

Services And Support For Sight Loss Your Care Pathway

A summary to the care pathway for people
who use services across Northern Ireland.

Background

This leaflet has been created to provide anyone who has experienced sight loss or difficulty with their (sight) vision, information about the care pathway for services and support for anyone with a sight loss.

This pathway is the product of several years of listening, engagement, and collaborative working in both formal and informal meetings and conversations. The document has been delivered by the Regional Sensory Impairment Group, which brings together service users, community and voluntary sector organisations, and Health and Social Care professionals to focus on improving services and support for people with sensory disabilities. The members of the group are experts by experience, practice, and training. The group was established under the Regional Physical and Sensory Disability Strategy and Action Plan 2012-15/18.

We are pleased to share this pathway with people who use services across Northern Ireland to address and manage their sight loss. It has been designed with you, your families and carers in mind, to support your journey.

Alternative Formats

This leaflet can be made available upon request and where reasonably practicable in an alternative format. Any enquiries regarding this document should be sent to:

Strategic Planning and Performance Group,
12-22 Linenhall Street Belfast BT2 8BS

Email: SPPGcommunications@hscni.net

For an alternative format, please contact: Communications Department,
Telephone: 028 9536 3020

Glossary

Advocacy	Advocacy means getting support from another person to help you express your views and wishes, and help you to stand up for your rights. Someone who helps you in this way is called your advocate.
Assistive Technology (AT)	Assistive Technology is any item, piece of equipment etc. that can be used to increase, maintain or improve the functional capabilities of people with a disability.
Befriending	Signpost to other agencies who will provide support and advice i.e. Community Navigator, Community Access Support Worker, Age Concern.
Communication Support	Ways of helping you see/read information in a way suitable for you. This could be by braille, moon, using good lighting or magnifiers.
Daily living skills	Daily living skills is the term used to describe the activities that you do throughout your day e.g. getting dressed, cleaning your teeth, making a cup of tea, preparing snacks and meals, going shopping etc.
Emotional Support	One to one support with your emotional wellbeing to help you comes to terms with the impact of your sight (or hearing) loss.
Employment advice	Support and information that is available for those who have sight loss. This is available from agencies such as RNIB and Access to Work. They can also advise on or provide equipment that can be of assistance within the workplace, as well as making the workplace safe and accessible for you. They can advise on the options available in getting to your place of work.
Group work	Meeting other people who have similar sight loss to share experiences and learn from each other how to deal with challenging situations.
Information and Advice	Information about your eye condition, equipment, groups or organisations to help you make the right choice about the training, care and support you need.
Mobility skills	Orientation and mobility training provided by rehabilitation workers

Ophthalmologist	Sometimes referred to as an eye doctor, an ophthalmologist is a medical doctor who specialises in the diagnosis and treatment of disorders in and around the eye. Treatment may involve medical intervention or surgery. Only consultant ophthalmologists can decide if an individual meets the criteria for being certified as sight impaired or severely sight impaired.
Optometrists	Optometrists are health care professionals who are qualified to perform sight tests and screen individuals for ocular disease and abnormality. They can prescribe spectacles or contact lenses if necessary. They can work in a hospital setting or in the community. Some optometrists have advanced roles within hospital eye clinics with independent prescribing status. Optometrists work in a variety of hospital clinics, including the Low Vision Clinic.
Orthoptists	Orthoptists are health care professionals who are qualified to investigate, diagnose and manage abnormal eye movements and visual defects such as squint, lazy eye and double vision. Orthoptists are involved in many areas of care and work as part of a multi-disciplinary eye team.
Person Centred	Ensuring you as the service user are placed at the centre of everything we do.
Provision of equipment	Equipment to enhance your independence may be provided following a needs-based assessment.
Rehabilitation	Rehabilitation aims to promote independence and improve quality of life. This can be achieved by provision of equipment, doing something in a different way and talking and learning from other people in a similar position to you.
Transition	This refers to when a person moves from one stage to another, and normally refers to moving from children services to adult services.

