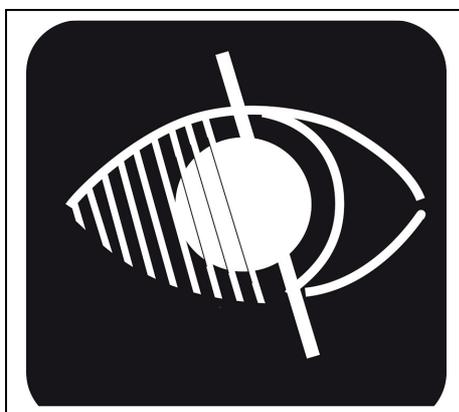


# Supporting People with a Learning Disability & Sight Loss

## Information for Carers



January 2014

## Contents

<u>Title</u>	<u>Page</u>
Introduction	3
Capacity, Consent & Acting in Best Interests	4
Sight Loss & Learning Disabilities	5
Identifying Sight Problems	5
Seeing an Optometrist	6
Local Optometrists	8
What if the Optometrist has concerns?	9
Eye Hospital Services	9
Eye Conditions	11
Social Services – Brighton & Hove	17
Registration (inc. concessions)	18
Voluntary Organisations	21
Benefits /Housing /Education /Employment	22
Talking Books / Large Print	23
Transport	23
Younger People & Parents	24
General	26
Appendix	
Tips& Hints – supporting people with sight loss	27

This is an updated version of the December 2012 edition of the information pack

Please note that every effort has been made to ensure the accuracy, reliability and completeness of the information provided in this pack at the time of publication.

Readers should be aware that changes in circumstances after the time of publication may affect the accuracy of the information, and the authors can take no responsibility for this.

In addition, the information contained in the pack does not constitute a recommendation or endorsement by the authors of any service or organisation listed in the pack.

## Introduction

This is an information pack for carers of people with a learning disability ('PWLD') and a visual impairment.

A learning disability is a lifelong disability and includes the presence of:

- A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence)
- A reduced ability to cope independently (impaired social functioning)
- Which started before adulthood, with a lasting effect on development

(Valuing People, 2001, Dept of Health)

People with a learning disability find it harder to learn and understand - most have difficulty learning new things and understanding how information fits into a bigger picture. They may have difficulties with everyday practical skills like cooking or using public transport, and social skills like holding a conversation. A learning disability does not mean that someone is unable to learn - people with a learning disability can achieve a lot if they get the right support.

Learning disabilities are one of the most common types of disability experienced by people within the UK but it is also the least understood. The way learning disability affects people's lives varies greatly. Some people need support with daily activities like getting dressed and washing. Those who have severe learning disabilities may need 24-hour support and care throughout their life, but those with milder forms can often live fairly independent lives. Some people may have physical disabilities as well.

A learning disability should not be confused with a learning *difficulty* - which can be behavioural or environmental, does not necessarily impair social functioning and usually involves specific problems with reading, writing, or arithmetic such as dyslexia, dyspraxia etc. It should also not be confused with acquired brain injury in adults, where development prior to the injury has been normal. Autistic spectrum disorders are also different to a learning disability, as these will usually only present as difficulties with social functioning. It is however fairly common for people with autism to also have a learning disability.

## **Capacity, Consent & Acting in Best Interests**

We wish to treat our patients with learning disabilities with respect and will do our best to help them understand their eye problem and explain what treatment is needed and why.

### Mental Capacity Act (2005) – Key Principles

- Every adult has the right to make their own decisions & must be assumed capable of doing so until proved otherwise
- Everyone should be given all the support they need to make their own decisions before conclusions are made that they cannot
- An individual may choose to make what seems to be an unwise decision
- Any act done or decision made under the act for or on behalf of a person who lacks capacity must be done in their best interests
- Anything done for or on behalf of a person who lacks capacity must be that which is the least restrictive of their rights and freedoms

For medical treatment and examination it will be the responsibility of the clinician proposing and carrying out the treatment to ascertain capacity to make a decision regarding that specific procedure. All findings must be recorded in the medical notes.

For more information about the Mental Capacity Act please look at the [www.justice.gov.uk](http://www.justice.gov.uk) web site and follow the link from the bottom of the home page to 'protecting the vulnerable'. For easy read information about the Mental Capacity Act please look at the healthy lives page of the learning disability partnership board web site [www.brightpart.org](http://www.brightpart.org)

## **Sight Loss and Learning Disabilities**

6 in 10 adults with learning disabilities need glasses to correct their vision. 1 in 10 Adults with learning disabilities are blind or partially sighted - ten times more likely than the general population. Sight loss in this group often isn't recognized, possibly because they struggle to express the difficulties they are having with their vision, so the problem goes undiagnosed and untreated. Some people may not want their eyes examined, or find it difficult to understand and tolerate eye health checks. They might forget or refuse to wear glasses.

Specialist workers called 'Rehabilitation Officers for Visually Impaired' people ('ROVI's) can advise people with significant sight loss, as well as their family, partners and carers, how to manage day to day sight related difficulties (see p.17).

Much of the following information is available in more detail from the SeeAbility website which contains a wide range of information and resources specifically for people with a sight problem and a learning disability.

