

# Suffolk Sight News



**Spring  
Summer  
2025**



**Suffolk Sight**

**Suffolk Sight** is your local, community-based sight loss charity supporting children and adults of all ages.

We work hard to provide services that are friendly and practical, and to raise awareness of the different aspects of living with sight loss. These can include daily living aids, emotional support, benefits advice and the latest tech solutions. You're welcome to book a visit to one of our resource hubs or we can arrange to visit you at home. Find out about our social opportunities; connect to our befriending scheme, and be put in touch with other services based on your personal interests.

Our dedicated team are here to offer support, advice and guidance based on your individual sight loss needs. We work closely with you for as long as you need, offering ideas and solutions to help with confidence and independence.

**Suffolk Sight** is an independent charity and as such receives no funding from the government. We rely on our amazing supporters to continue our work through donations, legacies and non-statutory grants.

## **Supporting You – Services**

As a beneficiary of **Suffolk Sight** you will be able to access a wealth of support and information. It's free and you can choose your level of engagement and involvement.

Our dedicated and highly skilled team of community workers and technical advisers understand the issues that people face as they live their life with a visual impairment.

They have extensive experience and knowledge of the opportunities and choices available to you. The list below highlights some of the areas we can support you with:

- Daily living and independence – aids and adaptations
- Low vision – magnification and assistive reading (with referrals to our low vision specialist where appropriate)
- Financial matters – benefits, grants and concessions
- Safety and security – in and around the home
- Tech solutions – gadget advice and demonstrations
- Social opportunities and befriending service
- Advice about services that can help you get out and about safely
- Children and Families Support Group

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Images show the Haverhill club (left) and the Bury St Edmunds club (right) enjoying their Christmas lunch.

## Primary contact number

Please note that we will be adopting 01473 611011 as our primary contact number to make it easier to contact us in the future – that way you only have to remember the one number!

# **Spring and Summer – a busy time for the team.**

In this edition of Suffolk Sight News, we look back at all the activities that have taken place over the autumn/winter period and you'll see there are a number of images that show the clubs, run by our fantastic teams of volunteers, having organised Christmas lunches for our members. As Maureen Clarke from the Shotley club says – "nothing is taken for granted and everyone appreciates just how much hard work goes into organising such events by those who give up their time to do so".

It does seem strange, as I sit here writing this piece on a glorious April Spring day, to see images of Christmas crackers, hats and festive food. However, the important work undertaken by the clubs does not just involve organising Christmas lunches, as highlighted in an article on page 11, where Ted Gee praises the work of the Mildenhall club and says that "joining this group is the best thing I have ever done." I commend you to read this piece in full, along with that from Maria Quinn on page 12, which further extols the work undertaken by our Access Technology and Community Worker teams. Their stories epitomise the mission of Suffolk Sight and the team, staff, volunteers, and trustees alike should be proud of the changes we collectively make. If we can help you in any way, please get in touch.

So, looking to the months ahead, the team have an extensive outreach programme, where they will be raising the charity's profile in outlining the services we provide. Of particular note is the Suffolk Sight Equipment and Information Day on 11 June in Bury St Edmunds (see inside back cover).

On page 18, we announce a new activity – a monthly walking group, so if one is taking place in your area, feel free to join us.

And finally, if you have similar experiences to that of Ted and Maria, we would love to hear from you. It is so important to all of us at Suffolk Sight that we can take heart knowing that we are fulfilling our charitable objectives.

**Geoff Staff**

*Chair of Trustees*

# A small, but important selection of the ways Suffolk Sight is supported...

## Barrow Over 60s Club

On 30 January, Suffolk Sight Services Manager, Amanda Eaves, was presented with a cheque from the Barrow Over 60s Club for £450.

Suffolk Sight was chosen as the charity partner for the group for 2024, having been nominated by one of their members, Simone Ruddock, who is herself living with sight loss.

The money was raised through collections and activities such as bingo, and we would like to thank the committee and members of the Barrow Over 60s Club for their time and generosity in raising such an amazing amount of money.



Image shows Amanda Eaves being presented with the cheque by Simone Ruddock.