10 ways the care pathway can make a positive difference for people with sight loss

The positive impact that the care pathway aims to deliver are summarised below, from the point of view of people who have experienced that positive difference in their lives:

1. I understand my eye condition when I meet with my Ophthalmic Consultant and/or Sensory Support Team Worker, who will explain my diagnosis.
2. I have someone to talk to. I will have help to come to terms with my condition and to understand the changes and adjustments I may need to make to the way I live. Staff from both statutory and voluntary organisations should be available to provide appropriate and timely information.
3. I can look after myself, my health and my home. I will receive help and support from statutory and voluntary organisations to enable me to maintain my independence.
4. I will understand my rights and will receive financial benefits and concessions that I am entitled to and any ongoing support when I need it.
5. I may have my remaining sight professionally assessed and then receive training in the use of low vision aids to enable me to carry out every day daily living functions.
6. I will be provided with information in a format that I can access and I will receive training to enable me to make the best use of any new technology.
7. I will receive training from a qualified professional. This will enable me to confidently access public buildings, spaces, shops and transport.
8. I have the tools, skills and confidence to communicate. I may need to learn new ways of reading, writing and keeping in touch and this will include trying out new and different forms of technology.
9. I have equal access to education and lifelong learning. I will have access to education, with specialist teaching and support across the curriculum with access to appropriate learning materials. I will develop new skills and will be able to access teaching facilities.
10. I can work and volunteer. I will be able to work or volunteer and play a full part in society and I will be able to do this following confidence building and retraining if I require this.

Objectives

This care pathway provides information about the care you can expect from professionals and support organisations to help you to manage your sight loss. It explains the roles and responsibilities of the different service providers that you will encounter. It also gives you contact details for relevant professional teams and support networks in both the health and social care and the community and voluntary sector.

This care pathway is a resource to help them deliver a consistent and standardised approach to managing your care.

Our collective goal is to ensure that individuals, families, and carers are at the heart of the process to support people with sight loss, and that our assessments of service user needs are person centred and comprehensive.