Web link - [www.seeability.org](http://www.seeability.org)

E-mail - [enquiries@seeability.org](mailto:enquiries@seeability.org)

Telephone - 01372 755 066

## **Identifying Sight Problems**

Sometimes you can tell by the appearance of the eye that it has some sort of condition, such as a sticky discharge, excessive watering, drooping lid, bloodshot appearance, unusual eye movement or colouring. Often, however, you can't see from looking at an eye that there is a problem which is actually impairing someone's vision. However, behavioural signs such as having poor balance, bumping into things or knocking things over, may be a result of someone experiencing poor vision. Such functional problems may have previously been attributed to a persons other disabilities or just seen as 'clumsy'.

Less obvious symptoms could include a loss of appetite, poor self care, excessive eye rubbing, eye poking, challenging behaviour, depression /anxiety and a loss of interest in activities and socialising, Impaired vision can affect a persons' social interaction – the majority of our communication is non-verbal, but people with reduced vision

can struggle to make eye contact and read body language. Other signs of poor sight could be if a person is confused and disorientated, reacts strongly either way to light, has 'unusual' head positions or movements, or is startled easily by people approaching or unexpected noises.

Some people with advanced sight loss experience visual hallucinations ('Charles Bonnet Syndrome') and 'see things' such as patterns, bunches of flowers, children etc. This is a common feature of some eye conditions and cannot be treated but these symptoms are usually temporary and reduce over time. It is still important to tell a professional eye specialist about this so they can try and reassure the person.

SeeAbility is an organisation specifically for people with sight problems and additional learning/physical disabilities /mental health problems (see p.21). Their website has an observational tool that can be used by carers to recognise how someone is using their sight (the Functional Vision Assessment Tool), as well as easy read forms that can be completed prior to a visit to the opticians, and after a visit to the opticians to record key information about a person's vision.

Sight loss can have a huge impact on someone's independence, confidence, and social skills. For people who already have other disabilities and difficulties understanding and communicating, having poor vision can be very frightening and isolating. It is therefore vital where possible, to ensure the person you support has their eye health regularly checked and they are getting all the help they need.

### **Seeing an Optometrist**

Optometrists usually work in high street opticians and carry out eye health checks to assess the quality of your sight, look for signs of eye disease which may need treatment from a doctor or ophthalmologist and prescribe and fit glasses or contact lenses.

Dispensing Opticians fit and sell glasses but do not give comprehensive eye health checks. Some can fit contact lenses. Dispensing Opticians can give you advice on types of lenses, such as single vision or bifocal and help you to choose frames.

Children and adults under 70 should see an Optometrist for a general check up at least every 2 years – like having a dental check up even when you have no problems. If you already have an eye problem, are over 40 with relatives with glaucoma, if you are diabetic or aged over 70 then you will probably be seen more often.

This examination is free under the NHS for some people e.g. those under 19 in full time education, over 60, on an income based benefit, have diabetes or glaucoma or are at risk of glaucoma, or are already registered as Sight Impaired /Severely Sight Impaired (see p.18). Please inform them when arranging the appointment if any of these apply.

Unfortunately many people often only visit an Optometrist when they already have a problem. However, optometrists can detect many health problems such as high cholesterol, diabetes, high blood pressure and even brain tumours or neurological conditions like Multiple Sclerosis just through an eye check.

You can contact any Optometrist for an appointment, but some have signed up to the national SeeAbility database for good practice regarding people with a learning disability. Some Optometrists in Brighton & Hove have signed up to the 'Thumbs Up' project showing a commitment to improving services for people with a learning disability.

Check these websites for most up to date information –  
[www.seeability.org](http://www.seeability.org) - select 'Eye Care Hub' from the menu, then click on the 'find an optometrist or optician in your area' link  
[www.brightpart.org](http://www.brightpart.org) - click on the 'Thumbs Up' page to look at the list

Whoever you choose to go to, when contacting them to arrange appointments please explain the person has learning disabilities and ask for a longer appointment, as well as mentioning any other factors that may help the person when they attend for an appointment. Ask what financial help they may be entitled to towards the cost of glasses.

## **Local & Domiciliary Optometrists**

The optometrists listed below are signed up to support people with a learning disability via the SeeAbility good practice database and/or the Brighton & Hove 'Thumbs Up' scheme. (NB – listing optometrists here does not constitute a direct recommendation)

- Barnard Optometrists, Hove (Seeability list & Thumbs Up! list)  
01273 772318
- Linwood Strong (Collisons), Brighton (Thumbs Up! list)  
01273 682 925
- Specsavers, Hove (Thumbs Up! list)  
01273 746 200
- Vision Express, Churchill Square, Brighton (Thumbs Up!)  
01273 737 901
- Vision Express, North Street, Brighton (Thumbs Up!)  
01273 328 063

For more information on finding local optometrists, please look on the NHS Choices web site and click on the link for 'services near you'. Then select 'opticians' from the list. [www.nhs.uk](http://www.nhs.uk)

Depending on where you live, the following optometrists can visit at home if someone is largely housebound:

- Complete Community Care Opticians  
01273 220 588
- Dr Khin Thaug  
07909 783 508
- Eyes at Home  
0800 345 7509 (free phone) or 07748 020 315
- Eye Visit (Mr Keri Davies)  
01273 701 439

## **What if the Optometrist has concerns?**

If the Optometrist is concerned that the person will need further investigations, they will send a report to the GP who will then ask for an Eye Hospital outpatient appointment. If you or the person you care for feels they will require additional support/reasonable adjustments to be made to attend a hospital appointment please ask the optometrist and/or GP to include relevant information in the referral letter e.g. longer appointments, pre-appointment visits.