## Quiz Night

Quiz nights have become a regular feature in our Suffolk Sight fundraising calendar. The most recent one was held on 15 March and saw seven teams taking part. Lots of fun was had by all and the night raised £300, which will be used to help fund our Telephone Counselling Service.



The winning team were presented with a rosette and an Easter Egg!

We would like to thank our fabulous quizmaster, Tony Mallet. Also, big thanks to Mark Dye, for allowing us use of the Stowupland Sports and Social Club for free.

Image shows one of the teams taking part.

## Hargrave Cross-country Run and Walk

We were delighted, for a second year, to be chosen by St Edmund's Church, Hargrave, to receive half of the funds from their annual cross-country event.

The 10K or 5K run and 5K walk, took place on Saturday 22 March. Unlike last year, the sun shone for the whole afternoon, and everyone could take in the scenic views of the local countryside.

The 1st prizes for both races, male and female, were delicious hampers filled with items donated by Nethergate Wines and Powter Sausages, local Hargrave eggs and honey, and bacon from Denham Butchers.

The runners up also received some Powters Sausages and a selection of chocolate treats.

The event raised just over £1200, which will be split between Hargrave Church and Suffolk Sight.

It was wonderful to see the community come together. A huge thank you to all of the organisers for their hard work to make the event such a success.



Image shows those taking part at the start of the Hargrave Cross-country Run and Walk.

# Social Club round up

## Shotley Club

Our Shotley Club have enjoyed some lovely social events over the past year. They wanted to share some of the feedback that they had received from their members.

Maureen Clarke, one of their long-standing members, recently said:

"Thanks to the committee for everything they do to ensure the monthly socials are run so well, providing entertainment and a lovely tea afterwards. Thanks also to all the drivers who transport members.

Enjoyable lunches, at different local venues, are provided in July and December. Nothing is taken for granted and everyone appreciates just how much hard work goes into organising such events by those who give up their time to do so. It is good to be able to meet up with fellow members on a regular basis."

Jill Grant, another long-standing member, always sends a Thank You note.



Image shows members of the Shotley Club enjoying their Christmas lunch.

An extract from one of her cards reads "My thanks for another lovely Christmas lunch. Everyone works so hard behind the scenes to ensure the success of the events. The monthly meetings are often the only time some of us can meet up with others due to both sight and other disabilities. Again, my heartfelt thanks to everyone"

The Shotley Club would love to welcome new members, so please get in touch if you would like to find out more. They meet on the last Wednesday of the month, 2.00pm to 4.00pm (Jan and Nov 12.30pm to 3.00pm) at the Stutton Community Hall, Manningtree Road, Stutton, IP9 2TA.

Please contact the Suffolk Sight office and we will pass your details onto the club.

Call 01473 611011 or email [info@suffolksight.org.uk](mailto:info@suffolksight.org.uk).

## **Cohere Arts**

Building on the success of their 2024 VI Arts Taster Programme and drama group, Cohere Arts are proud to have been awarded funds from Suffolk County Council's Culture Project Fund to support their arts provision for the visually-impaired community in Suffolk.

The funding will support continuation of weekly VI drama workshops in Ipswich, as well as the delivery of a new outreach programme bringing arts activities to Suffolk Sight club members across the county.

As part of this work, Cohere Arts would like to hear from Suffolk Sight members about their creative interests and aspirations. Are you interested in taking part in arts, crafts, music or drama activities? Hearing from artists and musicians? Learning about local heritage? Or are there arts and cultural venues in Suffolk that could be made more accessible?

Cohere Arts' Director Amy Mallett would love to hear your views, and will be dropping into club meetings over the next few months. You can also email her at [coherearts@gmail.com](mailto:coherearts@gmail.com), or call 07748 070647.



## Halesworth and Southwold Club

Our special thanks to Terry Dentith who has kindly taken over as the Club Leader for our Halesworth and Southwold Club.

Terry is really enjoying his new role and looks forward to welcoming more people along to the monthly meetings.

Image shows Terry Dentith, the new leader of the Halesworth and Southwold Club.

The club meet on the second Thursday of the month, 2.00pm to 4.00pm at the Central Co-op Community Room, Saxons Way, Halesworth, IP19 8LU.

