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## Introduction

Finding out that your child has a visual impairment can be an emotional roller coaster. At different times you may feel disbelief, anger, sadness, worry and frustration in addition to all the joys and pleasures that your child brings. Different feelings come and go and sometimes they catch up with you when you least expect it. All the while your baby needs food, love, warmth and security, which demands your energy, care and attention. This booklet is about creating a loving and stimulating environment within which to introduce your child to new experiences and awaken their interest in the people, things and places around them.

All children develop in their own way and at their own rate. Some are early talkers, others early walkers, some cry a lot while some smile a lot. Some sleep through the night and some don't. Children progress at different rates whether they have a visual impairment or not.

However, fully sighted children soon see things that they want to touch and they begin to reach out for them. Their sight gives them a fundamental motivation to explore, move and learn. Children with visual impairment may need help to make sense of the sounds they hear and to find out more about the toys, clothes and objects they touch. This booklet can help you to stimulate your child's curiosity and encourage them to discover things in the world around them.

Other families have suggested what should be included in this material, but you should use it only in the way that suits you and your family best. You may want to read all the sections straight away, or you may want to take your time. Different sections are likely be useful at different stages in your child's life.

Some of the information may seem too painful to read now. If so, put it to one side until you are ready.



## Understanding your child's visual impairment

Finding out that your child has a visual impairment can be a difficult and emotional experience. Other parents say good information and practical advice from families who have lived through some of the things you are experiencing before makes a real difference and can help you adjust.

This booklet answers some of the first questions you may want to ask. It starts by presenting basic information about eyes and eye conditions. Then it moves on to explain what you can do to help your child.

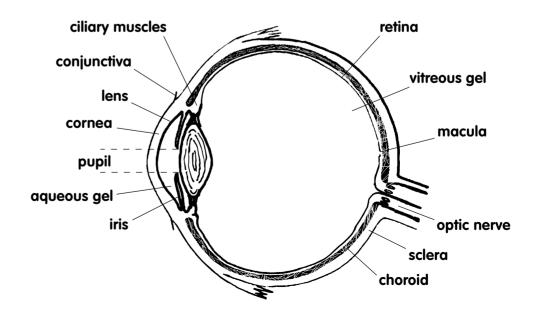
Some of the information presented is quite technical. Wherever you read a word highlighted in colour like this, you can look it up in the Glossary at the back of the booklet.

See **Glossary** on page 66

A basic understanding of how the eye works is the first step towards understanding your child's condition better.

#### Parts of the eye

In order to be able to see, three things need to work properly – the eye, the optic nerve and the brain. Although a child's eyes may appear to be fine, damage to the brain or optic nerve may cause sight loss.



This is a brief description of the main parts of the eye and their function: aqueous gel - a clear, watery-like substance between the cornea and lens choroid - the middle layer of the eye, composed of blood vessels supplying nutrition to innermost layers ciliary muscles - attached by ligaments to the lens to adjust the focus conjunctiva – the protective membrane covering the eye cornea - the transparent 'window' at the front of the eye iris - the coloured part of the eye in front of the lens and behind the cornea which expands and contracts to control the pupil lens - a transparent structure situated behind the pupil which focuses images upon the retina macula – the central area of the reting which is used for central detailed vision and for seeing colour optic nerve - a collection of around a million nerve fibres which send messages from the retina to the brain pupil – the circular hole (which appears black) at the centre of the iris through which light passes; the size alters to regulate how much light enters the eye retina - the inner lining of the eye which receives the images and transmits them to the brain via the optic nerve sclera - the white of the eye; a strong coat to protect the eye vitreous gel – a clear, watery-like substance between the lens and retina

visual cortex – the area of the brain responsible for processing visual images.



#### The development of vision in infants and young children

Vision is a major source of information supporting human learning – most estimates suggest it provides about 80% of what we need. The eye is the most developed organ of the body at birth and it develops more quickly than any other immediately after birth. At three weeks old, the eyes are one of the most active parts of a baby's body. Vision is still poor at this stage, so a baby needs objects that are of high contrast and that move. The human face is ideally suited to attract and hold a baby's attention and, even from birth, babies are able to imitate facial expressions and actions.

Much of our vision normally develops in the first year, particularly in the first four to six months, with a major growth spurt at two to four months. Babies at this stage are 'robotic looking machines' – their attention can be caught by more or less any visual stimulus. Vision is a learned process and by the time a baby is one year old, they have normally acquired a wide range of visual skills. Children's vision continues developing through the first years of life and becomes fully mature around the age of seven.

The development of visual skills and learning in general, passes through a number of characteristic stages which can be summarised in the following way:

- Awareness: We become aware of movement, sound, or touch that happens near to us.
- Attention: We pay attention to the sights and sounds and other sensory experiences going on around us of which we have become aware. We then begin to learn more about them, including how to find out where they are.
- Localisation: Once we have found out where a particular sound, smell or sight is, we learn to separate it from what is happening around it.
- Recognition: We remember that we have seen or heard or touched that particular object before. We also begin to have a view about whether we like or dislike it.
- Understanding: To develop understanding, we have to put together all the information we have gathered. This means we have to use our memory and problem-solving skills in order to work out what to do with the object we can see, hear, touch, smell or taste.

Vision develops when it is used. If your child has some usable vision, it's important they are encouraged to use it.

The brain combines information received through vision with information coming through the other senses (touch, hearing, taste, smell) and awareness of our position in space. The fact that 40% of the brain is devoted to processing visual information shows the complexity of vision. Children use their eyes to make sense of what they are experiencing and much of what they see leads to incidental learning.

Vision organises sensory perceptions of the world and makes connections. It's an important way that the world attracts and engages a child's mind.

# What does visual impairment mean for my child?

There are many terms to describe a visual impairment, some of which are used in this booklet. You may hear it described as 'partial sight', 'low vision' or 'sight loss'. You may also hear the terms 'special educational needs' or 'disability' being used. These are words that appear in legislation and so may be used by some of the professionals you meet. If you don't understand the descriptions that people use, ask for them to be explained. If there are any words in this booklet which are unclear, check the Glossary at the back, which explains some common eye conditions and some of the specialist language which is commonly used.

#### What can your child see?

Although doctors might be able to give some answers to this question, it often takes time to establish the exact nature of your child's situation.

Research suggests that sight continues to develop after birth, and that vision must be stimulated to reach its full, useful potential. Seeing also requires perceptual skills to make sense of the images sent from the eye to the brain. For this reason, it's often many months, sometimes years, before parents find out the full extent of what their child can and cannot see. See **Glossary** on page 66



Total blindness is very rare. Most children can see something, though it may not be very much and it's important to remember that whatever sight a child has is likely to be useful. For example, children who can only see light and dark may be able to tell where a window is and use this information to find their way round a room.

Various aspects of vision can be measured:

- Near and distance vision can be tested to assess how clearly your child can see fine detail (visual acuity).
- Colour discrimination, visual fields (what is visible around us at any one moment), the effect of lighting, adaptation to darkness, and movement perception can also be assessed.
- Refraction is the measurement of the correct lenses needed to bring the images seen by the eyes into best focus. Children with reduced vision should be refracted to check whether they would benefit from glasses. Not all children will need glasses, but early diagnosis and correction of refractive errors is very important in young children because a blurred image on the developing retina can cause amblyopia.

If you have been for an eye test yourself you will have seen the letter chart. To use this chart, children need to be able to read, and to recognise and name the letters shown there. So charts have been devised for use with young children where they are asked to identify and match pictures, not letters. Other means can be used that don't require the same level of co-operation, such as electrical measurement, which uses electrodes to measure the signals being sent along the visual pathways. These types of tests are done in hospital.

Another way of testing is called 'preferential looking'. This relies on the fact that if a child is presented with two visual targets, one plain and one patterned, their reflex response is to look at the pattern – that is, the more interesting one!

Read more about this in the **Glossary** 

Visual acuity is recorded as a fraction: the top number is the distance that the chart is placed from the eye (usually 6 metres) and the bottom represents the smallest line on the chart which can be read at that distance – in other words the distance from which a standard eye could see that line. 6/6 describes standard vision. The large top letter on the chart can normally just be made out at a distance of 60 metres. So an eye that could only read the top letter of the chart at 6 metres would be said to have an acuity of 6/60, meaning that what a standard eye can read from 60 metres, this eye can only see from 6 metres away. This is sometimes called 10% of standard visual acuity.

It is important to remember that visual acuity recorded in a clinic may not be the same as the functional acuity of your child in the home or early years setting where objects are in colour, close as well as at a distance, and moving. Seeing is a complex activity and children with a visual impairment often surprise us by what they can see and do.

Language is required to describe exactly what we see and perceive and it may be several years before a child is able to communicate to us exactly what they can and can't see. But observing how your child functions in everyday settings provides a lot of useful information about how much they are seeing.

If your child has a language delay in addition to a visual impairment, greater skill and patience will be needed to explain to them how to maximise the use of their sight and for them to understand and communicate just how their eye condition affects their vision.

No one will understand your child's needs as well as you do. It's important to share the observations you have made about your child's sight with any professionals you meet.



#### **Certificates of vision impairment**

The information gathered about your child's vision may be used to issue a Certificate of Vision Impairment. This is signed by a consultant ophthalmologist to register your child as sight impaired/partially sighted or as severely sight impaired/blind. Very young children may not be given a certificate until they are older. Some parents are worried that having a certificate may 'label' their child, although families with older children report that this doesn't seem to be a problem.

Registration has no direct connection with the assessment of your child's needs or planning for the support they may need. However, it does enable information to be collected about the number and causes of severe sight problems in children, which helps with the planning of services for children with visual impairments. You may want to talk this through with your ophthalmologist when you are ready.

#### Handling news or no news

There are many reasons why children have visual impairments. Sometimes it's genetic or the result of an infection or injury. In many cases no specific cause can be identified. While a simple explanation may be given, diagnosis is often difficult, especially if the condition is rare and little understood. It's not unusual for the diagnosis of a child's medical condition to take months or even years. Sometimes families never get the neat explanation they would like of why their child has a visual impairment with the implications spelt out.

If you have been given a diagnosis of a particular condition affecting your child's vision, you can find out more about it in a number of different ways. There's a lot of information available on the internet. For example, www.viscotland.org.uk is a website with medical information about visual impairments written specifically for parents. You can also access the websites of specific eye condition groups through SPECS (specific eye conditions) at www.eyeconditions.org.uk. SPECS also produces a directory of eye conditions. If you are not an internet user, ring the Royal National Institute of the Blind Helpline. Contact information is at the end of the booklet.

Sometimes your child's diagnosis may have implications for you and other members of your family. If this is the case, you can ask to be referred to a genetic specialist to find out what the chances are of any known condition being passed on.