If you get a letter with an appointment, and would like to discuss any arrangements needed or concerns please use contact numbers given on the letter in the first instance.

When attending a hospital appointment please bring along details of any medication the person is taking and their 'hospital passport' and/or 'health assessment booklet' if they have one. If they do not have one, these can be downloaded from the healthy lives page of the Brighton & Hove learning disability partnership board web site - [www.brightpart.org](http://www.brightpart.org)

If the Optometrist thinks there is an urgent issue they will advise you to attend the A&E department in the Eye Hospital – please bring any relevant medical letter or report from the Optometrist or GP. When you arrive at the Eye Hospital A&E department, please explain any concerns you have or any particular help the person will need while they are in the department and staff will do their best to support you.

## **Eye Hospital Services**

Sussex Eye Hospital – Eye Clinic Liaison Officer ('ECLO')

Kerry Leask 01273 696955 ext 7528

Employed by Action for Blind People charity and based at the Eye Hospital Monday - Friday, Kerry can offer information and advice regarding eye conditions, specialist social services Rehabilitation assessments, registration, voluntary organisations, low vision referrals for magnifiers etc. as well as basic emotional support.

## The Learning Disability Liaison Team

01273 696955 ext. 4975 Mon-Fri 8.30-4.30

The Learning Disability Liaison Team provide active support, education and advice for professionals, acute hospital staff, the patient and their family during all types of hospital visits including planning for hospital admissions, outpatient appointments, planned surgery and A&E admissions.

This team works across Brighton & Sussex University NHS Trust sites, including the Royal Sussex County Hospital, Princess Royal Hospital, Hove Polyclinic and the Eye Hospital.

More information can be found on the Healthy Lives page of the Brighton & Hove Learning Disability Partnership Board web site - [www.brightpart.org](http://www.brightpart.org)

## Low Vision Clinic (LVC)

Based in Montague House, (Somerset Street entrance) Brighton. Often, even with the best prescription glasses, people with an eye condition struggle to read.

'ROVIs' (see p.17) assess people at the LVC and help them to maximise the vision they have with advice about better lighting, large clear print, reading techniques, colour contrast, glare problems and low vision aids such as magnifiers which are provided under the NHS on long loan at no charge.

There is a clinic in Brighton (held twice a week) and in Haywards Heath (less frequent than that held in Brighton). Please ask either the Optometrist or Eye Hospital for a referral.

## Eye conditions

Different eye conditions affect different parts of our vision e.g. the central area we use for detail and colour for tasks such as reading, watching TV and recognising faces, and the more peripheral 'outside' field of vision we use often without realising, to get around safely and avoid bumping into things.

### 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. Ocular albinism- lack of pigment in the eyes only.

### Amblyopia ('lazy eye')

Refers to an eye (or eyes) that have reduced vision which can not be corrected with spectacles. It is usually caused by under developed sight due to an eye turn (strabismus/squint), unequal focus or cloudiness in the eye. It is most likely that only one eye will be affected. This can often be improved with patching the eye but only before the age of 7 as the eye continues to develop until then.

### Anophthalmia

When a baby is born without eyes.

### Astigmatism

Irregular shaped cornea or lens. 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.

### Blepharitis

Eye lids become inflamed because the oil glands have become blocked, and may cause 'dry eye'. Because the eye is not being effectively lubricated naturally, it may feel itchy and gritty with red crusty/flakiness. It cannot be cured but rarely affects the vision. Eye clinic staff can advise about regular lid hygiene routine, lid massage and warm compresses which should help reduce the symptoms.

### Cataract

Cataracts occur when the lens in your eye becomes cloudy, often due to ageing. They are very common and can cause blurred / misty vision, 'washed out' colours and you might become dazzled by bright light. Occasionally they are present from birth (congenital cataracts).

Cataracts are NOT a 'skin' nor do you have to wait until they are 'ripe' before having surgery these days thanks to modern technology.

Unless you have other eye conditions, cataract surgery is now very quick and your vision should be better instantly. Most people can have a local anaesthetic and leave hospital within hours of surgery. The operation takes approximately 20 minutes, and a small opening is made in your eye to remove the cloudy lens and replace it with a clear plastic intraocular lens implant. Sometimes after surgery, the membrane of the sac in which the lens 'sits' can cloud over with time. Simple laser treatment is quick and painless and usually resolves this.

### Conjunctivitis

Inflammation of the conjunctiva (outer layer of eye, inner eyelids). It is usually viral but can also be bacterial (both very contagious) or allergic. Often white of eye is pink and feels very itchy /gritty, and may have a discharge.