## Let's do lunch!

Our roving lunch group are now meeting up again in Bury St Edmunds. The group meet on the last Thursday of the month, between 11.30am and 1.30pm

Location: The Lounge & Garden, 2 Hatter St, Bury St Edmunds, IP33 1LZ. Please note that the lunch will be self-funded.

Please call 01473 611011 for more information.

## Mildenhall

A big thank you to volunteers Jim, Colin and Lewis, not forgetting Schubert the guide dog, for helping to raise money for the Mildenhall Club.

We're very grateful to Helen, the local Sainsbury's Community Champion, who offered us the opportunity for a cash collection for Suffolk Sight, on a busy weekend.

Image shows Jim, Agnieszka and Schubert at Sainsbury's Mildenhall.



## Special thanks to a special couple bringing joy to our clubs

Pauline and Brian Cann have been 'on tour' entertaining members of a number of our clubs around Suffolk. Before 'retiring' they were professional entertainers on the cruise ships, and their selection of Country 60's and 70's music is appreciated by all who have been lucky enough to hear them. You are guaranteed a really good singalong, and a bit of a bop, if that takes your fancy. They are pleased to be featured in Suffolk Sight News, and we quote: "Especially if it means we [Pauline and Brian] get the chance to share our music with more clubs." Please contact Suffolk Sight on 01473 611011 if you are interested in taking them up on this kind offer.



Images show Pauline and Brian entertaining members of clubs around Suffolk.



## Suffolk Sight Juniors

At the March session of the Suffolk Sight Juniors, we were visited by John Hollowell and his wife Beata, who talked to the children about their passion for lawn bowls and how it can be played by people with sight loss. John writes the following about his experiences:

"After finding out I was diabetic seven years ago, I lost my vision very quickly. Four years ago, I was registered Severely Sight Impaired. A year after my diagnosis, I took up VI lawn bowls and found I had a talent for it.

Within a year I had won my first England cap. After winning three national titles, me and my wife Beata, who is my bowls director, were selected to play in the international disabled bowls World Championships, which were held in South Africa.

We were lucky enough to win a gold and bronze medal, so now the next goal is to try for selection for the Commonwealth Games in Glasgow in 2026.

We have also been selected to play in the International blind bowls World Championships in New Zealand in 2027, so we have a busy time ahead!"

Suffolk Sight Juniors meet between 10.30am and 12.30pm on the first Saturday of the month at Red Gables, Ipswich Road, Stowmarket, IP14 1BE.

Image shows John and Beata wearing their World Championship medals.



## Winter Warmer Fundraiser

On 22 February, the Bury VIPs club teamed up with the Old Cannon Brewery in Bury St Edmunds to stage a fundraiser – The Winter Warmer – the first of what we hope will be a regular event. The Old Cannon Brewery offered the club four specially-selected beers at trade cost, with proceeds from the sale of these going to the club. Along with a raffle, a 'guess how many jelly babies in a jar' and a 'wine or water lucky dip', the event raised over £800 for the club, which will go towards a special trip to Felixstowe for fish and chips at The Hut. It was a fantastic opportunity to promote Suffolk Sight, particularly as there was a large crowd watching the Six Nations Rugby – England versus Scotland – at the same time.

Image shows volunteers Joshua Curatolo and Debbie toasting Suffolk Sight.



## East Anglian Beer & Cider Festival 2025

This year's festival runs from 20 to 25 August and again takes place in St Edmundsbury Cathedral.

Suffolk Sight are fortunate in being one of the chosen charities to benefit from the festival. The more hours volunteers put in, the larger the donation to Suffolk Sight. If you would like to volunteer, please contact Suffolk Sight on 01473 611011.

The image shows Meg Staff receiving a cheque from Martin Bate of CAMRA.

# Sharing your success stories

As a charity, nothing gives us more pleasure than to hear your feedback about our services and what a difference we have made to you or a family member.

In this edition of our newsletter, we have the kind permission of Ted and Sue Gee and also Maria Quinn to tell you about their journeys with sight loss, and how Suffolk Sight have supported them.

