Where can you go from here? Scotland
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Introduction

This booklet contains some of the information you may need after your child has been diagnosed as having a visual impairment. Unfortunately it can never be complete but we do hope that it is useful and provides some answers to some of your questions and guides you towards the most appropriate help.

You may want to know more about the diagnosis and outcome and because of the stress of your visit; you may not remember all that you were told. The doctor will understand this.

If a follow up appointment was not made and you would like to speak to the ophthalmologist (eye doctor) again please do telephone the hospital and ask to speak to the secretary for the ophthalmic clinic. S/he can then either arrange an appointment for you or ask the consultant to phone or write to you at home.

Make a list of the things that you wish to discuss with the doctor so that you do not forget them. (This is a very useful tip). If you are unable to contact the consultant, your GP may be able to advise you.

You may find it helpful to take a relative or friend to the next appointment to remind you of the information discussed.
What do the different health professionals do?

Orthoptist
An orthoptist is a person who assesses vision and eye movements. They use methods of assessing vision that are most suitable for young children. They can assess squints and patients complaining of double vision. They usually work in eye clinics with ophthalmologists.

Ophthalmologist (The Eye Doctor)
An ophthalmologist is a person who has qualified as a doctor and specialises in the diagnosis and treatment of eye conditions. They can prescribe spectacles and drugs. Most ophthalmologists will perform surgery although they may specialise in different types of surgery.

Optometrist and Optician
An optometrist is a person who examines eyes to see if spectacles will improve vision. Optometrists write a spectacle prescription that is given to the patient and passed on to the optician. An optician is a person who makes spectacles based on a prescription. He or she can decide on the best type of lens and spectacle frame to suit the individual. Optometrists are sometimes called opticians.

Community Paediatrician
Community paediatricians are children's doctors who are experts in child development and in how ill health / disability affect children at school. They work in child development centres, health centres, schools and sometimes in hospitals. They assess and monitor children who have a visual impairment or other special needs, and link with other services – education, social work, physiotherapy, occupational therapy, speech therapy etc, to ensure children are adequately supported. They link with the general practitioner and hospital services too. They also monitor the vision of children who have other developmental problems or disabilities. They are responsible for providing medical advice and support to schools.
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Other Help Available in the Community

Health Visitors

Health Visitors are all Registered General Nurses who have specialised in Community Health Care. They work to promote Individual, Family and Public Health. They provide a wide range of nursing services including: home visiting, accident prevention, behaviour management, continence and feeding advice. They also offer advice on family stress, welfare, and benefits.

Do contact your GP and/or health visitor as soon as possible and tell them about the diagnosis. Visual impairment is very rare so they may not have much experience of children with visual impairment but they can give support and can introduce you to the local community paediatrician and Social Services. They can also help you to find more information about your child’s condition.

The ophthalmologist will write to your GP giving information about the diagnosis and plans about future appointments at the hospital.

Peripatetic Teacher for the Visually Impaired (PPTVI)

The PPTVI is a qualified teacher with additional training and a special interest in children with visual impairment who will help you whatever the age of your child (from birth onwards). S/he should visit you at home and offer advice about early visual stimulation, suitable play materials and facilities available locally. S/he may also be able to introduce you to other local families who have a visually impaired child. The teacher will maintain contact during the pre-school years and beyond and help with suitable nursery and school placements. S/he will follow your child’s progress throughout school and assist with any problems that may arise.

Your ophthalmologist or paediatrician should make a referral to the PPTVI after a diagnosis has been made, but otherwise, the advisory teacher can be contacted through the Special Education Needs Service of your local council’s Education Department (See your local phone book or library for details).

Visual Impairment Scotland has a contact list of all the local councils should you wish to get in touch with them.
Social Services
Finding out about services and benefits can sometimes be confusing and frustrating. Contact with your local social services is important in the early stages of diagnosis so that you can have as much information as possible. Your child does not have to be registered as blind or partially sighted for you to obtain help and advice.