Cortical or Cerebral visual impairment A condition where the eyes are healthy but there has been neurological damage to the brain. May result in difficulty recognising objects, field loss, and poor vision.

### Diabetic maculopathy /retinopathy

Diabetes mellitus is a condition where the body cannot process sugar and other carbohydrates normally due to a lack of insulin. It usually starts in later life and is controlled by diet, tablets, or insulin injections. It can affect many different parts of the body, including the eyes, but won't necessarily affect your vision, particularly if it is well controlled. Annual eye examinations are therefore crucial.

Diabetic maculopathy and retinopathy can affect the central and wider, peripheral field of vision, when retinal swelling occurs and weak new blood vessels grow in the wrong places, making them prone to bleeding and creating scar tissue. This distorts the retina and can lead to a retinal detachment. Laser treatment is often given to prevent further bleeding but cannot restore lost vision.

Diabetes UK – 0345 123 2399

Diabetes UK Careline – via 0345 123 2399

[www.diabetes.org.uk](http://www.diabetes.org.uk)

[careline@diabetes.org.uk](mailto:careline@diabetes.org.uk)

### Dry eyes

Eyes feel gritty and uncomfortable when the tear film which lubricates and protects the front of your eye isn't working effectively, and is often age-related. Sometimes 'dry eye' may cause them to be very watery and 'run' a lot as your body over produce tears to try and combat this problem. Other health conditions, various medications or lid problems like blepharitis can cause this. Artificial tear drops and lubricants can help relieve the symptoms.

### Entropion

Eyelid turns inwards and the cornea is scratched by the lashes. This can cause infections, permanent scarring and cloudy vision.

### Glaucoma

There are four main types of glaucoma - chronic, acute, secondary and congenital. Glaucoma refers to optic nerve damage with loss of visual field and for which raised pressure can be a risk factor. Chronic glaucoma happens gradually over a long period of time as the drainage channels slowly become blocked, and might not be noticed for some time, as it is painless and gradual. The field of vision, however, is being damaged, usually in an arc-shape just above and/or below the centre when looking ahead. Eventually sight becomes 'tunnel vision' – like looking through a tube. You may start bumping into things and knocking objects over, yet still be reading.

Various factors increase your risk of chronic glaucoma – being over 40, being of African descent, having a close relative with glaucoma, short sighted people and diabetics. People at risk should see an Optometrist annually and have their optic nerve examined, the eye pressure checked and a visual field test. Damage from glaucoma cannot be cured but usually can be managed well through long term daily eye drops, laser treatment or an operation to improve drainage.

Acute 'closed angle' glaucoma is a more uncommon condition when the vision can deteriorate suddenly, the eye become very red and it is likely to be very painful. You might feel sick and see misty coloured rings around white lights, usually in the evenings - contact your doctor or the hospital urgently for hospital admission. If caught early, it can be treated within a few hours and your vision might return almost to normal. Again, your treatment could be a combination of drugs, laser or an operation. You will probably be advised to have your other eye treated too.

With secondary glaucoma, pressure rises because of another eye condition. Developmental/congenital glaucoma is rare and potentially serious condition in babies.

International Glaucoma Association

[www.glaucoma-association.com](http://www.glaucoma-association.com)

[info@iga.org.uk](mailto:info@iga.org.uk)

Sightline 01233 648170 – Mon to Fri, 09.30am until 5.00pm

### Hemianopia / Hemianopsia /Quadrantiopia

A number of medical conditions can cause this sight problem where part of your field of vision (the peripheral, 'outside' vision) is missing, but a stroke, a tumour or injury are the most common causes. It can be left or right sided and range from being so mild it's unnoticeable, to very severe. There are different types of field loss and unfortunately no specific treatment though it may show improvement with time in some patients. It is however important to diagnose the condition in and to treat any underlying problems e.g. abnormal blood pressure. Although stroke is not itself a genetic illness, it may result from other health problems that exist within families and discussion with medical advisors will help to identify whether there might be genetic implications.

The Stroke Association – Stroke Helpline 0303 303 3100

[www.stroke.org.uk](http://www.stroke.org.uk)

[info@stroke.org.uk](mailto:info@stroke.org.uk)

### Hypermetropia (long-sightedness)

Objects are seen more clearly in the distance.

### Keratoconus

A 'cone-shaped cornea'. The cornea (clear 'window' at the front of the eye) becomes more pointed as the corneal layers near the centre become thinner. This is particularly common in people with Down's Syndrome.

### Macular Degeneration

Deterioration of the macula (the part of the retina that we use for our central vision) which is often the result of ageing, and means reading and writing, recognising faces etc. become difficult. Vision may become distorted and blurry, straight lines become wavy or a dark patch might appear in the centre. Some people become sensitive to bright light, have difficulty adjusting from dark to light situations, and colours can fade. Often people complain that they struggle to recognise faces and 'lose' words in sentences. MD might eventually

affect both eyes, but is painless and as it affects your central vision, should never lead to total blindness.

There are two types of MD – wet (less common) and dry (much more common). Unfortunately there is currently no medical treatment for dry MD but any deterioration is usually a slow, gradual process. Certain nutrients from food or supplements may help slow this deterioration.