Some families receive information that their child has a visual impairment as part of rare syndrome or particular condition. Contact a Family is a national organisation offering support and advice to families of children with a range of disabilities. The organisation maintains a database of specific conditions and rare disorders in addition to those listed in the *Contact a Family Directory*, which can be purchased or accessed on-line at www.cafamily.org.uk. Each entry contains a short medical description of the condition with details of inheritance patterns and pre-natal diagnosis. This information is followed by contact details for related support networks: their activities, publications, and what they offer to families. Contact information for Contact a Family is at the back of this booklet.

#### Effects of a visual impairment on development

Children with a visual impairment develop in much the same way as other children, although there may be differences in the rate and sequence in which skills develop.

The difficulties experienced by children with a visual impairment are not always obvious.

Different visual conditions give rise to a range of effects, with different implications for each child. Different eye conditions create different ways of seeing: some pose difficulties with seeing things at a distance, others with seeing things that are near; some affect what your child can see clearly, others what they can see in their wider field of vision; some mean that children don't see in colour. It's important to remember that each child is an individual and that even children with the same eye condition may appear to see very differently. Read more about this in **Useful organisations** 

## Read more about this in **Useful organisations**



It's also important to understand that your child's level of vision may not be constant from day to day, or even from moment to moment. It may depend on their surroundings, as lighting changes from place to place. Even mood can affect a child's ability to see and make sense of the indistinct picture their brain is receiving. If your child is tired, unwell or under pressure, they may not be able to use the vision they have as well as they usually can.

Children vary in the way they adapt and compensate for their visual loss by using and interpreting information from other senses to learn. Many skills which other children might be expected to simply pick up may need to be deliberately taught to children who have a visual impairment. In general, they have fewer opportunities to learn incidentally in the way that their sighted friends do.

A child with any degree of visual impairment may not have the same range and variety of life experiences as other children. For example, they may not participate as actively in the daily routines of eating, bathing and dressing which lead to independence. They may also be less sure of their ability to get about, which affects the way they interact with the physical environment.

Both the quality and the quantity of information available are usually reduced. There are fewer clues to help them understand the meaning of sounds or the function of objects. Your child may perceive only part of an object or activity. The result is that their development may take place relatively slowly and unevenly, with unexpected gaps in understanding.

It may take your child longer to complete activities that involve vision. This can be frustrating for you and for them. The extra time and effort it takes to do everyday things can also make children with a visual impairment more tired than other children of the same age. However, there is danger in concentrating too much on how visual impairment interferes with making sense of the world. Understanding the impact on communication, on self-esteem and on attitudes to learning are equally important for your child's development as a whole. Visual impairment can be particularly significant for their relationships with other children and adults because eye contact, facial expressions, body language and gestures may simply go unnoticed or be misinterpreted.

Having read this, you may wonder how your child will cope. But with support – active involvement, guided exploration of real objects and experiences, and lots of verbal explanation – your child will learn and achieve a lot. The important thing to remember is that your child is a child first. Understanding visual impairment and the effect it may have is just a starting point. It leads to being able to help your child play and learn.



### **Getting started**

#### What other families say about their experiences

One parent of a disabled child, Emily Perl Kingsley, wrote about her feelings in the following way.

Welcome to Holland

'I am often asked to describe the experience of raising a child with a disability – to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this...

When you're going to have a baby, it's like planning a fabulous vacation trip – to Italy. You buy a bunch of guidebooks and make wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland".

"Holland?!?" you say. "What do you mean, Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland, and there you must stay. The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guidebooks. And you learn a whole new language. And you meet a whole new group of people whom you would never have met otherwise.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around... and you begin to notice that Holland has windmills... and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and

they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say, "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever go away... because the loss of that dream is a very, very significant loss.

But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things... about Holland.'

## Family support

Many parents or carers find it helpful to talk over the news of their child's diagnosis and to meet other families who have a child with a visual impairment.

Some choose to contact or join a parent support group. Many of these are organised by local education authority (LEA) visual impairment services. Parent groups vary enormously in size and in terms of how active they are. Some cover only part of a city, while in rural areas they may bring together parents from across a whole county. Some parents keep in touch by phone and meet informally in between group meetings.

Group meetings give parents an opportunity to:

- share experiences and emotions
- learn from each other and meet other people who understand what it's like to bring up a child with a visual impairment
- meet older children with a visual impairment
- listen to guest speakers
- attend social events which involve all the members of the family.

There are support groups specifically for people with particular eye conditions like albinism, retinoblastoma, nystagmus or retinitis pigmentosa, and for their families. Read more about this in **Other professionals** interested in your child's learning and development

Read more about these conditions in the **Glossary** 



Read more about this in **Useful organisations** 

- LOOK, the national federation of families with visually impaired children, brings families together. It has regional co-ordinators and local representatives and is in contact with parent support groups across the country.
- The Royal National Institute of the Blind (RNIB) also offers a range of services for families with a child with a visual impairment, including family weekends, family days and play schemes.
- The National Blind Children's Society (NBCS) run events for children and can help with resources.
- Local organisations for blind and partially sighted people may also be able to help, although these groups vary in size and in the services they are able to offer children.

## Looking after yourself

It's exhausting looking after a young child, particularly when that child has a visual impairment and needs you to help them develop and make sense of the world. Other families say it's important to know your limits and to avoid becoming overwhelmed and exhausted.

They offer the following advice:

- Meet other families who have children with visual impairments. They're a unique and invaluable source of information and experience.
- Approach big tasks one step at a time.
- Be realistic when estimating time and try to build in a big enough margin for your child to do things at their pace. This isn't always possible, but when you can build in the extra time likely to be needed, everyone arrives happier. Often parents feel most stressed when they have to be at a certain place at a certain time, for example on time for school or work.
- Find some help and when you have found it, use it!
- Take a break. Plan small breaks for yourself during the day. When your baby is having a daytime nap, ten minutes with your feet up reading a magazine will do you more good than ten minutes doing the housework!

- Get out on your own from time to time. However hard it is to make the necessary arrangements for your child to be looked after, it's worth it. It will do you good to go out without a bag crammed with nappies and spare clothes, and to be able to have some uninterrupted, adult conversation.
- Recognise that it's difficult to cope with the unknown. Acknowledging this may help you deal with uncertainty better. A positive outlook and the opportunity to take action to help your baby can help you feel more in control.
- Spread the load. Involve grandparents, aunts, uncles and friends. Invite other parents in for a coffee and a chat in the early years, this will also encourage your children to play together in a natural way.
- Laugh if you can it can help in difficult situations.



## Who can help?

This section will introduce some of the doctors and eye specialists you might meet and suggest some questions you might want to ask.

Sometimes it can feel like armies of experts are advising you about your child. At other times you may wonder, 'Who really knows my child and can help them?' Your child is unique and it's important to understand that some of the professionals you meet may not have as much experience as you do of children with the particular combination of needs you live with on a daily basis. Your observations are crucial to ensure the success of any professional support.

## Doctors you might meet

#### **Family doctor**

Your family doctor (or GP) is a family doctor who works in the community. They are the first point of contact for many families. They are concerned with the general health of your child and can advise and arrange further examinations, and refer you on to clinics, hospitals and specialists when needed. They may also support welfare benefit applications and/or other types of help.

#### **Paediatrician**

A Paediatrician is a doctor who specialises in working with babies and children. They check the overall health of newly born babies, and are usually based at the hospital or child development centre. It's usually a paediatrician who refers your child on to any specialists that they need to see. You may also meet a paediatric neurologist who has particular expertise in how the brain works in very young children. A paediatrician can offer advice, information and support about any medical condition(s) your child has.

Read more about some of the language introduced here in the **Glossary** 

#### Ophthalmologist

An opthalmologist is a doctor based in a hospital who specialises in the diagnosis and treatment of eye defects and diseases. They have special qualifications and experience in eye disorders and in treating them with appropriate medicine and surgery. You may be referred to one to check that your child's eyes are healthy.

Your GP may refer you to a child health or child development clinic where you may meet a community child health doctor or senior medical officer. They are specially trained in the development of very young children and in detecting problems which need treatment.

Questions it might be worth asking a doctor, ophthalmologist or paediatrician:

- What's the cause of my child's visual impairment?
- What's my child's condition called and how do you spell the name?
- Can anything be done to cure or help the condition? Is any special treatment necessary? What might help? What can I do to help?
- Is this a family or inherited condition? If so, will we be referred to a genetic counsel and have genetic tests?
- I there anything my child must not do (for example, rub their eyes or shake their head)?
- Is the condition likely to get worse, better or stay the same?
- What risks are there? What should I look out for?
- When should my child be examined again?
- Where should we go for further advice and help?
- Have you any information on the eye condition that I could take home and read? Is there a website?
- When do you want to see my child again?



## Other eye specialists

#### Orthoptist

The Orthoptist is a health professional who specialises in correcting vision by non-surgical means (especially by exercises to strengthen the eye muscles). They often work with ophthalmologists in hospitals, but you might meet one working in a health clinic or visiting a school. They test children's sight, look at eye movements, assess how well both eyes work together and check for squints (turning eyes).

#### Optometrist

The Optometrist or ophthalmic optician is a health professional who specialises in measuring children's sight and prescribing glasses. They can identify eye diseases and are usually based at a hospital or optician's. The dispensing optician will help you choose frames and make sure they fit properly but cannot test your child's sight or prescribe glasses. It's important that if your child needs glasses, they are encouraged to wear them.

Questions it might be worth asking an orthoptist or optometrist:

- Will glasses help and if so, when must they be worn?
- What can I do if my child doesn't want to wear glasses?
- Can you tell me how much my child can see?
- Are there any low-vision aids which could help my child see better?
- Where should I go for a low-vision assessment?
- How well can my child see:
  - at a distance?
  - to the side?
  - in colour?
  - in the dark?
  - in bright light?
  - with movement?
  - with 3-D vision?
- Is there any special lighting that will help my child?
- How will this affect them when they go to school?
- Can you supply information for the people working in my child's play group or early years setting?

# Other professionals interested in your child's learning and development

#### **Health visitor**

A Health visitor is a qualified nurse or midwife with additional special training and experience in child health. They visit family homes in the early years to check on children's health and development. They give help, advice and practical assistance to families about the care of very young children, normal child development, sleep patterns, feeding, behaviour and safety. You should automatically receive a visit from a health visitor, as all families are visited in the early years. If you don't, they can be contacted through your GP. Health visitors can help you contact doctors, hospitals and other services in your area.