Visual Impairment Societies
A visual impairment society is an organisation that provides statutory and non-statutory help. This can include needs assessment, provision of equipment, advice, and information. Each visual impairment society is different; contact your local one directly to get information on the full range of services they provide.

Scottish Visual Impairment Societies Contact Details
1. Dumfries & Galloway Association for the Blind
   Mount St Michael
   Craigs Road
   DUMFRIES
   DG1 4UT
   Telephone: 01387 248784

2. Dundee Society for Visually Impaired People
   Thomas Herd House
   10/12 Ward Road
   DUNDEE
   DD1 1LX
   Telephone: 01382 227101

3. Fife Society for the Blind
   Fife Sensory Impairment Centre
   13 Wilson Avenue
   Kirkcaldy
   FIFE
   KY2 5EF
   Telephone: 01592 412666
4. The Forfarshire Society for the Blind  
76 High Street  
Arbroath  
ANGUS  
DD1 1AW  
Telephone: 01241 871215

5. Glasgow & West of Scotland Society for the Blind  
2 Queens Crescent  
GLASGOW  
G4 9BW  
Telephone: 0141 332 4632

6. Grampian Society for the Blind  
21 John Street  
Aberdeen  
AB25 1BT  
Telephone: 01224 625622

38/39 Ardconnel Street  
INVERNESS  
IV2 3EX  
Telephone: 01463 233663

8. Perth and Kinross Society for the Blind  
St Paul’s Centre  
14 New Row  
PERTH  
PH1 5QA  
Telephone: 01738 626969

9. RNIB Edinburgh and the Lothians  
12/14 Hillside Crescent  
EDINBURGH  
EH7 5DZ  
Telephone: 0131 557 1004

You do not have to be registered blind or partially sighted to get help from these societies.
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Social Services

In the Hospital
Enquire about these services at the hospital where your child has been diagnosed. There may be a social worker based at the hospital. Here you can obtain advice on fares to hospital, financial benefits, blind and partial sight registration and help with many other issues facing you at this stage. Most important is that you obtain information about your local Social Service Department. The hospital social worker can help you make your initial contact with the appropriate person.

In the Community
Social Services have statutory responsibilities to provide a range of services for you and your child. These services may be provided by your local visual impairment society. You can make direct contact with your local social services department. The telephone number and address can be found in the telephone directory or contact VI Scotland.

Benefits for Children with a Visual Impairment

Fares to Hospital
If you are on Income Support, Family Credit or disability working allowance and if you have limited savings, you are entitled to travel costs to and from the hospital for NHS treatment. If you are on a low income, but don’t receive any of the above benefits you may still be able to get help although it may only cover part of the cost. Form HC1* can be obtained from the hospital Social Work department or you local DSS (Social Security) office.

If you are having difficulty with travel costs, ring the Benefit Enquiry line on 0800 882200.
There are many benefits and services available for visually impaired children.

They fall into two main categories

- Benefits that are only available to children who are registered. These can include services and benefits provided by the local social work department or by a visual impairment society. These services are available to any visually impaired child but are most easily accessed by being registered.

- Other financial benefits available to any child with visual impairment.

Generally there are more benefits available to children registered blind than partially sighted. Many of the benefits and services available to visually impaired children are provided through a variety of different local organisations. Depending on local agreements and level of funding, services may vary between areas. Some financial benefits are awarded based solely on a child’s level of visual impairment and any associated disabilities. Other financial benefits depend on how much you earn.

Applying for financial benefits is very complex. You should always seek advice from an experienced welfare officer when applying for benefits.

Benefits & services available only to children on the blind or partially sighted register

- Free travel on buses, trains, underground and ferries within Scotland for children over 5 years of age who are registered blind or partially sighted. A companion travel pass is also available.
- Half price TV licence for children registered blind.
- Free BT directory enquiries service and help with line rental if on the blind register.
- Free postage of bulky items such as Braille or audiotapes to and from a child on the blind or partially sighted register.
- Disabled Parking Badge for all children registered blind (or partially sighted if they also have difficulty walking).
- Motability Scheme
Financial Benefits that may be easier to access if on the register.