However, it is possible for dry MD to develop into the wet type. This can occur fairly suddenly and can progress in marked phases of deterioration but early diagnosis and swift treatment such as monthly injections in to the anaesthetised eye can often help stop the vision deteriorating.

Local Macular Disease Society Support Group - 01273 476 206

Macular Society - 0300 3030 111

[www.macularsociety.org](http://www.macularsociety.org)

Myopia (short sightedness)

Objects are seen clearer close up.

Microphthalmia

Being born with unusually small eyes.

Nystagmus

Involuntary, uncontrollable and repetitive eye movements as if they flicker, or wobble from side to side. Often associated with Albinism.

Optic atrophy

Degeneration of the optic nerve causing blurred vision and central or peripheral field loss.

Optic Nerve Hypoplasia

A condition present from birth may give reduced sharpness or part of the vision may be missing.

Retinal detachment

This is preceded by sudden flashes and floaters before a shadow or curtain moves across the vision. This needs urgent surgery to prevent severe permanent visual loss, and is more common in very short sighted people.

### Retinopathy of prematurity

Infant has an increased risk of detachment of the retina. Can lead to reduced vision or blindness.

### Retinoblastoma

A malignant tumour of the retina, usually treatable at a specialist centre. May have first been noticed as a 'white eye' in a photo where a flash is used.

### Retinitis Pigmentosa

A group of hereditary diseases of the retina. Can result in reduced night vision and a gradual loss of peripheral and or central vision.

### Septo-Optic Dysplasia

An underdevelopment of the optic nerve. The degree of visual impairment is variable. Often associated with Nystagmus.

### Stargardt's Disease

Inherited disease that causes gradual degeneration of the macula. Effects vary from minor to total loss of detailed vision.

### Strabismus (squint)

Sometimes called an 'eye turn', where both eyes point in different directions due to muscle imbalance. Patching may be suggested in children under 8 as the vision is still developing.

For more information about eye conditions you can visit the following web sites:

Royal National Institute for the Blind - [www.rnib.org.uk](http://www.rnib.org.uk) - go to 'eye info'

SeeAbility - [www.seeability.org](http://www.seeability.org) – go to the 'Eye Care Hub'

## Social Services (Brighton & Hove area)

Further information about all of the teams below and other social care services can be provided by Social Care Access Point on **01273 295555**, or under the section 'Social Care and Health' on the Brighton & Hove City Council web site [www.brighton-hove.gov.uk](http://www.brighton-hove.gov.uk)

### Adult Social Care

Various professionals can advise about support for adults with health problems or disabilities which make their daily life difficult, e.g. washing or dressing themselves, cooking, getting out and about, are becoming forgetful or confused about medication or meals, are unsafe because of falls etc.

- 'ROVI's' (Rehabilitation Officers for Visually Impaired people)  
Specifically trained to help people who are having difficulties because of their sight around issues such as safety indoors (cooking, hot drinks etc.) and outdoors (crossing roads, bumping into objects, tripping over kerbs etc.). They can also advise on lighting, provide free magnifiers through their Low Vision Clinic and register people Sight Impaired ('Partially Sighted') or Severely Sight Impaired ('Blind') if they receive a certificate of Visual Impairment ('CVI') from the Eye Hospital. They have information on local social groups and can demonstrate useful equipment to help people cope with their sight loss.

- Social Work Resource Officers and Care Managers  
Advise people with hearing difficulties, and possibly provide equipment such as doorbell/smoke alarm/telephone flashing light alerts. Clients must have had a hearing test in the last three years for assistance.

- OT's (Occupational Therapists)  
Assess people with illnesses or disabilities which mean they are having difficulties with their mobility e.g. getting in/out of the bath, on/off the toilet, climbing up/down stairs.

### Community Learning Disabilities Team (CLDT)

For adults with a learning disability, this multi disciplinary team consists of staff such as social workers, physiotherapists, speech & language therapists, community learning disability nurses, psychiatry, psychology, occupational therapy, and behaviour support officers.

## **Registration**

If your binocular vision (i.e. what you can see with *both* eyes open with your best glasses/contact lenses if relevant) is permanently down to a certain level, or you have significant impaired field of vision (i.e. peripheral sight), you can ask your eye consultant if you can be registered 'Sight Impaired / SI' ('partially sighted') or 'Severely Sight Impaired / SSI' ('blind'). Loss of vision in one eye only does not qualify. Also, failing DVLA driving standards does not necessarily mean you qualify for registration.

Besides alerting the local authority to your level of sight loss and resulting difficulties, registration also means you are registered as disabled and protected under the Equality Act (2010). Being registered as SI or SSI might also be of benefit to you practically or financially in all sorts of ways – just ask. You do not usually need to be registered for a Low Vision assessment (pg. 10) or a 'ROVI' assessment (pg. 17).

You will be registered by your local authority Social Services once they receive the Certificate of Vision Impairment ('CVI') from the Eye hospital. They will assess your difficulties, and provide you with a registration card and number.

Registration is voluntary and you can be de-registered if you change your mind in future. You need to inform your new Social Services department if you move area that you are registered. Please call RNIB helpline 0303 123 9999 for more information regarding registration.