#### Qualified teacher of visually impaired children

Your local education authority (LEA) should have at least one Qualified teacher of visually impaired children (QTVI). These specialists are gualified teachers who have additional qualifications and experience working with children with visual impairments. They support children, their family, and other teachers. They are sometimes called teachers of children with visual impairments. Some QTVIs are based in schools – others are known as visiting or peripatetic teachers. In the pre-school years, they visit and support families and children in their homes. Ask your LEA to put you in contact with a QTVI as soon as possible. They can support you and your baby or toddler as soon as a visual impairment is suspected or diagnosed. Ask them to visit you to suggest ways of encouraging your child's development with toys, play, talking, moving and so on. They can work with you alongside other early years teachers or a Portage worker if your child is already in contact with these services. If you have difficulty getting help, or need the contact details for a qualified teacher of visually impaired children (QTVI) working in your area, ring the RNIB Helpline. Contact information is at the end of the booklet.

Read more about this in **Useful organisations** 



Points that might be worth discussing with the specialist teacher or adviser:

- What can I do to help my child understand what they see and handle?
- What are the best things for my child to play with?
- Can they learn to read print or should they learn Braille?

Some services for children with visual impairment are also able to put you in touch with a mobility officer. They can advise you on how to encourage your child to move around more independently.

#### Specialist social worker or rehabilitation worker

Your local social services or social work department may have a Specialist social worker or rehabilitation worker for people with visual impairment who works with children and their families. Social workers can provide practical help and advice about counselling, transport, home helps, and other services. They may be able to help you with equipment at home and suggest lighting or décor to help children to locate door frames, walls and furniture more easily and to move about at home with more confidence. Rehabilitation workers teach mobility and daily living skills and will be able to answer some of your questions about sight loss.

Child legislation requires social services to offer practical help to disabled children and their families. If you experience any difficulty making contact or getting help, ask to speak to the person in social services with responsibility for children with disabilities.

If your home language is not English, ask your local education authority to provide an interpreter for you. The interpreter can work with you, when you are meeting with professionals to make sure that you are able to participate fully in any decisions being taken. It's important that you inform professionals about your language requirements. If you have a hearing impairment, you can ask for a signing interpreter.

It is also important for you to inform professionals about any particular cultural and religious needs your family has from the start, so they understand your wishes and can support you and your child appropriately.

## Other professionals you may meet

#### **Physiotherapist**

A Physiotherapist is a health professional specialising in physical and motor development. They can assess your child and develop a tailored treatment plan that might include helping your child to control their head movement, sit, roll over, crawl or walk. Physiotherapists can also teach you how to handle your child at home for feeding, bathing, dressing and advise on equipment which might help your child's mobility.

#### Speech and language therapist

A Speech and language therapist is a health professional specialising in communication development and disorders (and associated eating and swallowing difficulties). They offer support and advice to parents of children with any type of communication problem. They assess, diagnose and develop programmes of care to help children develop their communication, language and speech, including sign language.

#### **Occupational therapist**

An Occupational therapist helps children improve their developmental function by therapeutic techniques, environmental adaptations and the use of specialist equipment. OTs are concerned with difficulties that children have in carrying out the activities of everyday life. This could include sitting in a chair, holding a spoon and fork or drinking from a cup.

#### **Educational psychologist**

An Educational psychologist is a qualified teacher who has additional training as a psychologist. Educational psychologists help children who find it difficult to learn or to understand or communicate with others. They can assess your child's development and provide support and advice.



## Voluntary organisations

Read more about this in **Useful organisations** 

Voluntary organisations provide information and services linked to particular needs. They are usually charities and operate at national and/or local level. Many families find they provide valuable information and support. A list of the voluntary organisations most likely to be of interest to you in the first three years of your child's life is provided, with contact information, at the end of this booklet.

## What can you do to help your child?

#### **Developing the senses**

Learning is the key to development. This section explains how you can help your child to develop by helping them to listen, to touch and, if they have some vision, to look. All children with a visual impairment, even those with relatively good partial sight, will benefit from learning to use their non-visual senses to give them more information about their surroundings. Children can be taught to interpret and piece together the information being sent to their brain from all their senses. These are skills which are learned over several years and can take a lot of practice.

#### Learning to listen

Babies are surrounded by adult speech from day one. When a baby is lying very still it's easy to interpret this as a lack of interest in what is going on. However, babies or toddlers with a visual impairment often become really still precisely so that they can listen and work out what is happening. For example, in the morning a child with little sight may listen to the bedroom door open and hear their parent's voice. Gradually they learn the routine and begin to smile with pleasure in anticipation of being picked up and cuddled. Your child needs to be rewarded for their smile by hearing the pleasure in your voice and feeling your warmth. In this way they will learn that smiles are important. Children soon learn to tell when their parents are happy or cross by the tone of their voices. During their first few years of life most children gradually learn to associate meaning with words. Here are some ideas for talking together:

- Encourage people to use your child's name when addressing them. They will begin to hear the difference when people talk to them and when people speak away from them. They will also learn that adults usually use a different, higher tone when they are talking to babies and young children, and that they use only simple sentences and repeat what they have said. Gradually, they will begin to recognise the voices of people they spend the most time with and understand when someone is talking to them.
- Name objects such as bottles, spoons, vests and coats every time they are used by your child. Naming things every day will make the words become familiar and help them to associate them with objects and events.
- Sing or say nursery rhymes, and help them to do any actions that go with the song.
- Use repetitive games like 'Round and round the garden'. As your baby gets to know them they may show excitement, kick their legs or flap their arms. They will learn to join in by laughing, gurgling, clapping or banging, and in time attempt to say some of the words.
- Praise every attempt your child makes to use language, repeating the sounds they make and giving them meaning. They will learn faster if they know you like to hear them talk.
- Help young children make sense of what they hear in settings where they are bombarded with lots of other sounds too. It's often best to take children with a visual impairment to the source of a sound to explain what it is and where it's coming from.
- Gain your child's attention before you encourage them to notice a sound and begin to make sense of it. For example say, 'Listen, Sarah' and then take them to the vacuum cleaner so they can hear and feel the noise it makes.



- Take your child around the house, naming all the sound clues they can hear. A wind chime, a ticking clock, a humming fridge, and a spinning washing machine are all cues. Let them have a go with the doorbell, or listen to the phone ringing and the sound of someone's voice when it is answered.
- Take them to the same sounds over and over again. This gradually reinforces the experience, until sounds become familiar and gives children a sense of security.
- Turn off the radio or television when you want your child to hear and learn to listen to other sounds. It's easier for children to tune in to what you are saying and develop their own speech when there is no background noise.
- Use songs and story tapes. They're great for encouraging language development.

#### Learning to touch and feel

Touching and holding different objects is one of the most important ways for your child to find out about their world. It's important that your child learns to use both hands.

Within a few months of birth fully sighted babies discover their moving arms and this brings their hands in front of their eyes where they can see them. This may not happen spontaneously for a child who has little or no sight. Some children with a visual impairment will notice that the little light they can see seems to disappear momentarily when their hands wave in front of their eyes. You can help your child to discover their hands by putting wrist rattles on their arms, or little finger puppets which make different noises. When you sing finger and hand rhymes such as 'Pat a cake, or 'Tommy Thumb', blow on your child's hands too and stroke them. Some children enjoy having a little baby oil massaged into their hands. Once your child has discovered their hands, you can help them to use them so that they become stronger and more skilful. Your child may repeat some actions endlessly but tire easily with others. Some children with a visual impairment find it difficult to use their hands or to experience touch in a pleasurable way. Sometimes it helps to stimulate their sense of touch by gently dabbing or placing items in their hands or on their fingers. If this is too threatening or unpleasant for your child, use their feet as a means of experiencing touch, as this might be more acceptable to them. Many children prefer to explore hard surfaces with their hands. Furry objects like teddy bears have a less definite shape and feel, and some children with a visual impairment find this off-putting.

Here are some ideas to try.

- Always position your child where they feel secure. Many children with a visual impairment feel safer if they can feel the edges of their space. This might be lying in your arms, on your lap, or sitting next to you on a sofa or chair, or in a baby activity nest. They should be able to reach and hold things easily so that they can use both hands to explore objects and toys. As well as their hands, children use their mouths to explore, often licking, biting and chewing their toys. This is an important way for them to find out about things and should not be discouraged. It's also important that infants experience different secure positions as time goes by, not always the same one.
- Make a noise with an interesting feely toy that has different textures and then put it near their hand.
- Use safe household objects. Pan lids and wooden spoons that can be banged and shaken make good toys.
- Lie your child under a baby gym and show them how the toys feel when they move.
- Introduce them to a variety of different materials and textures. Wood, metal, rubber, carpet, paper, sponge, towelling, felt, denim, wool and velvet are more interesting to feel than smooth plastic.



 Assemble a treasure basket of objects from around your home for your toddler to dip into. Safe, clean items with interesting textures appeal to young children- for example, a squeezy sponge, a bodywash puff on a string, the cardboard centre of a kitchen roll, or an orange or lemon. You can change the items so that your toddler will always have something new to root around for in the treasure basket!

#### Learning to look

When babies are born, their vision is not yet fully developed. Children's sight continues to develop in the first years of life by being used. So, it's very important, if you think your child can see anything at all, or if you aren't sure, that you encourage them to look as well as listen. Children with visual impairments can be encouraged through play activities to make the most of their sight and they find special ways of viewing objects and handling materials, maybe holding things close to their eyes, or to one side.

It can be very hard to tell how much your baby can see. Watch closely and ask yourself:

- Do they tilt their head to look?
- Do they look at mirrors or brightly coloured objects?
- Do they stare at sunlight or artificial lights?
- Do they see better in dim light or bright light?
- Do they look at objects or faces?

If the answer to any of these questions is yes or if you have noticed them doing other things, it suggests your child may have some vision, so encourage them to use it. Here are some ideas to encourage looking. And don't worry – sitting close to the television or computer will not harm their eyes, and looking at things very closely will not strain their eyes.

- Position your baby so they feel secure. To put them in a good position for looking you may need to put them on their side or their front.
- Place your baby so they can see your face. If they can see, babies react best to faces first of all.

- Talk, coo, nod your head and make big smiles to attract their attention. Play 'Peekaboo!'.
- Place one brightly coloured toy against a plain contrasting background.
- Play naming games with toys and objects.
- Use shiny, silvery paper and mirrors to attract their attention. For example, inflate the inside of a wine box to make a reflective balloon. Unbreakable festive decorations also make good toys.
- Use toys with lights to attract your child's attention. Torches and coloured lights are fun and work well, too.
- Make a mobile with shiny foil or holographic card. A spotlight or angled lamp may make it easier to see, but be sure that the light doesn't shine directly into your child's eyes.
- Suspend objects on a baby gym or frame. Sometimes real objects are more exciting than toys. Try a CD, a reflector, a shatterproof mirror, something striped, high contrast simple black and white patterns or pictures.

