

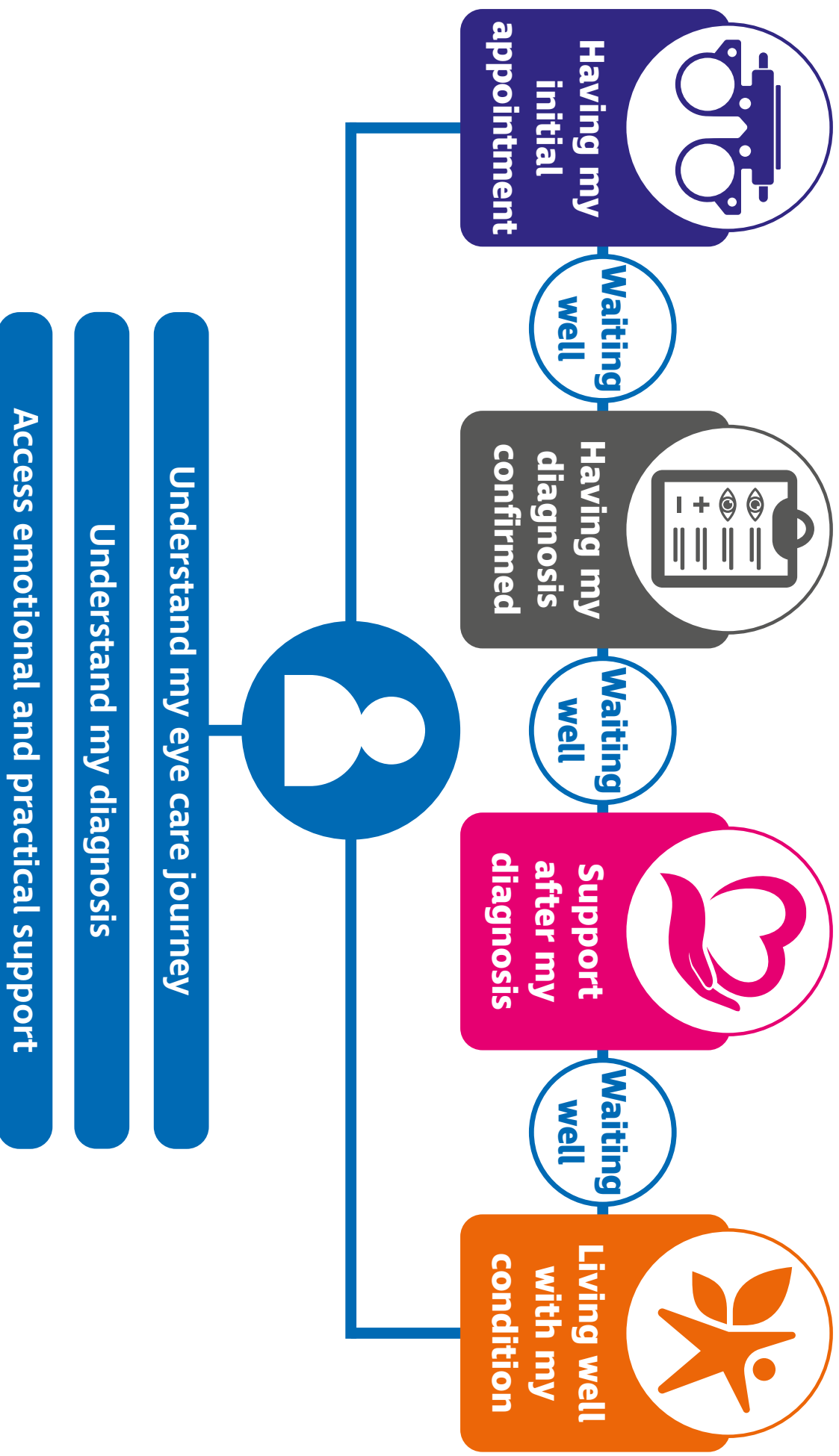
The Eye Care Support Pathway

Supporting you at every stage of your journey



Eye care support pathway

Supporting you at every stage of your journey



Introduction: How this guide can help you

Being diagnosed with an eye condition – and beyond - can be fraught with uncertainty. A lack of clear signposting and information can cause further anxieties and make it difficult to understand where you are in your journey and what to expect next. We've written this booklet to explain the Eye Care Support Pathway which breaks down the eye care journey into four clear steps.