## **Concessions**

Some registration concessions are nationwide and others will depend on your local area. See below for examples that may be available.

### **Benefits**

Registration can add weight to a benefit application for clients or carers e.g. Disability Living Allowance / Personal Independence Payment (DLA/PIP) or Attendance Allowance (AA), which could also increase Pension Credit (PC). If someone is having significant daily difficulties because of their sight and / other health problems /learning disabilities, please contact a benefit advisor (see pg. 22).

### Blue Badge Scheme (disabled parking)

People registered SSI (not SI) qualify for a badge for use in any vehicle in which they travel. Ask local council for application form.

### Bus

CountyCard - Available to all over 60 years of age, and under 60's registered SSI or SI. Bus services are free to anyone with county card.

### Cinemas

Odeon and Cineworld - if person is registered SSI or receive DLA/AA benefit, they can apply for a CEA (Cinema Exhibitor's Association) card so companion/ escort goes free but no direct discount for person themselves. Application form from [www.ceacard.co.uk](http://www.ceacard.co.uk) or cinema.

Duke of York – No direct discount but companion goes free with proof of SI or SSI registration card, not CEA card.

### Coach

National Express- Anyone registered SI or SSI can buy a Disabled Coachcard guaranteeing 1/3<sup>rd</sup> off any standard ticket on/off peak time.

### Council tax

Reduction to those registered SI or SSI who can show a room is mainly designated for their visual impairment equipment e.g. a quiet room with Braille equipment or talking books etc. (not including a bathroom, kitchen or lounge). Ask local council for application form.

### Hearing aids

Please tell your Audiology department if you are visually impaired as you may be given a spare pair of moulds.

### Income tax

People registered SSI and paying tax on income, savings, private pensions etc. are entitled to an additional £2,160 on top of their existing personal tax allowance. This can be transferred to a live-in spouse. Tel: 0300 200 3301 [www.hmrc.gov.uk](http://www.hmrc.gov.uk)

### Leisure centres

Concessions are often available for those registered SI/SSI or on certain benefits – please enquire directly with individual centres

### NHS costs

Possibly entitled to free NHS prescriptions if you have a continuing physical disability which means you cannot go out without the help of another person or have other health condition on the list. Ask your GP

about this medical exemption certificate (form FP92A). Free NHS sight test if SI or SSI, or on income related benefit. You must tell optometrist before test, and ask if entitled to a voucher towards the cost of glasses. If on low income/savings, consider form HC1. For more advice call 0845 850 1166.

#### Postage ('Articles for the Blind')

Free postage for information prepared specifically for visually impaired people e.g. large print /CD /braille. Need proof of visual impairment e.g. a letter from optician/eye hospital if not registered SI or SSI. Call Royal Mail 08457 740740 or [www.royalmail.com](http://www.royalmail.com) (articles for the blind)

#### Radio / tape cassette / CD player (free loan)

Provided by British Wireless for the Blind Association for those registered SI or SSI in receipt of means tested benefit (e.g. pension Credit/income support/income related ESA etc.). Tel: 01622 75 47 57

#### Rail

Disabled railcard costs £20 per year -1/3 off most rail travel (there are exceptions) also note - travelling companion also gets 1/3 off rail journey, unlike standard over 60's railcard and works out slightly cheaper to buy. Also, can ask for practical assistance at start/end of journey. Tel 0845 605 0525 for more enquiries.

#### Telephone

Fault priority, large print/Braille bills and equipment available to hire e.g. big button telephone may be provided to those registered SI/SSI. Some companies will provide these services with proof of sight problems & reading difficulties (e.g. from Eye Hospital / low vision clinic /Sensory team) even if you aren't registered. Speak to your phone company directly. Local Social Services may occasionally help with installation and line rental charges depending on individual circumstances. For free directory enquiries call 0800 587 0195.

#### Theatres, Galleries, exhibitions etc

Please contact venue directly about concessions for those registered.

#### TV Licence

Free for anyone over 75 years anyway. 50% discount if registered SSI. Tel 0300 790 6071.

#### VAT relief

Available to those registered SI /SSI on certain products related to sight loss. Call HM Revenue & Customs on 0300 123 1073.

## **Voluntary Organisations for Sight loss and Learning Disabilities**

SeeAbility

01372 755 066

[www.seeability.org](http://www.seeability.org)

Support for people with sight problems and additional learning and/or physical disabilities. This website has many simple factsheets with photos to help people understand what is happening and a 'Functional Vision Assessment Tool' for carers to download

RNIB - supporting blind and partially sighted people

0303 123 9999

[learningdisability@rnib.org.uk](mailto:learningdisability@rnib.org.uk)

### **General Visual Impairment Organisations**

Action for Blind People (in association with RNIB services)

0303 123 9999 RNIB Helpline

Action for Blind People offer visually impaired people a number of services, including help with finding a job, applying for benefits, housing issues, aids and adaptations, holiday breaks and information on local services. Contact Action for Blind People via the RNIB helpline.

[www.actionforblindpeople.org.uk](http://www.actionforblindpeople.org.uk)

Blatchington Court Trust (for 0-30 yr olds in Sussex)

(01273) 727 222

Provide advocacy, counselling, education, IT & employment advice, and family support for younger people with sight loss (usually need to be registered Sight Impaired or Severely Sight Impaired).