You can help your child by ensuring that there is sufficient (but comfortable) light in the environment. Be alert for the smallest sign of interest. It may be just the tiniest movement of an arm or a tilt of the head or a wiggle of the toes. But if you notice it and can work out which object, which direction and at what distance they appeared to see something, you can build on that interest by repeating the experience.

Some children need extra help because they have physical and learning needs in addition to a visual impairment. They may need more time and help to learn to make sense of visual information and to look. Learning to look is sometimes called visual stimulation. Visual stimulation takes place naturally for most children but may need to be carefully structured and planned for children with complex needs. For children who have very little or no sight, alternative forms of stimulation have to be found to encourage them to explore the world around them.



An important point to consider is that many children with multiple disabilities and a visual impairment need more time to process information and respond to it. It's very easy to take something away from a child before they have had a chance to organise their response.

Visual understanding can be supported by having lots of very familiar things to look at. It helps if objects and toys can be held or positioned close to your child so they can look at each part and not be confused by a cluttered background. Objects and toys that are simple in design and with a clear contrast between colours or features are easier to understand visually. In the early stages of children's visual development, large objects with chunky features are more interesting to them than small things which are visually complex.

You may want to set up a small special area for visual stimulation, maybe in your child's bedroom, using objects that interest them.

## Learning day by day

Children like routine. A structured day enables a child to recognise, and then anticipate, familiar events and helps them to cope with the different things that happen. Events such as eating, bathing and bedtime provide a pattern for young children's lives.

#### Eating

Whether you are breastfeeding or bottle-feeding your baby, it's a special time for you and your baby to get to know each other. It's important to take time to enjoy the closeness of regular feeds in the first few months. It gives your child several opportunities every day to feel your warmth, the familiar way you hold them, to get to know your scent, the feel of your clothes, the sound of your voice and perhaps the look of your face. This is important, too, for children who may be fed by non-oral methods, such as tube feeding.

Your baby may be more reluctant to drop feeds than other infants, so they may be a little later being weaned.

If feed times are difficult or if you are concerned about your child's weight gain or growth there are professionals who can help. For example, speech and language therapists often help with sucking and swallowing difficulties, and health visitors can advise on early feeding patterns and weight gain, and can assess whether to refer your child to a paediatrician for extra help.

If you are returning to work, you may need to plan very carefully how and when you wean your baby. If you are breastfeeding you may have to introduce a bottle earlier, and then go on to solids. Most babies with a visual impairment enjoy sucking, and you may need to transfer from breast to bottle to cup very gradually.

When your baby is ready to start eating solids, take it slowly. Their main nutrition continues to come from milk and it takes time for babies to accept new flavours and learn to swallow lumpier food. If your child regularly chokes or gags on their food, you should express your concern to your health visitor or GP.

Introduce new flavours early on. Your aim is for your child to like a wide range of foods. Encourage them to taste something again if they don't like it the first time. Remember that new experiences are accepted best when a child is feeling well, so don't push them if they seem a bit under the weather.

There are clues that help your baby know that it's meal time:

- they have that 'hungry' feeling
- you put their bib on them
- you put them in their highchair
- they hear familiar sounds that indicate food is on the way
- you give them a spoon
- they smell delicious food.



Some children show they want to feed themselves by grabbing their spoon. Others may need you to encourage their independence. To be able to feed themselves, your baby needs to be able to hold a spoon, scoop with it, put it in their mouth, close their lips round it and then replace the spoon. Learning these skills takes time and you may have a long period where you both have a spoon.

At mealtimes, babies learn many skills:

- in crawling or walking to their highchair, they are learning to orient themselves
- when they show they want to get in the highchair or that they want the food they can smell or hear you preparing, they are communicating
- if they are offered a choice of two foods, they are learning about different flavours, smells and textures, and also learning about making decisions
- if they are helping with feeding, they are refining the use of their hands to pick up finger food or control a spoon.

#### Learning to drink from a cup

- Introduce a cup early so your baby gets used to handling it.
- Alternate between using a bottle and a cup, and gradually increase the amount of time they have the cup. Some parents find it helpful to give their child the cup at the beginning of a feed and give them the bottle as a reward, after they have taken a few sips.
- Start with a small amount of water or milk in the cup. This makes it easier to control the flow of liquid and reduces the risk of spills.
- Children with visual impairment need to be taught the sequence of picking up a cup, holding it, and putting it down again, rather than letting it drop or throwing it.
- When your child can drink from a cup with a spout, gradually introduce them to a cup with no lid.

#### Introducing solid food

- Fingers were invented before spoons and forks, so concentrate on them first.
- Let your child feel your own jaw when chewing and listen to you eating crunchy foods. They'll love it, and it helps them understand what actions are required for eating.
- When introducing your child to using a spoon, put your hand over theirs, holding the spoon. As they get the idea, you can gradually move your hand further up their arm so that they are controlling it more.
- Tell them what you are doing: 'I'll help you to scoop up the potato.' All children enjoy a commentary on what's happening and it helps children who can't see know what the food is.
- Your child may be able to get the spoon to their mouth once you have helped them to load it, but they may need help to put it back in the dish. It's worth putting a damp cloth or a dicem (non-slip) mat under the dish to prevent it from sliding around.
- Alternate between helping them do it and letting them do it by themselves. But don't let mealtimes go on too long or make your child feel frustrated by forcing the pace of independence. As meals take place at least three times a day, try to make them happy occasions for both of you.
- Always show you are pleased with your baby when they can do something new for themselves. You can show your pleasure by touching them and through your voice. This stage needs lots of patience with all children.
- All children make a mess and eat with their hands, throw their spoons and even put their bowls on their head. Your child will be no different. A long-sleeved bib, a big splash mat and a flannel or wipes make cleaning up easier. Clean up at the very end, rather than all the way through the meal. Some parents tie toys to the high chair for their child to play with while waiting for their dinner.



- Let your child put their fingers in the dish to explore their food. It may be the only way they can find out what they've been given.
- Some babies eat all the food they're given, while others are fussy eaters or simply not interested. Try to relax – all babies can pick up on the feeling that you're worried. If they don't eat much, or indeed nothing, they can always have a bit more next time.

#### **Bathtime**

- Bathtime provides a natural opportunity to talk about and learn the names of body parts. When getting your baby ready for a bath say, 'It's bathtime now. Let's get you undressed.' Remember to use a non-slip mat and watch and stay with your child at all times. Hot taps are dangerous and children slip very easily.
- Give your baby time to explore. Toys that stick to the side of the bath with suction cups and that they can feel are a good idea, as well as foam shapes.
- Some families put up textured tiles, or a soap dish in which they put a toy for their child to discover.
- Show them how to pat the water to make splashes.
- If you have a shower attachment, turn it on gently and listen to the different sounds of water spraying on a shower curtain, the side of the bath, into the bath or onto your child's body.
- Scented soap and bubble bath make bathtime more interesting.
- Practise pouring and squeezing and tasting bath water.
- Find toys that make interesting noises when they are filled with water or emptied.
- Use a piece of plastic tubing to blow bubbles in the water. Some children like the sensation of bubbles being blown against their body.
- Use towelling flannels or a mitten that feels velvety when dry. Sponges of different shapes are fun too.

- Take turns in games and talk about what your child is doing.
- If your baby is afraid of water you could use a small baby bath so they can feel the sides and don't feel lost in a big space, or use a baby bath seat or a sponge insert.

Once your baby enjoys the bath, you might like to take them swimming. Many pools have parent and baby sessions that are quieter, and sometimes warmer, than public sessions. It's good to take your child swimming at an early age so they become confident in water and learn about water safety.

### **Bedtime**

Many newborns fall asleep at the end of a feed in your arms or are easily rocked off to sleep and drop off in the buggy or car. As they get a older it's important that they learn to fall asleep by themselves and become less dependent on being rocked or patted. It helps if you begin to put them down just before they fall sound asleep, so they learn this important skill. It takes time for babies to learn this, sometimes many months, but it's worth persevering so that your child develops good sleep habits. Babies who can fall asleep by themselves can often get themselves back to sleep when they wake in the night. So you'll get more sleep too!

You can help your baby to recognise bedtime and to begin to tell the difference between night and day. Bedtime will be smoother and easier for both of you if you establish a clear routine. Activities near bedtime that are quiet and relaxing help your child to wind down, rather than wind up. For many children bedtime follows bathtime, a drink or a story. Your baby will gradually get to know it's time for bed when they puts on pyjamas or sleep suit or they hear you drawing the curtains. Children with a little vision may see that it's getting dark or that you have dimmed the lights. Some babies have a favourite object or blanket to take to bed. Quiet songs or lullabies, or a gentle wind-up musical toy, may help your baby go to sleep.



If your baby doesn't see, they won't know that darkness means time for sleep, but they will get used to night-time sounds. If you keep evening sounds gentle and soothing they will come to associate those noises with slowing down and going to sleep.

If your baby has trouble sleeping, ask yourself:

- Are they comfortable?
- Have they had enough to eat and drink during the day?
- Are they too warm or a bit cold?
- Are they in pain?
- Are they tired?
- Have they had too many naps during the day or close to bedtime?
- Have they been busy enough to make them tired?
- Are they wound-up or over-excited?
- Are they afraid of something?
- What happened last night at bedtime?

Many children find it difficult to settle into a regular sleeping pattern. Sleep deprivation can quickly exhaust your daytime energy and lower your spirits, so ask your health visitor or GP for help. Many health centres run sleep clinics, and there are organisations to support parents having problems getting their children to sleep, such as Serene. Call the CRY-SIS Helpline on 020 7404 5011 to get help from someone in your area. Contact details are at the back of the booklet.

Read more about this in **Useful organisations** 

### Dressing and undressing

Even when your baby is really tiny you can begin to help them learn about dressing and undressing.

- Dress and undress your child in the same order every time. Talk through the actions each time.
- Undressing is easier than dressing and is worth learning first using loose clothes. Many babies delight in pulling socks off!
- At first, choose clothes that are easy to get on and off. Pull-up trousers are easier than dungarees.
- Choose attractive, comfortable clothes with 'feely features' where possible.
- The backs of clothing can be marked with a small button, or piece of Velcro on the label at the neck. Use Velcro wherever you can – children with visual impairments love the sound of it. They love zips too!
- Coats with hoods can be placed on the back of the head for your child to start putting the coat on. Add extra length to the sliding bit of the zip with a short length of ribbon to make it easier for them to hold and pull up and down.
- If your child has a little sight, choose clothes in colours you think they might see.
- Later on, teach them that their clothes are always to be found in a certain place to encourage their independence.



### **Personal care**

How do you tell if your child is ready for toilet training?

- Are they happy and comfortable sitting on a potty? Let them play with one for a week or two before starting.
- Do they ever tell you there's a pooh in their nappy?
- Have they ever noticed themselves doing a wee without a nappy on?
- Are they happy to be in the bathroom?
- Do they know that you go to the toilet?
- Will they usually respond to your request to perform ('do things')?