Please use this booklet to ask questions, take notes and learn more about your journey and what might come next.

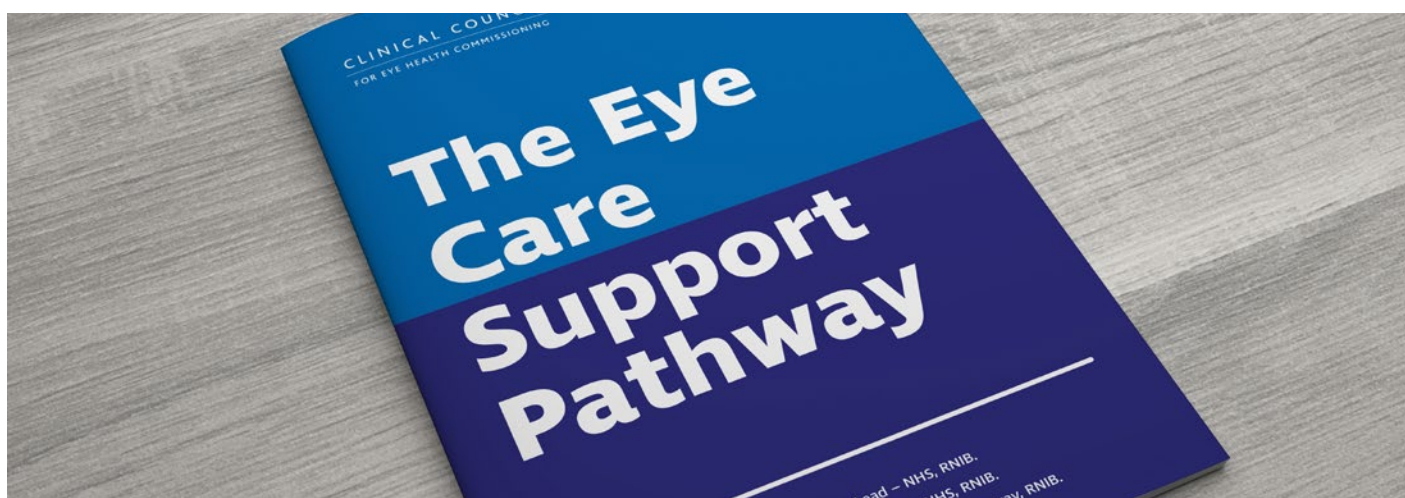
About The Eye Care Support Pathway

The Eye Care Support Pathway is a framework which shows the support needs at four key stages in an eye care journey.

- 1. Having my initial appointment**
- 2. Having my diagnosis confirmed**
- 3. Support after my diagnosis**
- 4. Living well with my condition**

At each stage, you should be able to:

- Understand your eye care journey – what is going to happen, who is treating you and when.
- Understand your diagnosis – know what condition you have, how to manage it and what it might mean for you.
- Access emotional and practical support – know how to get in touch with people and organisations, including RNIB, that can help you manage your condition.



We've published a full report about the development of the Eye Care Support Pathway – and plans for implementation.

**You can
find it here:**



rnib.org.uk/your-eyes/the-eye-care-support-pathway

This booklet has been developed for adults with eye care needs and family, friends and carers so they can help to give further support. It has been created with people who have eye care needs and sight loss to give the most accurate and helpful support possible.

Of course, every person's information and support needs may be different at each stage of the Pathway. This document has been designed to give access to

the right information at the right time for you. Many people with eye care needs may only need minimal support. For this group of people, the "Looking after your eyes" segment and stages one and two of the Pathway are most relevant.

Why support matters?

"Information should be provided at every service touchpoint. From the high street optician, to engaging with Local Authorities, accessible information should be given guiding people through available support - even it's just one phone number, that's gold for someone with no information or support."

(People's experiences of accessing eye care services, RNIB 2023).