[www.blatchingtoncourt.org.uk](http://www.blatchingtoncourt.org.uk)

British Red Cross

0800 0280 831

General, rather than sight-specific equipment on display. Hires out wheelchairs and commodes and useful on-line equipment shop

[www.redcross.org.uk/shop](http://www.redcross.org.uk/shop)

City Synergy

01273 697 339

Social /activity group for all ages with a visual impairment.

[www.citysynergy.org.uk](http://www.citysynergy.org.uk)

Daily Living Centre (Montague House, Montague Place, Brighton)  
01273 296132  
Equipment on display including for sight and hearing loss.  
[www.brighton-hove.gov.uk](http://www.brighton-hove.gov.uk)

DeafBlind UK  
0800 132320  
Local social groups, volunteer scheme and free 24hr helpline for people with significant sight and hearing loss and their carers.  
[www.deafblind.org.uk](http://www.deafblind.org.uk)

East Sussex Association of Blind and Partially Sighted People (ESAB)  
01323 832 252  
For anyone in Brighton/Hove/East Sussex with a significant sight problem. Offers equipment display, monthly social groups, home visiting scheme, talking books and videos, free radio/ tape/ CD player for those registered and assessed as in financial need. Local Brighton dual sensory impaired social group. Maggie Gnyer (ESAB worker) links in with Brighton & Hove Low Vision Clinic.  
[www.eastsussexblind.org](http://www.eastsussexblind.org)

The Partially Sighted Society  
0844 477 4966  
Information, advice, training, equipment and clear print material for the benefit of people with a visual impairment  
[www.partsight.org.uk](http://www.partsight.org.uk)

### **Benefits /Housing / Education / Employment Advice**

RNIB Helpline (also associated with Action for Blind People services)  
0303 123 9999  
For advice about benefits, housing, eye conditions, leisure, IT, gadgets, education, training & employment, telephone counselling, & support groups, Children and Young Peoples team, and a national directory of visual impairment services - [www.sightlinedirectory.org.uk](http://www.sightlinedirectory.org.uk)  
[www.rnib.org.uk](http://www.rnib.org.uk)

The Fed Centre for Independent Living  
01273 296747  
A user led organisation promoting independent living for people with disabilities, offer a range of services including support and advice  
[www.thefedonline.org.uk](http://www.thefedonline.org.uk)

## **Talking Books / Large Print**

Brighton & Hove City Libraries

01273 296900 – general enquiries

Provides a service to sheltered, care & nursing homes. Information on books in various formats e.g. large print, cassette, CD & on the Mobile Library.

[www.brighton-hove.gov.uk](http://www.brighton-hove.gov.uk)

Calibre

01296 432 339

Talking books on tape posted out. £30 adult /£20 children one off registration fee

[www.calibre.org.uk](http://www.calibre.org.uk)

East Sussex Association of Blind and Partially Sighted People (ESAB)  
(see above, p.22)

Large Print Bookshop

0800 009 6036

[info@largeprintbookshop.co.uk](mailto:info@largeprintbookshop.co.uk)

[www.largeprintbookshop.co.uk](http://www.largeprintbookshop.co.uk)

National Talking Newspapers & Magazines (TNAUK)

01435 866102

National newspapers and over 200 magazines and journal titles in a number of formats for a fee (tape, audio CD, Daisy CD's etc).

[www.tnauk.org.uk](http://www.tnauk.org.uk)

RNIB Talking Book Service

0303 123 9999

Also Big Print weekly national paper and TV/radio guide

## **Transport**

Blue Badge scheme

01273 296 622

Free parking badge for people with disabilities e.g. registered SSI ('blind') or serious mobility difficulties.

[www.brighton-hove.gov.uk](http://www.brighton-hove.gov.uk)

### Concessionary Bus Pass

01273 291 924

For people registered with a sight impairment. Talking bus stop fob available through Access Point (see pg.17)

[www.brighton-hove.gov.uk](http://www.brighton-hove.gov.uk)

### Easy Link

01273 677 559

Special bus service for people who have difficulties with public transport. Wheelchair accessible. Contact for further info re: local w/chair accessible transport.

### Red Cross

0800 0280 831

Provide door to door car transport for appointments, holidays etc. Donations suggested at approx. 50p per mile with minimum £5 charge. Long journeys may incur overnight expenses.

### Taxi Voucher Scheme

01273 291 924

Limited amount of vouchers towards taxi fares for people unable to use public transport.