If you're not sure whether your child is ready, or if you know your child has other special needs too, you might want to talk it through with a health professional first.

And finally - are you ready?!

- Are you sure you can be patient when accidents occur? They probably will.
- Has your child got enough clothes that are easy to pull on and off?
- Have you got time to sit and talk to them while they sit on the potty or toilet, so that they feel more secure? Small children need to try very frequently at first.
- Choose a potty with a solid base that is hard to tip over. Put it where
  they feel secure, such as within reach of a wall or something to steady
  themselves on. Alternatively, you could use a potty chair. When they are
  older they might want a toilet seat, but these feel less secure to a child
  with a visual impairment and so are best avoided when you first try.

Think about what you'll do when you go out together. Here are some toileting tips.

- Use the same routine every time on entering and leaving the toilet. Think about a simple route in and out and add tactile points to the room that your child may understand (bells on the door, an elastic band on the handle, etc).
- Be flexible about the use of a potty or toilet. A lot of children with visual impairment fear sitting on a toilet. Don't leave them on their own, and offer lots of talk and support such as holding hands. Singing aloud helps too.
- Some children need to explore what they have done and where it is, once they have done it. Don't be too squeamish about this, although this can be gradually discouraged as the child develops their skill.
- Praise each success. Most children love to hear the toilet flush and to do it for themselves. Or use taped songs or favourite toys or anything else that your child would recognise as a reward. It is also possible to buy musical potties.
- Accept accidents in a matter of fact way there will be many. It's important not to tell your child off, as this leads some children to deliberately wet or dirty their clothes as a way of getting attention. Try to have a 'Never mind, better luck next time' attitude. But do take your child to the bathroom to change wet clothes so that the act becomes associated with the appropriate place.
- Be sure your child always does the whole process, including washing their hands, every time.



### Learning on the move

Early movement helps your baby to learn about their position in space. Sighted babies see other people moving around and learn by trying to copy. You may need to teach your baby ways of moving. This section suggests ideas for helping your child to move independently and develop stronger muscle tone. Babies who do not move can develop repetitive actions, such as rocking backwards and forwards, to increase stimulation.

A baby sling or backpack carrier enables your child to experience your movement, while held close, warm and secure. They also provide an alternative view of the world for children with some vision.

If your baby has a condition that affects their movement, they may find moving tiring or frustrating. If your child appears to see better on one side or holds their head in a particular position to view an object it will have implications for how you introduce them to new experiences. If they also have difficulty controlling their muscles, supporting their body or moving, it's important to get professional advice from a physiotherapist on how to position, lift, and carry them and also how to encourage them to move.

Your child may need extra equipment to support their movement or position. Some children require specialist buggies, standing frames, body jackets, or bolster rolls to support them. As a child grows heavier you may need help with lifting or supporting them. There are many different supports, seats and standing frames, but it is essential to receive professional advice to ensure that specialist equipment suits a child's particular needs as they grow.

### Getting your baby moving

Your baby needs lots of opportunities for physical exercise. Take them walking, running, climbing and play plenty of physical games with them. In fact, the more active the play, the more confident they are likely to become. They will be a fitter and happier child and far more able to join in with their sighted friends. Help to guide them at first by holding their hand, but as they get older, encourage them to hold only your finger and when tall enough, your elbow. Babies and young children with visual impairment need people who are loving and confident when handling them. When playing physically, include some repetitive games that follow a pattern so your child can learn the pattern, anticipate what will happen next and enjoy it. Most children love rough and tumble play. It gives them experience of different positions – high up, low down – and of different movements such as swinging and bouncing. Talk about what you are doing while you play. If your child also has a physical disability, or problems controlling the movement of their body, talk to your child's physiotherapist about safe games to play. You may also want to ask their advice or the health visitor before using a baby walker.

Before a baby can learn to sit unsupported they have to be able to lift their head when they lie on their back and on their front. They need to move their head from side to side to strengthen their neck muscles. You can encourage them to lift and turn their head by attracting their attention with musical or squeaky toys, brightly coloured lights or toys that are interesting to feel.

Your child needs to experience lying on their back, tummy and sides, and to be propped up securely against a person, or with cushions against a piece of furniture.

- Put them on their back, and gently tilt their hips from side to side.
- Rolling games help them get the idea of moving from one position to another. Lie them on a large inflatable bolster or ball and roll it gently back and forth. Put them on your lap and gently roll from side to side.
- Use favourite toys which make sounds to motivate them to move towards you.
- Help them to rock in a baby rocking seat or bouncy chair.
- Give them a go in the baby swings at the park.
- For toddlers, push-along toys that make a noise motivate children to move at the same time as protecting them from bumps.



Finally, remember that if a child is engrossed in playing it can be frightening to be suddenly picked up with no warning. So as you approach your child to move them to a new position or take them to another room, tell them that you're there. Say their name and lightly touch them before you pick them up.

### Safety

Before your child starts to move around the house on their own, you need to make sure they can't do themselves any harm.

- Fit guards to fires and the cooker.
- Keep doors fully open or properly closed.
- Pad sharp edges of the furniture.
- Move breakable objects and houseplants well out of reach.
- Keep small objects that they might swallow or choke on out of reach.
- Fit plug guards to electrical sockets and pin back trailing wires.
- Lock bleach, cleaning fluids and medicines away.
- Fit cupboard locks.
- Fit safety gates to stairs.

### **Stairs**

Most children enjoy climbing stairs. Don't wait until your child can walk before introducing them to them, but supervise them closely at all times.

- Encourage them to climb. Let them climb on cushions or low items of furniture first.
- Take them to a soft playroom at a leisure centre, to climb on and off big foam shapes.
- When you introduce them to the stairs, stay right behind them and watch them climb safely. Teach them to come down backwards, feet first.
- Once they can climb by themselves they will love clambering up and down. But remember that even a confident young climber can be easily distracted and fall, so stay with them.

### Up and walking

Many children have dens and hideouts, which are in effect, small spaces over which they have complete control. This experience is even more essential for children with sight difficulties. They need to learn that a space has walls or sides, a bottom, a ceiling and a floor and an entrance or exit. Huge cardboard boxes are a good way to teach this and are fun, or you could corner off a bit of a room with armchairs. The aim is to create a space in which your child is confident and in which they can control their toys. Gradually the space can be made bigger, encouraging them to move and explore further.

Children with a visual impairment need lots of experience of exploring small, safe spaces. It builds their confidence and makes it more likely that they'll want to move round larger spaces, like a room or garden, independently.

Some parents set up a travel cot or very large play pen with lots of toys to encourage their child to explore in safety.

- Let your toddler play 'house' or 'boat' or 'car' inside a large cardboard box.
- If you have the space, keep an old mattress for jumping on.
- Let them climb on a small strong box, and help them learn how to jump off it.
- Sit and ride toys such as toy cars give your child some freedom of movement with some protection from bumps.

Learning to stand and learning to walk are real milestones in a child's development. Your baby may be a little later in learning to do these things than other children and you may find they prefer to shuffle on their bottom instead. Babies with poor sight are often reluctant to crawl as they are likely to bump their heads, so encourage them to get up on their feet as early as possible.

• To gain the confidence to start walking around, your baby will first need to to stand. You can encourage this by bouncing them on your lap to strengthen their legs and by standing them leaning against your chest when you are sitting down.



- Help them to stand on the floor holding on to a sofa, and encourage them to move along it. They may feel more secure with you standing or kneeling behind them.
- When they have gained confidence moving along furniture, try standing behind them, leaning forward, holding their hands so they're no higher than their shoulders.
- When they are comfortable in this position, gradually move their feet forward with your toes, so they get the idea of moving one foot and then the other.
- If they are still frightened of moving and are clutching on tight, practise around the furniture a bit more until they gain confidence.
- Give them a favourite toy to hold in one hand, while you hold the other.

### Developing your child's confidence

As children begin to move around the house on their own they still want to know where you are. You'll find they call out very often and need you to reply so they can be reassured by your voice that you are still around.

Try not to be frightened for them, as they will sense your worry. Remember, all toddlers fall over and bump themselves many times every day.

You can help your child by putting up sound, scent and tactile clues to help them know where they are in the house – for example, a wind chime in the hall, scented pot-pourri, wallpaper of different textures on the walls, and floor coverings that sound different, such as tiles, stripped wood or carpet.

If your child has some vision, try to find out if they can see better in bright or dim conditions and then consider the implications of this at home. For example, is the hallway a bit dark or do any of the rooms need blinds when the sun is strong? In general, it's easier for children with visual impairments to find toys against a plain background, so plain carpets and table tops are likely to be most helpful. Alternatively, you can spread out a plain cloth so that your child's toys are easier to see. If your child finds very bright light uncomfortable, look out for glare caused by light reflecting off shiny surfaces, like sinks, tables or worktops. Here are some things to try.

- Try to keep furniture in the same place, so they can find their way confidently around the room. If furniture has to be moved, tell them about it.
- When they are moving around the house, talk to them about where they are going, what they can hear, what they can see, what they can feel or smell. Teach them the language for describing positions such as on, under, next to, above, forwards, backwards, and eventually left and right. Count steps with them and make it fun. Gradually all this will help to give them a sense of distance and direction.
- Let them go round the room by themselves they will find their own way around.
- Encourage your child to work out what each door in the house is like. The front door may have a panel they can feel, or have a mat in front of it, or a letterbox that they can reach up and feel. A back door may have a cat flap or a different shaped handle. Internal doors can offer clues too. Some open easily while others drag a bit on carpet. You can point out different floor coverings too. If the door is by tiles or lino it might be the bathroom or kitchen. Encourage your child to use all these clues. And remember to leave doors fully open or completely closed to prevent your child from walking into the edge of one.



# Exploring the world outside

Each time you walk to the shops or to the park or to pick up brothers or sisters from school your child has an opportunity to learn about the outside world. A baby in a buggy will feel the difference between a warm sunny day, a crisp cold day or a wet day. Not only is the temperature different but the sounds are different too – on a wet or foggy day the sounds are more muffled, and it's possible to hear spray on the wheels and the raindrops hitting the buggy covers. Some children with visual impairment are reluctant to wear hats as it makes hearing and interpreting sounds more difficult. Likewise some toddlers dislike gloves if it stops them feeling walls, fences and things that they pick up. Try to make regular walks fun and use them as a chance to notice something new, or reinforce something from last time.

Look out for interesting things along the way which may be large enough or colourful enough for your child to see:

- bright red post boxes
- cracks in the pavement
- bubble paving stones at crossings
- bus shelters.

Listen for interesting sounds and explain:

- cars and lorries on the road
- children playing
- dogs barking
- wind in the trees
- squeaky gates.

Collect interesting things like:

- leaves, twigs and pine cones
- stones
- feathers.

