TV Licence. See the following link for more information:-  
<https://www.gov.uk/financial-help-disabled/television-licence-discount>

## U

### Useful Vision

Useful Vision is a registered charity providing positive opportunities and fun-packed events for blind or partially sighted children around the North East. They work with children and their families to give them the help they need to flourish. Their Mission is to provide accessible, positive opportunities and activities to visually impaired children and their families throughout the North East region.

## V

### Vision Impairment

In the North East, we have a wonderful specialist optician called Simon Berry, he is located in Durham and has access to SEN specific frames, i.e. Tomato glasses, etc He has access to unique equipment to help to test the eyesight and health of your child eyes and he offers a bespoke service to meet the families needs.



## W

### Wheelchair Services

NHS Wheelchair Services assess people with mobility needs, to decide what sort of wheelchair or other mobility equipment they should be provided with. Usually, it is your GP, hospital doctor or occupational therapist who makes the referral to wheelchair services. The child's mobility will be assessed and a suitable option of a specific pushchair, wheelchair or other mobility aid will be offered and maintained by the Local Authority, each time your child's needs change, they will be re-assessed and given the appropriate equipment.



If what is being offered to you is not suitable or not what you would like, a Personal Budget is now offered as a voucher which you can use towards paying for more fully-featured equipment that you might prefer – as long as it also meets or exceeds your clinical requirements.

Within the voucher scheme, there are two options; Partnership and Independent.

The Partnership option provides a voucher for the cost of a basic wheelchair, but allows you to choose a chair from a slightly wider range, approved by the NHS. You pay the difference in the cost, to an agreed supplier, but the chair remains the property of NHS wheelchair services. This means that they are responsible for maintenance and repairs.

The Independent option gives you a voucher for the cost of the chair the NHS would supply you with, together with some extra money to cover the maintenance and repairs they calculate will be needed in its lifetime – generally five years.

#### Purchase or rental supported

If you choose the independent route, the chair that you buy (from an agreed supplier) can be of any design, brand or value, as long as it meets your needs. It is your property, and you are responsible for the costs of insurance, maintenance and repair, whether this amounts to more or less than was calculated in the voucher.

You can also now use the voucher to rent a wheelchair on a long-term basis. In this case, the monthly rental payment also includes insurance, and provision for maintenance and repairs, making it a particularly good choice for anyone who likes to know exactly where they are financially, without the risk of an unexpected repair bill suddenly arising.

Any specialist postural seating or pressure relief elements are provided by the wheelchair service, and do not form part of a voucher.

## Wheelchair Accessories

### Cozy toes / footmuff

Bundlebean supply amazing cozytoes which fit over most pushchairs and wheelchairs, including many matching accessories.

### Raincover / Hood

You can purchase a raincover and hood from most wheelchair suppliers but they are very expensive – often hundreds of pounds, but Mothercare offer a universal raincover which fits most wheelchairs, again make sure you try before you buy. Mothercare stores are usually very helpful in allowing you to take it out of the box to try it in store.

### Buggyboards

Again you can purchase buggyboards from most wheelchair providers but are super expensive, but a few hves universal fittings and is suitable for most wheelchairs

### BuggyPod

The Buggypod is a light robust extra side seat for buggy or wheelchair that attaches easily to the side of your pushchair/wheelchair and can easily be converted into a single pushchair as and when you need it. Designed, engineered and tested in the UK, the Buggypodis the award-winning convertible chair which adapts to your family's needs.



## WAV (Wheelchair Accessible Vehicle)

Choosing a Wheelchair Accessible Vehicle (WAV) is a big decision to make and can be a complicated and lengthy process so to help you find a vehicle that will meet your needs now and in the future check out “Motability” who can answer all your questions and show many examples of the adaptions available.



## Water Rates

There is a scheme called WaterSure which can help with the cost of water rates. This is based on benefits and certain medical conditions, so this isn't just a means tested scheme. See the following link for more information.

[https://www.nwl.co.uk/assets/documents/LF0989\\_Watersure\\_leaflet\\_NW\\_LR\\_V2.pdf](https://www.nwl.co.uk/assets/documents/LF0989_Watersure_leaflet_NW_LR_V2.pdf)

X

## Y

### Young Carers

A young carer is a child between the age of 5 to 16, or a Young Adult Carer aged 16 to 25 who looks after someone in their family who has a long-term illness, disability, mental ill health or substance misuse problems that impacts on the young person. This may be taking on responsibilities, emotional and/or practical support that would normally be expected of an adult.



Local authorities must take proactive steps to identify and support young carers in their area. Where it appears to a local authority that a young carer may have needs then they must carry out an assessment. Young carers or their parents can also request an assessment. If you wish for an assessment to be carried out, you will need to contact the Sunderland Carers' Centre on 0191 5493768. Sunderland Carers' Centre offer information and advice to young carers, they also offer group sessions and one to one support. It can often be beneficial to inform the young carer's school of their caring role within the family as often schools can provide support to the child during school hours.

Z

## Additional Notes



If you would like to know more our work visit  
[www.thespeciallioness.com](http://www.thespeciallioness.com)