[www.brighton-hove.gov.uk](http://www.brighton-hove.gov.uk)

Bluebird Community Partnership - Transport to Princess Royal, Royal Sussex County or Sussex Eye Hospital

01444 471919 (advanced bookings 9.30am –11.30am Mon-Fri)

[www.bluebirdcommunitypartnership.co.uk](http://www.bluebirdcommunitypartnership.co.uk)

## **Younger People (And Parents)**

### Amaze

01273 772289

For parents of children with special needs

[helpline@amazebrighton.org.uk](mailto:helpline@amazebrighton.org.uk)

[www.amazebrighton.org.uk](http://www.amazebrighton.org.uk)

Blatchington Court Trust (for 0-30 yr olds in Sussex)

(see p.21)

Brighton and Hove Sensory Needs Service for Visually Impaired  
Children  
01273 293610  
Assess the developmental and educational needs of 0-18 year olds at  
home /school.  
[www.brighton-hove.gov.uk](http://www.brighton-hove.gov.uk)

LOOK - National Federation of Families with Visually Impaired  
Children  
0121 428 5038  
[information@look-uk.org](mailto:information@look-uk.org)  
[www.look-uk.org](http://www.look-uk.org)

LOOK Sussex  
01273 677731  
[www.looksussex.org.uk](http://www.looksussex.org.uk)

NBCS - National Blind Children's Society  
01278 764 770  
For 0-25 yr olds, can provide grants.  
[www.nbcs.org.uk](http://www.nbcs.org.uk)

RLSB - Royal London Society for the Blind  
01732 592 500 – Seal Office  
020 7808 6170 – London Office  
Provide advice, counselling and contact with other families.  
[www.rlsb.org.uk](http://www.rlsb.org.uk)

RNIB Family Services Officer - London & South East  
0303 123 9999- via main RNIB helpline

Spiral  
01273 295 180  
Wide ranging activities and opportunities for people with a learning  
disability  
[Info@spiralsussex.co.uk](mailto:Info@spiralsussex.co.uk)

## General

Action for Blind People (Via RNIB Helpline)

0303 123 9999

Advice and support re: employment, housing, benefits, children and young people's education & activities, peer support, holidays, technology.

[www.actionforblindpeople.org.uk](http://www.actionforblindpeople.org.uk)

Age UK

01273 720 603

Wide ranging generic support for over 55's including provision of counselling, and contacts for gardeners, cleaners etc.

[www.ageuk.org.uk/brightonandhove/](http://www.ageuk.org.uk/brightonandhove/)

Carelink Plus

01273 673 105

Range of telecare alarm services for vulnerable adults in Brighton & Hove e.g. those at risk of falls, people with disabilities. Concessions might possible.

[www.brighton-hove.gov.uk](http://www.brighton-hove.gov.uk)

Carers Centre

01273 746222

Activities and support for carers of relatives/partners / friends/neighbours who are sick or disabled.

[info@thecarerscentre.org](mailto:info@thecarerscentre.org)

[www.thecarerscentre.org](http://www.thecarerscentre.org)

\*\* Please contact Kerry Leask or Les Hall on 01273 696955  
Ext. 7528 to correct any errors \*\*

**Tips & Hints – supporting people with sight loss**  
**please consider consent /best interest issues where appropriate**

- Consider including information in person centred plans and health action plans (with consent or as part of best interest decision)
- Check they are having any treatment or drops recommended by the doctor
- Keep the persons hands and nails clean and trimmed
- Visit an optometrist *at least* once every 2 years unless under the eye hospital or otherwise advised
- Be patient! People can experience eye conditions differently and their vision can vary from day to day and throughout the day. Many factors can affect vision e.g. weather and lighting conditions, general health, tiredness, sugar levels if diabetic etc.
- Don't assume what people can /can't see – even most people registered 'Blind' have some useful vision
- Avoid clutter and try to keep things in the same place to help them remember where they are
- Always make sure a person is aware you are approaching them and explain if you are going to do something before you do it – preferably ask too! It's very frightening to be surprised.
- Tell someone when you are leaving them so they don't feel confused and ignored or embarrassed and continue the conversation.
- Encourage them at meal times, explain what is on the plate and where e.g. mash at 12 o'clock or at the top etc. Always check they have finished their meal rather than just whisking it away.
- Write in large clear print – not capital letters which are harder to decipher. A thick black felt tip used on white or yellow paper is often the best contrast.

- Encourage a healthy lifestyle - no smoking (you are *much* more likely to lose sight if you smoke), limiting alcohol, eating a good balanced low fat diet with 5 daily portions of fruit and vegetables, twice a week portions of oily fish, regular exercise, looking after any medical conditions such as diabetes or high blood pressure or cholesterol, protect eyes from sunlight with UV filter sunglasses / hat.
- Check their friends, family, day service and other carers are aware of their problem and how they can help
- Arrange for a Rehabilitation Officer to assess them in their home and outside environment. They may suggest gadgets or aids like a magnifier, anti-glare glasses, advice about encouraging someone to wear glasses /patches, advise about lighting and colour contrast in the home, safety mobilising outdoors, helping them enjoy their hobbies more etc.
- Ask the Rehabilitation Officer to advise you about assisting the person with sight problems e.g. guiding techniques. Some people like to hold your shoulder, other prefer to hold your arm just above your elbow on whichever side is easiest for them. This way they stay close to you, can tuck in behind you (straighten your arm behind you a little) in narrow spaces and feel more in control than being pulled by their hand. Keep the person to the side of hand rails and guide their hand to the front or back of a chair rather than pushing them into it.
- If their vision is significantly impaired in *both* eyes, ask the optometrist or eye hospital consultant if they can be registered Sight Impaired ('partially sighted') or severely sight impaired ('blind')