- Disability Living Allowance (DLA) application maybe more successful if a child is on the register. There are two categories of DLA, one awarded for ‘Care’ and the other for ‘Mobility’. There are different levels of financial award within these categories.
- If the middle or higher component of DLA has been awarded the parents may also be able to claim Invalid Care Allowance and Income Support.
- If the higher mobility component of DLA has been awarded this enables parents to access the Mobility Scheme if they so wish.
- If parents are entitled to both Income Support and Invalid Care Allowance then they may also be entitled to ‘top-up’ premiums.
- Parents claiming Income Support are eligible for many other benefits such as hospital and housing grants.
- Parents may be entitled to a reduction in Council Tax if their child is ‘substantially and permanently’ disabled or in receipt of the higher rate care component of DLA.
- If a parent is already claiming Disabled Persons Tax Credit or Working Family Tax Credit and they have a child with a disability or a child in receipt of the higher rate care component of DLA they are also entitled to further ‘disabled tax credits’.

Health Benefits

All children are eligible for free prescriptions, eye tests and also help towards the cost of glasses.

Family Fund

This fund is to help families caring for a severely disabled child and is financed by the government. It is sometimes able to give lump sums for certain necessary items where the cost cannot be covered by existing services.

If you think the fund could help you write to:
**The Family Fund, PO Box 50,YORK Y01 22X**

Further information about benefits is available from:
The Benefits Enquiry Line Tel **0800 882200**
Registration as Blind or Partially Sighted (form BD1)
There is a register of blind and partially sighted people, which exists to enable your local council to plan its services. If your child is registered, it might help you if you need to claim certain benefits and concessions. It can help with obtaining specialist advice and support from social services as well as educational advice and resources from your local council’s Education Department. Social Services are obliged to keep a register of blind and partially sighted people. It is important to note that being registered as blind does not necessarily mean that your child is completely blind - it is just the measure of a certain level of vision.
Your ophthalmologist will decide whether your child is eligible for registration and after signing the BP1 form, a copy will then be sent to you and to the Social Services.
A leaflet giving full details of the benefits and concessions following registration can be obtained from Visual Impairment Scotland.

Education
You may be concerned about how your child’s eye condition will affect his/her education. This section tells you a bit more about schooling.

Record of Needs
A record of needs is a document produced following a full assessment of your child’s individual needs. The record of needs will take into account the additional help your child will require and what type of equipment will be needed in school. Not all children who are assessed will get a record of needs, and not all children need a record of needs.
Your local child development team or the PPTVI may suggest getting a record of needs for your child but you can ask for this yourself by contacting the local council’s Education Department.
The type of schooling available for children with visual impairment will vary, but, whatever is suggested in your area, it is important that your child’s needs are assessed before school begins.
If your child loses vision when s/he is older and is already in school, the record of needs process should be started to ensure that support is provided as soon as possible.
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Mainstream School
The majority of children can attend their local school providing that they have sufficient help and regular input from the peripatetic teacher for the visually impaired. The amount of support will vary according to the level of visual impairment but may include a classroom assistant and equipment such as a video magnifiers (CCTVs), computer or Brailler, as well as simple changes in lighting or enlarging print. Whenever possible, the extra support and equipment should be discussed before your child starts school, to make sure that s/he is able to follow the school curriculum. Some mainstream schools have a special resource unit within the school which provides extra facilities for the visually impaired child.