Looking after your eyes

It is important for everyone to look after their eyes and know what to do if a problem occurs.

You should know:

- It is important to go for regular eye tests
- Eye tests also check your eye health and are not just about needing glasses
- Regular screening appointments are vital, especially if you have any other health conditions which can affect sight such as diabetes
- You may be entitled to more support if there are hereditary eye conditions within your family. For example, you can ask about whether you are entitled to more regular or free eye tests
- Where to go in the case of an emergency/acute eye problem
- Who to ask if you have any questions about your sight
- Who to get advice from if you have any other conditions which may affect your sight

If you notice sudden changes in your vision, seek medical help immediately. Problems

which need immediate medical attention include:

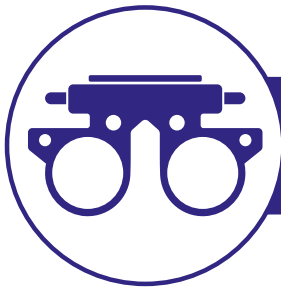
- A sudden change in your vision
- Loss of all or part of your vision in one eye or both eyes
- An accident involving your eyes
- You suddenly start seeing flashing lights or floaters
- You have double vision which starts suddenly and is constant
- You experience sudden or constant pain in your eyes
- You suddenly become very light sensitive

If you notice any sudden changes in your vision, you should seek medical advice on the same day. You can contact your GP or optometrist or call 111 for advice. Depending on your symptoms, you might need to go to the Accident and Emergency department at your local hospital.

nhsinform.scot/self-help-guides/self-help-guide-eye-problems

There is a Directory of Support on page 18 for organisations which can help and support you at each stage of the Pathway.





Having my initial appointment

Who you will meet during this stage:

Optometrists or ophthalmic opticians (often called opticians) are trained to examine your vision, prescribe glasses or contact lenses and detect eye conditions. If necessary, they can refer you to

other health professionals.

Dispensing opticians are trained to fit and supply glasses, and some have additional training to fit contact lenses.

At this stage you should know:

- Who you are seeing and why you are seeing them
- What tests you are likely to have and why you are having them
- Where to get more information in the format you need
- That you are able to ask questions
- What support you may need following your appointment and what the next steps are
- How to access support while you wait for the next stage
- How to get in touch to speak to someone if you need further support

- If you need to be referred for more tests or treatment - you have the right to choose the hospital or service you would like to go to
- When to go back to the optometrist if you have any changes in your sight which you're not sure about

"At the start I wanted specific information, not general information. I wanted to know what would happen next and what to expect with my condition."

(People's experiences of accessing eye care services, RNIB 2023)

Waiting well

If you have been referred for further tests while you are waiting for your appointment, you should know:

- What to expect next and when
- How to get updated waiting times
- Who to contact if you have any questions
- How to get information and advice about the eye condition you may have
- How to access emotional support
- How long you might be waiting and how urgently you should be seen
- Who to contact if your eye conditions/symptoms change or get worse while you are waiting

To help prepare for your appointment, you should know:

- You can prepare questions you may have in advance
- You can let the hospital know in advance of any support needs you may have

Notes:



Having my diagnosis confirmed

Who you will meet during stages two and three:

Ophthalmologists are specialist doctors who diagnose, treat and monitor eye conditions.

Orthoptists are qualified to identify and treat certain eye conditions such as squints or double vision.

Ophthalmic Nurses provide nursing care and treatments to people with eye conditions and sight loss.

Optometrists are also often part of the eye care team in hospitals.

Eye Care Liaison Officer (ECLO)

ECLOs are based in hospitals around the UK and can provide immediate support following a diagnosis.

They can talk to you more about what happens next. Check before your appointment to see if your hospital has an ECLO.

Visit [rnib.org.uk/sightline-directory](https://www.rnib.org.uk/sightline-directory) and search ECLO and your postcode or call RNIB on **0303 123 9999**.