Talk to your child as you turn corners, introducing the language of directions, for example left, right, straight on, let's turn round, stop and so on. See if they can begin to remember which way to go on walks that you do together often.

### **Gardens and parks**

Take your child to the park or let them go out in the garden in all sorts of weather and during all seasons of the year, so they know how different gardens and parks sound and smell when it is rainy or sunny. Introduce them to grass, gravel paths, tarmac, wood chips and springy safety surfaces. Let them feel and smell safe plants, and notice the difference between cold metal swings and a warmer wooden fence. When it's warm enough, let them experience grass barefoot too.

Give them a sturdy wheelbarrow to collect things in and play ball games with an audible ball.

Let them help you plant some herbs which have a definite smell – for example, rosemary or thyme release a strong smell when stroked and are not too prickly. You might put these in the garden or in pots. Some children will use different scents to remind them where they are and find their way around.

If you have a space big enough for a climbing frame, hang something noisy on it such as a wind chime so that they can find it by themselves. Sandpits and paddling pools have great play value as well if you have the room. Introduce these things slowly, and supervise closely.

Gardens and parks can be magical places, but they can also be dangerous:

- Make sure the fence is secure so they can't wander out, and that the fence itself is safe.
- Make sure the garden gate is securely fastened.
- If you have a pond in the garden, cover it over so they can't fall in.
- Watch out for wires, hose pipes, poisonous berries, cat mess, slug pellets, stinging nettles and thorns.
- If you use garden canes, cover the tops so your child can't hurt themselves if they fall.



### **Car rides**

Car rides are often helpful in soothing a fretful baby, but as they get older, your baby may become bored and frustrated at being strapped in a car seat. Keep them entertained by talking or singing to them. Explain the sounds they can hear, or put on a music or story tape, and give them some favourite toys to play with. For long journeys, it may be helpful to introduce a new toy or activity centre attached to the car seat to keep them happy and interested for some of the time.

### Handling comments from strangers

When you explore the world outside, you meet new people all the time. It can be difficult when a total stranger asks you questions about your child's eyes and what they can see in front of your child. Shopping with a young child can be stressful enough without unsolicited questions. However, it does happen and it's difficult to avoid other people's curiosity or well-meant interest. Eventually you become hardened to it. If you can prepare your own matter-of-fact answer it may help, and stop you getting upset. Your answer can reinforce the positive attitudes you want your child to have. Brothers and sisters often become very good at explaining what their sibling can or can't do. Eventually most children learn to answer for themselves. Encourage people to talk directly to your child and support your child so that they learn to answer politely and appropriately.

# **Encouraging social skills**

### Learning to communicate

Learning to communicate is vital for development and for forming relationships. Often children who have a visual impairment do not babble as much as a sighted child – possibly because they are listening more. In general, their language development moves forward more slowly than other children of the same age.

Some children have particular difficulty learning to communicate and may need speech and language therapy. This may be particularly relevant for children with other learning difficulties in addition to a visual impairment who may need to use an additional, alternative means of communication. If you feel you need specialist advice, from a speech and language therapist, the earlier you get this, the better.

It is important to establish some sort of basic communication with your child early on, using touch. You can play simple, repetitive games, such as 'Round and round the garden'. After a couple of goes, wait for your child to react, and then respond. This allows them to tell you that they want you to play the game again. You could imitate the movement they made in response, to show them you have understood. This will help them understand that they need to take the lead sometimes, for two way communication to take place.

One of the first breakthroughs in communication is when a child can make their parent or carer understand what they want. If you are spending a lot of time with a child who finds it difficult to communicate, you need to actively look for the signals children give before they can ask for what they want, using words. Many parents in this situation become expert at reading the body language, vocal sounds and gestures of their child.

Some children with complex or multiple needs, who may have a very individual way of communicating use communication passports. A communication passport is a small booklet made up of information about a child, presented from the child's point of view in a positive way. A communication passport might say something like this:



'My name is Anna. I can see you if you stand on my right. I need objects to be presented to me from the right. I often need help to hold things, and like to be introduced to new experiences very gradually. If I like something, I smile and rock backwards and forwards. To tell you I don't like something, I make a noise and push away with my arms.'

Communication passports can be very useful for people meeting a child or helping with their care or education for the first time.

### Playing with other children

All children play alone or alongside each other at first and it takes time for them to be ready to mix with others and interact when they play. While a fully sighted child can quickly scan a room and see all the possibilities for play available to them, a child who has a visual impairment may only be aware of what is immediately within reach. Being able to move gives a child more choices about what to do. It takes time and reassurance to encourage them to include others in their play. If they join in with a small number of other children early on, they will soon be less reluctant to mix.

In general, children with impaired vision need more help to understand social conventions and to learn to use appropriate body language. Being with other children helps this process, as it gives them lots of opportunities to experience how other children behave and to experience reactions to their own behaviour.

### **Encouraging positive behaviour**

Some children with visual impairment press and push their eyes. This can cause damage, so you should try and stop your toddler doing it before it becomes a fixed habit. Children tend to do this when they are tired or bored- probably because it causes a pleasing sensation like flashing lights. Your child does not see that other people around them don't do this. Say in a gentle way 'Hands down' to discourage them from doing it and distract them with a toy. Consistent distraction is the best way of discouraging this particular behaviour. Learning to share, searching for independence and dealing with change are important parts of every toddler's development and it's important to expect the same things from them in terms of behaviour that you would of other children of the same age. However, when a child has other learning difficulties in addition to a visual impairment, be aware that unacceptable behaviour may be a signal that they do not feel well or because they are frustrated that they can't communicate something. Trust your judgement.

### **Setting boundaries**

Building up a child's self esteem and making them more secure involves establishing some ground rules to let them know what you expect of them and what responses they can expect from you.

- Be consistent about their behaviour. If you let them get away with something one day and not the next, they won't know whether it's right or wrong.
- If you say no all the time, your child will switch off and not take any notice of you. Say no to the things that really matter. And if you say 'no' mean it and carry it through – otherwise they learn that if they make a fuss you will change your mind.
- Take every opportunity to tell them they have done something well and that you are pleased. Praise and positive reinforcement are the best ways to let a child know that you value what they've done.
- Encourage other adults to behave towards your child in the same way as they would to any other. Your child is a child who happens to be blind, not a blind child or a child who happens to have partial sight, not a partially sighted child. Positive attitudes and high expectations make a significant difference to your child's view of their own abilities and to their self-confidence.



Children develop gradually, and in the beginning nobody can know where the strengths of a child with a visual impairment lie or what aspects of life they will find particularly challenging. For children with complex needs, it can be doubly hard to know what they might achieve, particularly if they find it hard to communicate and show you when they have understood. Children with multiple disabilities often stay at an early stage of development for a long time before first words and controlled body movement develop. The following may help:

- Assume your child can understand talk to them, not about or over them, and encourage others to do the same thing.
- Let them hear you talking about what they can do not about what they can't do.
- Assume that in time they will learn to do some things for themselves. For each new skill try to show them how to do one part of the process that you feel they could achieve on their own.
- Set them up for success and build on it.
- Discover their likes and dislikes and try to respect them.
- Use the things they like as rewards to encourage the repetition of positive behaviour.
- Find ways of showing them your interest in their smallest achievement.

### **Establishing routines**

It's important to establish clear routines so that children know what to expect. Routine helps young children feel secure, and it's very important for children who can't see, because they may have particular difficulty anticipating what's going to happen next. Routines can be built around taking children to nursery, meal times, or personal care. Doing things in the same order, day after day, helps children predict what will happen next and begin to understand more about the world. There will be occasions when normal routine is disrupted. Explain this to your child to help them understand and deal with change.

# Time for play

When children are playing, they are doing much more than simply enjoying themselves – they are learning to make sense of the world using all their senses: taste, smell, touch, hearing and sight.

It may be difficult for young children with a visual impairment to explore toys and materials and to play with other children, unless sensitive adults actively encourage, support and extend their play. You can help by:

- observing your child's behaviour closely to find out what interests them
- giving enriched descriptions of what they are doing and what you are doing
- providing a commentary so that children learn about the things they cannot see
- providing rich experiences which build on your child's interests
- giving them choice and control when they are playing
- making sure your child is able to engage with activity on their own terms.

### Choosing toys and activities

All babies need opportunities to make things happen. At the simplest level, a baby gradually works out that if they cry, someone comes. Toys are an important way for a child to learn they can make things happen. They help babies learn to do things for themselves. Toys that respond to action in a way that makes sense to a child who does not see well are the most powerful – for example:

- rattles which make a noise when they are shaken
- activity centres or toys with buttons to push which make different sounds
- balls that play a tune when shaken or rolled.

Your baby's position is important when they are playing. Make sure they feel secure and that they have both hands free to move and explore their toys.



Some toddlers are reluctant to use their hands to explore, and are not keen to let an adult guide them. Sometimes it's because they have had unpleasant experiences with their hands touching things that were sharp or hot, or just disagreeable.

Don't worry if your baby puts toys in their mouth for longer than their sighted friends, or if they smell them or run their tongue over them. As their touch becomes more finely developed they will use their hands to explore more and their mouth less.

All the usual safety considerations apply but there are a few special considerations when choosing a toy for a child who has a visual impairment:

- Is the toy easy to manipulate?
- Is it brightly coloured with good contrast?
- Does it do something, like make a noise or have parts that move?
- If you close your eyes, is it interesting to touch?
- What could a baby do with it?

The real thing is sometimes better than a toy version. A plastic animal or a furry teddy might not mean much to them, but meeting a warm, smelly, friendly, hairy, noisy dog will!

It isn't necessary to buy expensive toys. There are lots of other things that make good playthings. For example:

- Different kinds of paper, cardboard and corrugated card
- Fur, cellophane, bubble wrap, raffia and so on- a whole range of things that feel different and can be explored.
- Small containers filled with rice or dried pulses which make good rattles.
- Mini-beanbags made out of different fabrics and filled with dried beans.
- Cloth books made from different fabrics with shells, feathers, buttons, short strings and ribbons sewn to the pages.

- Feely boards or mats with different textured materials not just smooth fabric but leather, plastic, corduroy and so on.
- A tray of buttons, marbles, stones, milk bottle tops and cotton reels best for older children who have stopped putting everything in their mouth.
- Velcro and zips, which satisfy the 'fiddle factor' as do bicycle bells, bicycle pumps and clip purses, which snap open and closed.
- An old wind-up alarm clock and cardboard tubes from kitchen foil.
- A range of different brushes and spoons.