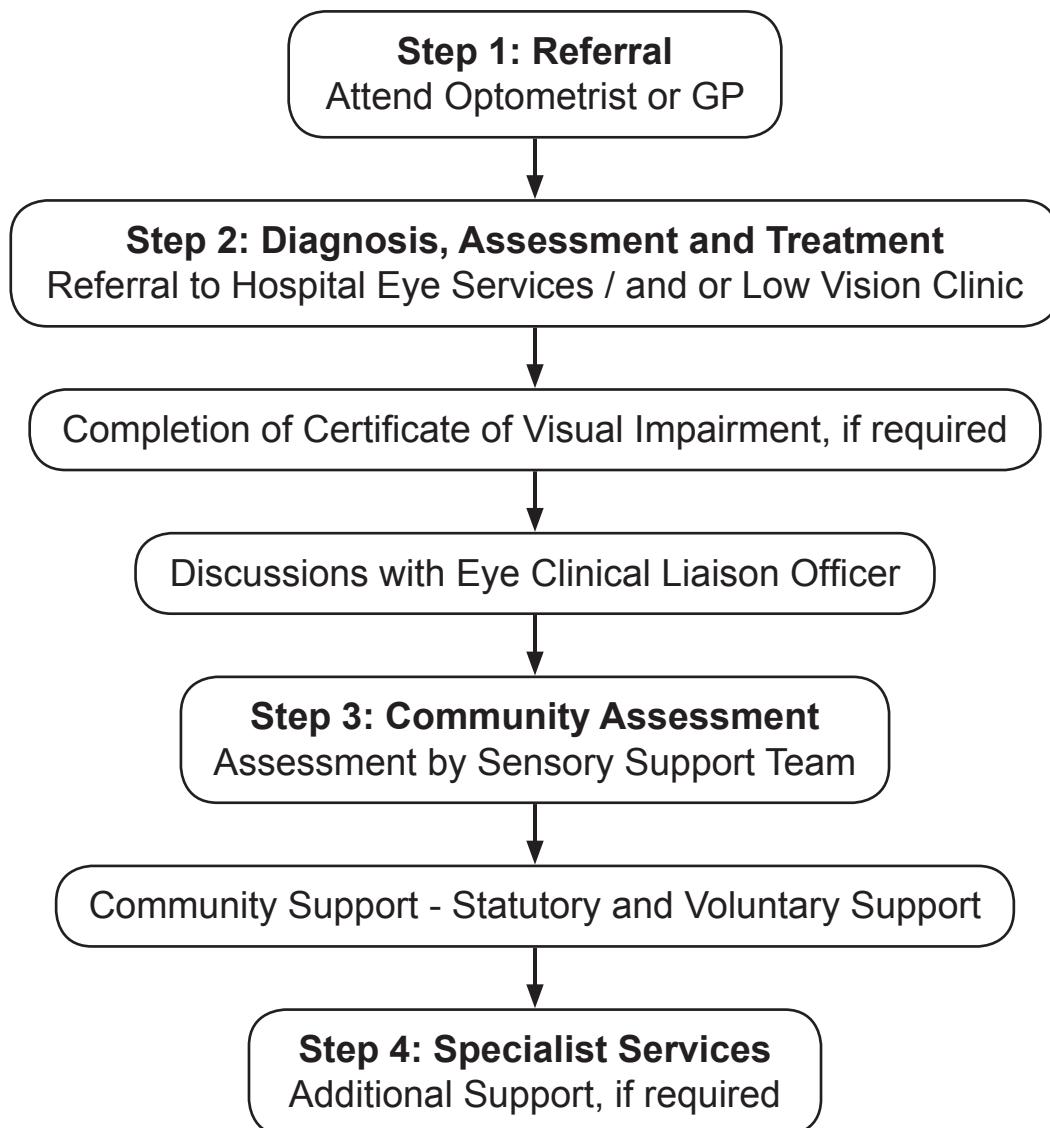
Scope of the Care Pathway

This care pathway helps people with sight loss in community settings from the point where initial concerns are identified, to the provision of equipment and follow up rehabilitation services.

The pathway also reflects specialist services which may be required to support those individuals with mental health difficulties or those who are Deafblind.

Flow Chart

The flow chart below outlines the journey along the care pathway.



The Care Pathway Flow Chart

The care pathway includes a number of key stages:

- Referral
- Diagnosis, Assessment, and Treatment
- Community Assessment / Support
- Specialist Services

This section outlines what is involved in each stage.

Step 1: Referral

I am experiencing difficulties with my sight loss. I attend my local Optometrist for a sight test or visit my GP and explain what I am experiencing.

Your GP or Optometrist will carry out a preliminary physical examination of your eyes and may refer you to an Ophthalmologist for further investigation.

Step 2: Diagnosis, Assessment and Treatment

My GP or Optometrist refers me to the hospital eye service where my sight and eye health will be tested. I may also be referred to a Low Vision Clinic where, after assessment, I may receive low vision aids to assist my vision.

My hospital Ophthalmologist Consultant may complete a form that will identify the nature and extent of my sight loss. This is called a Certificate of Visual Impairment. I will be able to speak to an Eye Clinic Liaison Officer who will help me understand the range of services available to support me and who can refer me to the Sensory Support Team provided by my local Health and Social Care Trust and/or to voluntary organisations.

Step 3: Community Assessment

My needs will be assessed by the Sensory Support Team and I will be advised about being certified as Severely Sight Impaired/Sight Impaired.

I will have the opportunity to avail of a range of social, emotional and practical support offered by both social services and by voluntary sector organisations that best meet my needs. This might include counselling or emotional support, equipment that could help me at home or work with my mobility, and daily living skills training that will help me maintain my independence.

Community Support

Types of support offered may include:

Statutory Sector (Health and Social Care Northern Ireland)	Voluntary Sector (charities and community-based organisations)
Advocacy	Advice and information
Community Access	Advice on daily living equipment
Communication support	Advocacy
Emotional support	Befriending
Equipment and aids to support my independence	Communication support
Group work	Emotional support and therapeutic counselling services
Information and advice on my condition	Group work
Low vision training	Guide Dog NI - Mobility Skill Training
Person-centred assessments	Peer support groups, social activities
Provision of equipment	Provision of equipment
Rehabilitation including mobility training, daily living skills training and support with technology	Support with technology
Sign posting to other agencies/ services	Transport Support
	Volunteering for specific services for children and young people affected by sight loss
	Welfare and employment advice and information

Step 4: Specialist Services

I may develop both hearing and sight difficulties, known as dual sensory loss. I may also experience problems with my mental well-being even after support from Ophthalmology or Community Services.

Should I have a physical or learning disability I may need additional support. If any of these things affect me, I know I can discuss them with a member of my Sensory Support Team.

Guiding Principles

Individuals, and their families and carers can expect:

- A person-centred pathway, which focuses on improving access, timely assessment and adapted for an individual.
- Access to personal information, communication and support, for service users with sight difficulties and their families.
- Access to specialist teams working to ensure the development of a co-ordinated and integrated care pathway.
- Equitable access to voluntary and independent sector services available in their communities.
- Referral access points that offer equitable service provision.
- Improved access to information about available services in statutory, voluntary and independent sectors.
- Client and family involvement central to assessment goal planning and decision working.
- A written Service Plan, agreed with the service provider, individual and their families.

Low Vision Clinic

If you are diagnosed with a significant visual impairment you may be referred to the Low Vision Clinic at your local hospital. The aim of the Low Vision Clinic is to maximise your remaining vision, helping to achieve its full potential.

At the Low Vision Clinic, the Optometrist will perform a low vision assessment. During the low vision assessment, it is possible that Sensory Support Teams may also be present at your appointment.