At this stage you should know:

- You can take any questions you have prepared into your appointment
- If the eye specialist is not able to answer your questions you can ask if there is someone else to speak to such as a nurse or an Eye Care Liaison Officer (ECLO)
- What condition you have and how it might develop
- How to access information about your condition and how it will be managed over time
- What your treatment options are
- That there may be no treatment available for your condition, what that might mean and what are the next steps
- That you can ask about genetic testing and how to access it if needed

- About research or any clinical trials which may be relevant
- How to access practical and emotional support and counselling

"People need to be put in the know about local provision, not knowing what is out there is the hardest thing."

(People's experiences of accessing eye care services, RNIB 2023)

Why information and support matters:

Anya (name changed for privacy) visited her high street optician and was told a referral would be made to the eye hospital as 'something wasn't right.'

The optician was unable to offer any additional information or advice. From that initial appointment, Anya waited twelve weeks for tests and a diagnosis. In the absence of information about what might happen, she used Google and became afraid. (RNIB research)

Your rights –

You have a legal right to receive accessible information about your health and care. You can ask for information to be sent to you in your preferred choice such as larger print, audio or braille. You can record your requirements on your health record so you receive information in the right format for you.

"When I got to see an ECLO it was like a whole block of concrete came off me."

(People's experiences of accessing eye care services, RNIB 2023)

Did you know?

You should let the hospital know of any support needs you might have so that your appointment is appropriate for you.



Support after my diagnosis

At this stage you should know:

- How your condition might develop
- How to follow your treatment plan if you have one and get support if you need it
- How to find out about research into your condition and how you can get involved if you want to
- What local support is available
- About any organisations which support people with your condition
- How to connect with people with the same condition or in a similar situation to you
- What the impact might be on your life eg. driving, work, hobbies, and where to get more information
- About the Certificate of Vision Impairment (CVI) and what it means
- About low vision services and how to access them
- About the registration process and what is available to you

- About how to access counselling or emotional support
- About Charles Bonnet syndrome and how it might affect you
- That you can contact your optician or eye clinic if you have changes in your sight between your appointments

What is the Certificate of Vision Impairment (CVI)?

If your sight loss reaches certain levels, you can be certified as severely sight impaired or sight impaired by your eye specialist (ask for details in your eye clinic). You need sight loss in both eyes to be considered for certification. A Certification of Vision Impairment (CVI) form is completed by your eye specialist.

Your local council or social services then have a duty to contact you to ask if you want to be registered and added to their confidential register of blind and partially sighted people.

What is Charles Bonnet syndrome?

Charles Bonnet syndrome (CBS) is a sight loss condition that causes images to appear in your vision that are not there. These images can be everything from simple patterns such as shapes or grids, to more complex hallucinations of people, objects or landscapes. CBS is not linked to any mental health condition and can be a side effect of sight loss.

What is registration?

Registration simply means being on your local council's register of people who are either severely sight impaired (blind) or sight impaired (partially sighted). It is voluntary and completely confidential.

After you are registered, social services should contact you to discuss carrying out a needs assessment, also known as a Social Care and Rehabilitation Assessment. The aim of this assessment is to find out what help and advice you need to remain independent. For example, this could include help with everyday tasks such as cleaning and cooking, checking lighting in the home, keeping in touch with friends and family, or with transport and mobility needs.

What are low vision services?

Low vision services are provided to help you make the most of your vision, by investigating the difficulties you are having and recommending equipment or techniques that can help overcome these difficulties. This might be with magnifying glasses or devices, or by helping you learn ways of using your vision, called vision strategies.

"Every person with sight loss shouldn't have to be the biggest detective of their life finding information, there should be something where they can just go, a go to place and that's it."

(People's experiences of accessing eye care services, RNIB 2023)



Living well with my condition

Who you will meet during this stage:

Vision Rehabilitation Specialists are professionals who are qualified to support adults with sight loss to enable and empower them to lead

independent and fulfilling lives. **Low Vision Specialists** can help people make the best use of their remaining vision.

At this stage you should know:

- What to expect from registration and what support is available from your Local Authority (Council)
- What vision rehabilitation is and how it can help you
- There may be a wait for vision rehabilitation and what you can access while you wait
- About support available locally and nationally
- About benefits which may be available to you
- What to do if your needs change
- That you can access further support at any time
- That with the right support you can live confidently and independently with your condition
- That you can always get in touch with your low vision service and ECLO for ongoing support

What are your rights?