There are a few additional points to consider when creating a play environment for children with other needs in addition to a visual impairment:

- Choose toys and play materials that can offer a variety of sensory experiences.
- Children need to be alert to play, so choose other activities when they are unwell or tired.
- Children learn from opportunities to experience challenge, risk and excitement but these have to be provided in a way that is appropriate for children with complex needs.
- Define and limit the play space around your child to create a den a secure, familiar base.
- It's especially important to find out what motivates children who have limited communication skills by observing their responses. Watching and listening to a child is the best way to find out what kind of play is likely to stimulate and interest them.
- Children with additional needs depend more on a sensitive play partner to encourage, support and extend their play with objects-someone who also knows when to withdraw.
- Make sure your child is in the most suitable position to use hands and eyes to best advantage, whether seated, standing or lying down.



- Keep toys within reach so that any of your child's movements can create an effect. Suspend toys for children who are lying down or use a container to keep objects together on a table top.
- Allow your child to explore objects with their mouth or feet as well as encouraging them to use their hands.
- Try to use your child's repeated behaviours, developing them into an activity that is more creative.
- Use language that is simple, descriptive and to the point to support activities.

Toy libraries are a good and inexpensive way of introducing your child to lots of new toys. Toy libraries are community resources which:

- offer play facilities
- provide a place to meet other parents
- allow you to borrow toys in the same way as you borrow books from a library.

Some are run by volunteers (often parents of young children) or by paid staff. Many are located in community centres, church or village halls, and schools, while others are housed in a bus, a van or caravan to enable them to cover a wide area. Regular borrowing of appropriate toys encourages all children to explore and develop new skills. Brothers and sisters are welcome too. For details of your nearest toy library, contact the National Association of Toy and Leisure Libraries. Contact details are at the end of this booklet.

Read more about this in **Useful organisations** 

### Playing in the kitchen

Parents spend a lot of time in the kitchen and your child will want to join you there. Encouraging your child to 'help' you in the kitchen can lead to useful play. It could include:

- banging saucepans with a range of spoons
- playing with plastic boxes and lids
- playing with cake tins of different sizes
- unpacking shopping bags
- unloading the washing machine into a basket
- putting plastic bowls and plates away
- sweeping with a dustpan and brush very hit and miss but often enjoyed!
- fetching vegetables from a rack
- washing fruit
- spreading butter on bread to make sandwiches
- mashing and mixing sandwich fillings
- licking the bowl
- stirring jelly or cake mixture
- washing up cups and plates
- cutting out biscuits or making their own with playdough.

Older children often play happily with a selection of screw top jars. Let them unscrew them and try to find a reward inside.



Keep a collection of empty egg boxes, clean yoghurt pots and margarine tubs in a cardboard box. Children need to learn about containers and their uses by taking things out and putting things in, and working out relative sizes. You may like to put some of these safe items in a low cupboard so your child can get things out for themselves. It's best to fit cupboard locks on cupboards where you store plates or glasses, or bleach, detergents and cleaning fluids.

Making food with your child helps them develop better control of their hands, and it's always more fun if you can eat the food you have made together afterwards.

The kitchen is often also a good place to introduce messy play, as it usually has the floor that is easiest to clean! All children need to experience a range of materials and have opportunities to express themselves through painting, drawing and making things. Some children will be able to see certain colours, fluorescent and metallic paints. Take care to choose nontoxic paints. Whatever their level of vision, children will hear colour talked about and will want to know about it. Give your child the opportunity to learn to use glue and modelling clay. Encourage them to make collages and models using boxes, different types of paper, card and fabric. Some children will enjoy making tactile pictures, and sand and other grains of various grades can be added to paint to achieve different textures.

### Special times of the year

On special occasions like birthdays and festivals there will be celebrations, when a lot is happening and there will be things to get ready at home. Children enjoy being involved. Cooking, making decorations, dressing up, wrapping gifts or sending cards all provide lots of opportunities for exploring by touch, taste and smell.

Children need to learn about the objects and events associated with special times of the year such as special customs, clothes or food, fairy lights, candles, incense, crackers, fireworks – and how to be safe near any of these things. Help them to find out so they can be included.

# Learning to read

It's never too early to introduce your baby to books. Babies enjoy the closeness of being read to, well before they understand the words that are being said. Babies with visual impairment are attracted to clear, simple images such as faces and bold black and white patterns like stripes and chequered squares. They are also likely to be attracted by movement. Some board and cloth books open out into a frieze of high contrast pictures which you can prop up for your baby to look at.

When your baby has developed some control over their hands, let them turn the pages as you share a book together. Babies will want to feel the pages, so books with textured pictures, crinkly pages or flaps to lift up are fun. Young children enjoy noisy and squeaky books too. Soft plastic books are fun to splash about with in the bath. You can adapt books and make your own with objects that have particular meaning for your child.

Let your child discover the things that you read and explain what they are – newspapers, recipes, catalogues, takeaway menus and junk mail as well as books.

Booktouch is an extension of the Bookstart scheme, which aims to encourage families to share books and enjoy reading together by giving out a free bag of books, advice for parents and an invitation to babies at their eight-month health check to join a local library. Some Booktouch packs contain specially designed materials for blind and partially sighted children up to the age of four.

If Booktouch is available in your area you can apply for a pack, either through your LEA qualified teacher of visually impaired children or directly from Booktrust by phoning 020 8516 2995, or by filling out and returning the Booktouch flyer on the website www.bookstart.co.uk

Read more about this in **Useful organisations** 



### Learning to read in print

If your child has some vision, try to choose books with bright, clear pictures with bold outlines to read with them. Babies are attracted to big, clear illustrations of familiar objects.

It's best if the words are in bold print on a plain background, as words are harder to see if they are printed on top of a picture.

Many children with a visual impairment are able to use print, although most will need to use a larger or clearer print than is normally found in books. Partially sighted children learn to read in the same way as sighted children, using suitably adapted large-print books or magnifiers, or other low-vision aids prescribed by a low-vision clinic to help them see the words more easily. It's important to remember that not all children will need spectacles, but you should find out all the options available to make it easier for your child to read print. You can find out about getting hold of books in large or clear print by ringing the Royal National Institute of the Blind Helpline. Contact details are at the end of this booklet.

# Read more about this in **Useful organisations**

#### Learning to read in Braille

Some children may learn to read and write in Braille or Moon as an alternative to print. Even though it may be far too soon to think about whether your child will learn Braille later on, you can borrow books with both print and Braille on them that you can share together. In the same way as we read print to children who are far too young to understand letters and words for themselves, you can let your child feel some Braille dots and introduce the idea that words and Braille dots tell you what to say.

Braille is a tactile form of reading made up of raised dots. Reading Braille requires the ability to discriminate by touch the patterns that are made by the sets of raised dots which represent letters or words. Grade 1 has 26 different patterns which represent the letters of the alphabet. Grade 2 is the complete Braille code, which contains the alphabet as well as 189 contractions and short form words that are used so that Braille takes up less space. Children learn to write Braille using a Perkins Brailler, a Braille writing machine with six keys, which make raised dots on special paper. Moon is another form of reading by touch, which looks more like print letters, using curves and straight lines. It is easier for some children to read, as it can be enlarged, but there are not as many books available.

The RNIB Braille Service has information about Braille reading schemes and the Certificate in Standard English Braille, which is a distance learning course designed for parents and support workers wanting to learn Braille to support their children. Contact information for the Royal National Institute of the Blind is given at the end of this booklet.

The ClearVision lending library has an extensive collection of mainstream picture books with added text in Braille or Moon. These include a number of two-way books that combine print and pictures with Braille, which blind and sighted children or adults can read together. The National Library for the Blind also has a number of Braille children's books for older readers.

The Living Paintings Trust offers a free library of children's picture books called Feel Happy.

Bag Books have a selection of multi sensory story packs.

### Stories on tape

Many children's stories, poems, songs and rhymes are available on standard cassettes through toyshops and bookshops. Charity shops are a good source of used children's tapes and many local libraries have titles suitable for children. Calibre is a lending library of books recorded on standard cassettes and has a collection of story tapes for children. The RNIB Cassette Library also offers a range of children's books on tape. Read more about this in **Useful organisations** 



## Going to school

Starting at nursery, school or playgroup is a big step, so contact your LEA qualified teacher of visually impaired children to discuss the choices and help available, if you are not already in regular contact with them. If these teachers have already been involved in supporting home-based learning for your child, they usually continue to support them as they make the transition into early years settings. They can help you make choices and help staff at the nursery or playgroup to understand your child's needs. They also directly support some children at playgroup or nursery.

Children with visual impairment may benefit from starting play group or nursery on a part-time basis when they are two or three years old – a bit earlier than other children. Most go to local mainstream nurseries or playgroups, but some special schools have nursery classes.

Early years settings offer young children with a visual impairment the opportunity to:

- broaden their experience
- learn to play with other children
- get used to moving about confidently in different and larger environments
- play with more and bigger toys than can be provided at home
- increase in confidence both indoors and out-of-doors.

All these skills are valuable and can help them make a better start at school later on.

It's never too early to begin finding out what educational opportunities are available in your area.

# Charter for families of young children with vision impairments

This Charter has been developed on the basis of a study of over 100 families with a child with a vision impairment.

### **Underlying principles**

Every child is an individual and every family is unique; this should be recognised at all times.

Services should attempt to minimise the disabling effect of any vision impairment, and society as a whole should also attempt to minimise the disabling effect of social and environmental barriers.

Children with a vision impairment should be valued for the contribution they make to their family, community and society as a whole.

Families and parents should be respected as active, knowledgeable participants in the care, support and education of their vision impaired children; as children get older, their views should also be sought.

Families, parents and children should be treated equally regardless of their personal backgrounds or current circumstances.

The enduring needs of children with vision impairments, their parents and families should be considered from a life long perspective.



### The rights of parents and families

As a parent or member of a family of a young child with vision impairment, you have a right to expect:

- that your expertise in your own child will be recognised from the start and that you will be involved as active partners in all decisions that affect you
- that you will have timely access to diagnostic and assessment processes so that any vision or other impairments present can be identified at an early stage
- that you will be referred swiftly to the health, education and social services appropriate for your child's vision impairment
- that your child's condition, vision impairment, visual needs and progress will be explained clearly, with empathy and in ways which will promote your understanding
- that information on all aspects of available care, support and services for vision impairment, including what they do and how to access them, will be provided as soon as possible and updated regularly
- that your child will receive the care, support and services that he or she needs as a child and as a child with a vision impairment
- that the related needs of parents, other members of the family and the family as a whole will also be recognised and addressed in the care, support and services provided
- that care, support and services for your child's vision impairment will be provided within a framework which promotes communication and co-operation between professionals and continuity over time
- that you will be directed to a range of sources of information and support for vision impairment, including specialist voluntary organisations, parent support groups and other families
- that you and your child will have access to the same range of opportunities and life experiences as other children and families.