Special School
There are a few schools throughout the country, which cater for children with severe visual impairment. These schools have a full range of aids and equipment for the children, and the classes are small in size. The children will follow the curriculum with allowances made for their special needs. Some of the schools also have facilities for children with other disabilities. If your child has a learning or physical impairment as well as a visual impairment, it may be suggested that s/he attends the nearest special school. This may well be the most appropriate school for your child, but as in any mainstream school, it is still important that s/he receives the necessary help and equipment for his/her visual impairment. However, deciding whether to send your child to a mainstream or a special school is a very difficult and a personal choice. If you would like help on this, please contact your local council’s Education Department, or Visual Impairment Scotland, or RNIB Scotland. It is important to remember that your child’s educational needs may change. This could vary from the provision of extra resources to a change of school and you can ask for the record to be reviewed at any time.
Low Vision Aids (LVAs)

What are LVAs?
LVAs are magnifiers, "Special" glasses or telescopes, which can be used for distance or near tasks. They can also include electronic aids such as video magnifiers (CCTVs) and text enlargement programs for the computer.

Which Children may Benefit?
Any child with a visual impairment, except where the vision is very low, for example when the top letter of the test chart cannot be seen at a distance of one metre. Children should be assessed before they start school as some children may benefit from a simple aid as early as three years old. It is important to help a child to use a LVA as soon as possible.

How do you get referred to a Clinic?
Your Ophthalmologist, Paediatrician or General Practitioner will refer you.

Where are they available from?
LVA clinics may be part of the hospital eye service. Some simple magnifiers may be available from the high street optician or optometrist. These are usually low powered magnifiers. Resource centres have a selection of aids on display and information about them. For your local resource centre contact Social Services or the RNIB. Optical aids are usually supplied on loan through the hospital eye services and exchanged if they are no longer appropriate. Video magnifiers and computers with text enlargement should be provided by your local council's Education Department. Some equipment may be provided by charities or (if for home/leisure use) by the social work department.
Support Organisations
As well as national groups and societies, there are also local organisations in some areas of the country, which are run to help parents of children with visual impairment. Below is a list of some of the national organisations.

Visual Impairment Scotland
Visual Impairment Scotland is a new organisation which aims to provide information and support to children with visual impairments and their parents. They provide clear and understandable medical information documents as well as a parent network support system.

Visual Impairment Scotland
Moray House
Holyrood Road
Edinburgh
EH8 8AQ

Telephone: (0131) 651 6078
Email: viscotland@ed.ac.uk
Website: http://www.viscotland.org.uk

Contact a Family
Contact a Family have a team of parent advisers who will help parents to find further information on their child’s condition as they keep a directory of conditions and self-help groups.

209-211 City Road
LONDON
EC1V 1JD
Tel: 020 7608 8700
Website: www.cafamily.org.uk
The National Blind Childrens Society
This is a national organisation that offer a wide range of services to visually impaired people aged between 0 and 24.

National Blind Childrens Society.
Bradbury House
Market Street
Highbridge
Somerset
TA9 3BW
Telephone: (01278 764 764)
Email enquiries@nbcs.org.uk
Website: http://www.nbcs.org.uk/

Look
Look is a parent run organisation, which was established to give mutual support to families of visually impaired children. There are local branches throughout the UK.

Queen Alexandra College
49 Court Oak Road
BIRMINGHAM
B17 9TG
Tel: 0121 428 5038 or 020 8678 0555
Website: http://www.look-uk.org

Royal National Institute for the Blind (RNIB)
Tel: 020 7388 1266
The RNIB offer a wide range of family support services. Contact the Education Information Service for an excellent free pack for parents.
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Royal National Institute for the Blind Scotland
Dunedin House,
25 Ravelston Terrace,
Edinburgh EH4 3TP
Tel 0131-311 8500
Fax 0131-311 8529

Books

"Can’t Your Child See"
Eileen P Scott, James E Jar, Roger D Freeman
Pro Ed Inc. Order from bookseller.

"Show Me What My Friends Can See"
Patricia Sonksen and Blanche Stiff
ISBN 0 95117526 1 8
Institute of Child Health Development Guide

Available from:
The Wolfson Centre, Mecklenburgh Square, LONDON WC1N N2AP

There are also several pamphlets on visual impairment available from various sources. Visual Impairment Scotland or the RNIB can provide help on any of the issues raised in this booklet.