During the low vision assessment, the Optometrist will:

- Assess your history and symptoms and discuss any difficulties you may be experiencing in your day-to-day life.
- Offer you explanations, information and advice in a way that you can understand.
- Measure distance and near visual acuity, which is the measurement of how well you can see far away and close up.
- Prescribe magnification aids or Low Vision Aids (LVAs), which are devices that can improve functional vision and support you with accessing information and written material.
- Perform any relevant additional tests which may include measuring glare sensitivity, contrast sensitivity, refraction (testing for glasses), colour vision, visual field testing and ophthalmoscopy (eye health test).
- Advice you on specialist lighting and Assistive Technology (AT) if appropriate.
- Consider if there is a need for emotional support or social care and offer referral to the appropriate services.

Certification of a Person as Sight Impaired (partially sighted) or Severely Sight Impaired (blind) in Northern Ireland - Patient Information

This Certificate of Vision Impairment (CVI) has three main functions:

1. It qualifies you to be on a database with your local Health and Social Care Trust as sight impaired (partially sighted) or severely sight impaired (blind).
2. It lets your local Health and Social Care Trust know about your sight loss. They also have a duty to contact you to see if you need help with day-to-day tasks. They have a duty to establish and maintain records of sight loss.
3. The CVI records important information about the cause of your sight loss. It helps the health and social care service to identify any trends in certain eye conditions and helps with planning services.

Next Steps

- Being certified as severely sight impaired does not necessarily mean that you are totally without sight, or will lose all of your sight in the future.
- If you have decided that your local Sensory Support Team can receive your details, they will contact you in the coming weeks to talk about vision rehabilitation and other support that might help you.
- Certification is often a positive step towards getting support to help you to be as independent as possible.
- Certification makes it easier for you to prove to service providers, employers, schools, colleges or other people what your level of sight is. Certification will also assist you, and anyone caring for you, to become eligible for certain entitlements, including benefits.

What happens to information which I have consented to share?

You have indicated whether or not you want information about your sight loss to be shared, and with whom. The information will be used in the following ways:

1. Your GP will keep this information in your medical record.
2. The Department of Health (and its agencies) will not use any of your personal information. They will use only the information about your sight loss for research and service planning purposes. Obtaining information about eye conditions is important as it can lead to improvements to eye services and medical developments in the future.
3. Your local Sensory Support Team keeps a record of patients who have sight loss to ensure that they are offered appropriate support. You do not have to accept any support offered to you.
4. RNIB will use the information to deliver the Eye Clinic Liaison Service.

Useful Contacts

Statutory Sector	Community and Voluntary Sector
Belfast Trust Tel: 028 9504 0200 Textphone: 028 9091 2197 Mobile (SMS only): 0773 888 3116	Angel Eyes Email: info@angeleyesni.org Tel: 07775 873072
Northern Trust Tel: 028 2586 3800 Email: sensorysupport@northerntrust.hscni.net Mobile (SMS only) 07881 328952	Deafblind UK National Centre For Deafblindness Telephone number is 0800 132 320 Email: info@deafblind.org.uk
Southern Trust Craigavon/Banbridge/South Down/Newry East Tel: 028 3839 4088 Minicom: 028 3839 4738 Mobile: 07834 929 124 Email: sensory.cherrytrees@southerntrust.hscni.net	Guide Dogs Email: belfast@guidedogs.org.uk Tel: 0345 1430193
Armagh/Dungannon/South Armagh/Newry West Tel: 028 3756 4444 Minicom: 028 3741 2421 Mobile: 07919 103 501 E-mail: sensory.jacksonhall@southerntrust.hscni.net	RNIB Email: helpline@rnib.org.uk Tel: 0303 123 9999
	Sense NI Carrickfergus, County Antrim Email: nienquires@sense.org.uk Tel: 028 9335 5665 Newtownabbey, County Antrim Email: nienquires@sense.org.uk Tel: 028 9083 3430

Statutory Sector continued

South Eastern Trust

North Down & Ards

Tel: 028 9151 0136

Minicom: 028 9151 0137

Mobile: 07734 282 646

Downpatrick

Tel: 028 4461 6915

Minicom: 028 4461 4744

Mobile: 07739 879 556

Lisburn

Tel: 028 9260 7746

Minicom: 028 9260 3120

Mobile: 07739 879 554

Western Trust

Derry/Londonderry

Tel: 028 7132 0167

Minicom: 028 7132 0166

Mob: 077 9644 8367

Fermanagh/Tyrone

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