# Glossary

### Some common eye conditions

Albinism – associated with a lack of pigment (colour) in skin, hair and eyes. Lack of pigment may mean that tinted spectacles are needed to maintain best comfortable vision. Albinism is commonly associated with nystagmus and problems with binocular vision.

Amblyopia – sometimes called a 'lazy' eye, refers to an eye (or eyes) that has a decrease in vision which cannot be corrected with spectacles. Amblyopia is usually caused as a result of lack of stimulation of eyesight due to an eye turn (strabismus/squint), unequal focus or cloudiness in the eye, so it is most likely that only one eye will be affected.

Anophthalmia - when a baby is born without eyes.

Astigmatism – an irregular shaped cornea. Vision is distorted because light rays do not meet at a single focal point. Very few eyes are perfect spheres so astigmatism is quite common.

Cataract – a clouding of the lens resulting in images becoming unclear. Most cataracts require regular monitoring for surgical correction; commonly age related, but can be present at birth or develop after birth.

Cerebral visual impairment or cognitive visual disorders – usually result from damage to parts of the visual cortex in the brain and may involve specific problems.

Colour confusion – not being able to distinguish certain colours from each other, sometimes called 'colour blindness'.

Conjunctivitis - inflammation of the conjunctiva.

Glaucoma – damage to the optic nerve generally associated with a build-up of pressure inside the eye.

Hypermetropia (long-sightedness) – things seen more clearly in the distance than close up.



Keratitis – an infection or inflammation of the cornea.

Keratoconus – a thinning of the cornea causing it to become cone-shaped and resulting in distorted vision. Keratoconus is more common in older children and young adults and can be managed with contact lenses or surgery.

Myopia (short-sightedness) – things seen more clearly close up than in the distance; the opposite of hypermetropia.

Microphthalmia - being born with unusually small eyes.

Nystagmus – an involuntary 'wobble' movement of the eyes from side to side or round and round.

Optic atrophy – the degeneration of the optic nerve.

Retinopathy of prematurity – damage to the retina in the premature baby's eye.

Retinoblastoma – a malignant tumour of the retina, treatable at a specialist centre.

Retinitis pigmentosa – a group of hereditary diseases of the retina.

Strabismus (squint) – sometimes called an eye 'turn', where both eyes point in different directions due to muscle imbalance.

### Specialist language

Accommodation – the ability of the lens to change shape to focus on objects at different distances.

Binocular vision – when both eyes work together at the same time; it enables depth perception.

Braille – a tactile form of reading made up of raised dots on a page.

Congenital - a word describing any condition present at birth.

Contrast sensitivity – the ability to distinguish different shades of grey from each other.

Field of vision – the total area that can be seen around you without shifting your gaze; detailed central vision as well as peripheral vision.

Focal point – the point of the retina where light rays meet and gives our most detailed vision; an object is in focus when it is being seen most clearly.

Functional vision - the ability to use eyesight in everyday conditions.

Light adaptation – the ability of the eye to allow in more or less light and process changes of light and dark.

Low vision aids (LVAs) – aids that improve a person's functional vision such as magnifiers; often training is needed for such aids to be used efficiently.

Mobility – training to develop orientation skills and independent movement, including use of a cane.

Monocular vision - sight through one eye only.

Moon – a form of reading by touch, which looks more like print letters than Braille. It uses curves and straight lines.

Occlusion (patching) – covering one eye to develop the sight in the other (lazy) eye.



Peripheral vision – everything that we see around us at the edge of our vision, outside our detailed central vision.

Pigmentation - colouring, usually associated with skin or hair.

Refraction – the process by which the eyes are measured for long or short sight or astigmatism.

Refractive error – a defect of the eye that prevents light rays being brought to focus exactly on the retina (such as long or short sight); correctable in most cases with lenses.

Visual acuity – a measure of the ability to see fine detail; often called central vision.

Visual perception – the ability to give meaning and understanding to what has been seen (not just to see it).

# **Useful organisations**

**Bag Books** (multi-sensory story packs) 60 Walham Grove London SW6 1QR

Tel: 020 7385 4021

Web: www.bagbooks.org

**Booktrust** (materials for children with visual impairment, through its Booktouch scheme)

Tel: 020 8516 2995

Web: www.bookstart.co.uk.

**Calibre** (free lending library of story tapes for children) Aylesbury Bucks HP22 5XQ

Tel: 01296 432 339

ClearVision (lending library of tactile books for children) Linden Lodge School 61 Princes Way London SW19 6JB

Tel: 020 8789 9575

Contact a Family 209–211 City Road London EC1V 1JN

Freephone Helpline: 0808 808 3555 Textphone Helpline: 0808 808 3556 Tel: 020 7608 8700

Web: www.cafamily.org.uk



### **Henshaws Society for Blind People**

88–92 Talbot Road Old Trafford Manchester M16 0GS

Tel: 0161 872 1234

Web: www.hsbp.co.uk

### Living Paintings Trust (free library of Feel Happy picture books for

children) Queen Isabelle House Unit 8 Kingsclere Park Kingsclere Berks RG20 4SW

Tel: 01635 299 771

Web: www.livingpaintings.org

LOOK (National Federation of Families with Visually Impaired Children) Queen Alexandra College 49 Court Oak Road Harborne Birmingham B17 9TG

Tel: 0121 428 5038

Web: www.look-uk.org

### National Association of Toy and Leisure Libraries

68 Churchway London NW1 1LT

Tel: 020 7255 4600

Web: www.natll.org.uk

### National Blind Children's Society (NBCS)

Bradbury House Market Street Highbridge Somerset TA9 3BW

Tel: 01278 764 764

Web: www.nbcs.org.uk

### National Library for the Blind

Far Cromwell Road Bredbury Stockport SK6 2SG

Tel: 0161 355 2000

Web: www.nlb-online.org

### Royal National Institute of the Blind (RNIB)

105 Judd Street London WC1H 9NE

Tel: 020 7388 1266 Helpline: 0845 766 9999

Web: www.rnib.org.uk Parents' Place: www.rnib.org.uk/parents

Sense (for people with deafblindness and associated disabilities) 11–13 Clifton Terrace Finsbury Park London N4 3SR

Tel: 020 7272 7774

Web: www.sense.org.uk

**Serene** (support for parents whose children have sleeping problems) CRY-SIS Helpline: 020 7404 5011 (to find someone in your area)



# **Useful websites**

SPECS (directory of eye conditions, details of support groups for specific eye conditions)

Web: www.eyeconditions.org.uk

### Visual Impairment Scotland

www.viscotland.org.uk (medical information about visual impairments written specifically for parents)

# Local groups

There are many local societies for people who have a visual impairment. It's worth getting in touch with them to find out if they have any activities for children and families. Contact the National Association of Local Societies for Visually Impaired People (NALSVI) on 01904 671921 or www.nalsvi.org. Or ask the RNIB Helpline.

# **Further reading**

This booklet has drawn on materials from the following RNIB publications:

### Your first steps

A guide for parents of children with visual impairment on medical terms, eye conditions, key professionals and services available. £4.95. Revised edition. ED289 (Print) ED293 (Disk)

### Setting out

Practical ideas for parents of children with visual impairment which will encourage your child to safely explore, communicate and learn during day-to-day routines and play activities. £5.95. Revised edition. ED294 (Print) ED295 (Disk).

### Which way?

For parents of children with visual impairments and additional complex communication, learning or physical disabilities. This publication supplements the information provided in *Your first steps.* £3.50. Revised edition. ED296 (Print) ED297 (Disk).

For further information on publications on early years, toys, games and play activities as well as videos and magazines, contact:

### **RNIB Customer Services Centre**

PO Box 173 Peterborough PE2 6WS

Tel: 0845 702 3153

Email: cservices@rnib.org.uk



The Early Support Pilot Programme (ESPP) is a Government programme involving the Department for Education and Skills, Sure Start and the Department of Health. The purpose of the programme is to improve the delivery of services to disabled children under three and their families. ESPP promotes service development in partnership with health, education and social services, service users and organisations in the voluntary sector. For more information, visit www.espp.org.uk

ESPP is putting into practice the principles outlined in the Government guidance document *Together from the Start* which was published in May 2003. The guidance recognises that where children have special needs and disabilities, it is important that these are identified at an early stage and that identification leads directly to effective early intervention and support for families and children.

This booklet is one in a series produced by ESPP in response to requests from parents and voluntary organisations for better information for parents. ESPP has produced booklets about a number of disabilities or known conditions and expects to develop more as the programme progresses. The following titles are currently available:

Autistic spectrum disorders (12) Learning disabilities (15) If your child has a rare condition (18) Speech and language difficulties (14) When your child has no diagnosis (16) Cerebral palsy (10) Down's syndrome (13) Multi-sensory impairment (9) Visual impairment (8) Deafness (11)

Copies of these booklets can be obtained from:

DfES Publications PO Box 5050, Sherwood Park, Annesley, Nottingham NG15 0DJ Tel: 0845 602 2260 Fax: 0845 603 3360 Textphone: 0845 605 5560 Email: dfes@prolog.uk.com

Please quote the appropriate reference number.

ESPP has also produced a Family Pack, which supports families through the first years of their children's lives. The Pack contains background information about the services you may need, the help you are entitled to and a Family File designed to help co-ordinate any support being provided for your family. They are resources that other families have said would make a difference. If you and your child are receiving regular support from a professional or range of professionals, please feel free to ask them about the Early Support Family Pack, which may help and which is available free of charge.

ESPP would like to thank all the parents and families involved in the production of these resources.

ESPP would also like to thank the Royal National Institute of the Blind for their help in writing, consulting upon and producing this resource.

There are around two million people in the UK with sight problems. RNIB's pioneering work helps anyone with a sight problem – not just with braille, talking books and computer training, but with imaginative and practical solutions to everyday challenges. We fight for equal rights for people with sight problems and fund pioneering research into preventing and treating eye disease.

RNIB provides a wide range of services for children who are visually impaired including those who have additional special needs. These services include specialist assessment services, family weekends and holidays, curriculum guidance, websites and a wealth of published information about the education and development of blind and partially sighted children. Our Education and Employment Centres are located throughout the UK. For more information on what RNIB can offer please contact the RNIB Helpline on 0845 766 9999 and ask for details of your nearest centre or visit Parents' Place at www.rnib.org.uk/parents to find out more about:

- Family matters
- Education
- Health and well being
- Leisure and play



**R**NIB Helping you live with sight loss





Copies of this publication can be obtained from: DfES Publications PO Box 5050 Sherwood Park Annesley Nottingham NG15 0DJ Tel: 0845 602 2260 Fax: 0845 603 3360 Textphone: 0845 605 5560 Email: dfes@prolog.uk.com We acknowledge with thanks the contribution of the following organisation in the production of this resource.



**RNIB** Helping you live with sight loss

Please quote ref: ESPP8

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