In England, local authorities have a legal obligation under the Care Act 2014 to help people with sight loss develop practical skills and strategies to maintain independence.

What is vision rehabilitation?

Vision rehabilitation is a period of training delivered by Vision Rehabilitation Specialists. It is designed to help people with sight loss maintain their independence through relearning practical and mobility skills.

Checklist

These ten areas are important to help you look after your eyes and feel supported through your eye care journey. If you can't tick one of the areas, reach out for more support and information.

I go for regular eye tests	
I understand who I am seeing at each appointment	
I understand why I need to have regular appointment	
I understand my eye condition	
I understand any treatment I have and how to manage it	
I understand what will happen next at each stage	
I know how to access information and advice	
I know how to access emotional support	
I know how to get support locally	
I know who to contact if I notice any changes in my vision	

If you receive the right support and information through your eye care journey - at stage one you should:

- Understand there is something to investigate
- Receive or know where to go for information and advice about different eye conditions and support
- Understand who you are seeing and why

While you are waiting you should:

- Understand you may have to wait
- Receive or know where to go for information and support while you wait
- Who to contact if you have any questions

At stage two you should:

- Understand your diagnosis
- Know where to access practical and emotional support
- Feel in control

At stage three you should:

- Be able to manage your sight condition, its treatment and care
- Understand the CVI and registration processes
- Know the benefits and concessions you are entitled to
- Know where to turn for further support

At stage four you should:

- Understand what support is available and how to access it
- Understand vision rehabilitation and how it can help
- Feel emotionally and practically supported
- Have the confidence to live safely and independently

Notes:



Directory of Support

Looking after my eyes

Who can help if:

You need advice about getting a sight test, to find out if you are entitled to a free eye test or if you need further information about what is available in your area –

nhs.uk/nhs-services/opticians/free-nhs-eye-tests-and-optical-vouchers

nhs.uk/nhs-services/opticians/visiting-an-optician

online.hscni.net/hsc-service-finder

nhsinform.scot/scotlands-service-directory/opticians

111.wales.nhs.uk/localservices/opticiansfaq

rnib.org.uk/your-eyes/how-to-keep-your-eyes-healthy/eye-examinations

nhs.uk/service-search/find-an-NHS-sight-test/location

locsu.co.uk/what-we-do/locsu-service-directory

seeability.org/resources

Stage one: Having my initial appointment

Some organisations offer general support to anyone with an eye condition or sight loss, and some are specific to certain conditions. This guide will help you find the right one for you.

Who can help if:

You have any questions about your sight or a suspected eye condition

rnib.org.uk/your-eyes

Ask your optician if they have patient leaflets or information available.

You need advice about any other conditions you have which may affect your sight -

Contact your GP or optician for advice.

diabetes.org.uk

stroke.org.uk

mssociety.org.uk

You need information about whether a condition is hereditary -

Contact your GP or optician for advice.

retinauk.org.uk

glaucoma.uk

gene.vision

You need support to manage concerns about what might happen next and if you have any questions about eye health -

Call the RNIB helpline on **0303 123 9999**

You want emotional and practical support -

Call the RNIB helpline on **0303 123 9999**

Waiting well

Who can help if:

You need more information about average waiting times (in England) –

myplannedcare.nhs.uk

You need information and support to help while you are waiting –

Call RNIB Waiting Well Team on **0303 123 9999**

You need help preparing for your appointment –

shop.rnib.org.uk/waiting-to-see-an-eye-specialist-booklet-94459

Stage two: Having my diagnosis confirmed

Who can help:

For any concerns about your eyes or for any eye condition:

RNIB: **0303 123 9999**

rnib.org.uk/your-eyes/eye-conditions-az

You need more information about your diagnosis and what it might mean –

sightadvicefaq.org.uk/your-eyes

You have questions about genetic testing –

Retina UK: **0300 111 4000 | helpline@RetinaUK.org.uk**

gene.vision

You have questions about clinical trials –

Be Part of Research ([nihr.ac.uk](https://www.nihr.ac.uk))

fightforsight.org.uk/our-research

moorfields.nhs.uk/research/research-opportunities-at-moorfields-roam

For condition specific support and information about inherited sight loss –

Retina UK: **0300 111 4000**

RetinaUK.org.uk

helpline@RetinaUK.org.uk

If you have Glaucoma -

Glaucoma UK: **01233 64 81 70**

If you have macular disease -

The Macular Society:

0300 3030 111

If you want local support – email

visionary@visionary.org.uk

or visit rnib.org.uk/sightline-directory

If you are from a Black, Asian and Minority Ethnic community and have sight loss – BAME Vision: bamevision.org

If you have learning disabilities or autism, and may also have sight loss – SeeAbility: **01372 755000**

If you want support around education or employment –

Thomas Pocklington Trust: **020 8995 0880**

If you are an ex-serviceman or woman with sight loss –

Blind Veterans UK: **0300 111 22 33**

If you want information about a guide dog and other services Guide Dogs can offer:

Guide Dogs: **0800 781 1444**
guidedogs.org.uk/getting-support/guide-dogs

guidedogs.org.uk/getting-support/help-for-adults

If you have sight loss and hearing loss: Sense: sense.org.uk

Stage three – Support after my diagnosis

Who can help if:

You need more information about driving –

gov.uk/driving-eyesight-rules

drivingmobility.org.uk

macularsociety.org/support/daily-life/practical-guides/out-about/driving

glaucoma.uk/care-support/driving-with-glaucoma

You have questions about the CVI or Registration process –

rnib.org.uk/your-eyes/navigating-sight-loss/registering-as-sight-impaired

You need support with your treatment –

Contact your eye specialist, ECLO or call the RNIB helpline on **0303 123 9999**

You want to connect with other people in your situation –

Contact your condition specific organisation if there is one.

rnib.org.uk/your-eyes/navigating-sight-loss/resources-for-mental-wellbeing/talk-and-support

You want information about work –

rnib.org.uk/living-with-sight-loss/equality-and-employment

You want more information about counselling –

rnib.org.uk/living-with-sight-loss/community-connection-and-wellbeing/sight-loss-counselling

You want information about low vision services –

rnib.org.uk/your-eyes/navigating-sight-loss/sight-loss-and-wellbeing/low-vision-and-low-vision-services

You have questions about Charles Bonnet Syndrome –

rnib.org.uk/your-eyes/eye-conditions-az/charles-bonnet-syndrome

charlesbonnetsyndrome.uk

Helpline - Esme's Umbrella at the RNIB

0303 123 9999

Stage four – Living well with my condition

Who can help if:

You want further information about vision rehabilitation –

rnib.org.uk/living-with-sight-loss/independent-living/social-care-and-rehabilitation

You want further information about low vision assessments:

rnib.org.uk/your-eyes/navigating-sight-loss/sight-loss-and-wellbeing/low-vision-and-low-vision-services

You want to know about support while you wait for vision rehabilitation –

rnib.org.uk/your-eyes/navigating-sight-loss/living-well-with-sight-loss-courses

Call the RNIB Helpline on **0303 123 9999**

You want further information about benefits –

rnib.org.uk/living-with-sight-loss/money-and-benefits/benefits-concessions-and-grants/benefits-rates-and-payments

You want information about available support in your area –

visionary@visionary.org.uk

You want information about what happens in your UK country **rnib.org.uk/information-everyday-living-your-rights/social-care**

You want to find out more about getting involved in regional groups led by blind and partially sighted volunteers.

sightlosscouncils.org.uk

You want information about how technology can help you –

guidedogs.org.uk/getting-support/information-and-advice/how-can-technology-help-me/tech-selector





The Eye Care Support Pathway was co-produced and endorsed by 23 key organisations from the eye care sector and we thank them for their ongoing support.

We would also like to thank all the people who contributed to the development of this booklet and shared their experiences of living with eye conditions and sight loss.

Contact us

For further information about the eye care support pathway please contact us:



EyeCareSupportPathway@rnib.org.uk

Call the RNIB Help line:



0303 123 9999

rnib.org.uk