**Ted** tells us why he decided to get involved with our Mildenhall Social Club.

"I wanted to go along to the Mildenhall club after receiving an invite because it is local, and I knew it was something that would get me out of the house for a couple of hours per month and allow me to socialise.

I have taken part in a wide range of activities including singing, art, drama, yoga and boccia, and listened to a couple of talks by the police and a visually-impaired attendee.

By going along to the group, I was able to obtain some good peer-to-peer support. I talk to everyone, and the activities pushed me out of my comfort zone, and I found that I really enjoyed them.

Joining this group is the best thing I have ever done. I have loved it and feel that my mental health has improved no-end. I find I



Image shows Ted and Sue Gee at the Mildenhall Social Club.

look forward to attending the group now and I hope it continues because I really value the sessions and the people. I feel like I belong as there are people with all types of visual impairment and we all get on.

I feel the club has transformed my outlook on life. I was not one to join social groups, but I have changed and now look forward to attending”

## **Maria Quinn**

Unfortunately, Maria has had a very frustrating journey, nine years in fact, to try and get a diagnosis for her sight loss.

“It started off by realising that I was colour blind and every optician I went to said women don’t get colour blindness, you must have been born with it, but I knew that wasn’t the case.

I’ve had countless appointments, backwards and forwards from eye clinics, and then discharged as they said they couldn’t see anything wrong with my eyes. They then said that we needed to go down the mental health route.

With that, I went back to speak to my GP. He suggested a private consultant in Cambridge, and during that appointment, it took less than 2 minutes to reach a diagnosis.

I have a rare form of dementia called PCA. My brain doesn’t process what my eyes see and that leaves me not being able to read and do basic tasks.

I almost fell upon Suffolk Sight after my GP surgery in Barrow suggested your support and got the ball rolling. I was still trying to work at that stage as we have our own business, and I do the invoicing.

I am still able to carry on with a small part of that thanks to Mel, one of the Access Technology Advisors. He has helped me with Windows Magnifier, screen readers and different apps I can use on my phone.

I can’t explain what a difference it has made... everything that has been taken away from me has been given back to me but in a different way.

Sam, one of the Community Workers, has also been a great help by suggesting gadgets for around the home and discussing benefits, which I have since successfully applied for.

I have come to terms with my diagnosis and accepted it. I'm very grateful for all the support I have received from Suffolk Sight. I will continue to make the most of life with the help of friends and family and a supportive village community"

**If you would like to share your experience of living with sight loss, or perhaps how Suffolk Sight have supported you, please get in touch.**

Email [info@suffolksight.org.uk](mailto:info@suffolksight.org.uk) or call 01473 611011

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## **Suffolk Sight *Looking Ahead* Emotional Support**

The *Looking Ahead* service has been running for a few years now and, for this edition of the newsletter, we thought it might be nice to hear from one of the counsellors, without whom the service couldn't exist:

"My name is Ruth and as a counsellor, it is my privilege to work with the wonderful beneficiaries from Suffolk Sight and I just wanted to give you a little insight into how the service works.

The emotional support service is designed to support people with issues directly related to their sight loss and its impact on them. Common themes of sessions include anxiety, grief, and overcoming emotions associated with, and adapting to, sight loss.

So, what happens if someone is referred for telephone counselling?

Once we have the referral, the first thing that I will do is contact the beneficiary to make an appointment for an initial assessment. This gives them an opportunity to ask any questions they have about the service. I will take some more details about how they are feeling and together we can work out if this is the right service for them. Once they are accepted, either myself or my wonderful colleague Angie will contact them to make the initial counselling appointment.

This model of counselling is short-term. This means that someone can have up to eight weekly sessions of counselling. We have

found that this is long enough to help support with a listening ear, provide techniques to help reduce anxiety and stress, and to help improve mood.

I have had the privilege of speaking to over 100 of you since the service started during the Covid-19 pandemic in 2020 and I am looking forward to being able to support many more of you in the future."

We are so grateful to our two counsellors, who have worked with us to build a great service. They have over 16 years' experience between them and are now valued members of the Suffolk Sight team! Of course, as well as the counselling, our emotional support service includes other things such as befriending, social clubs and ongoing assistance from our community workers, where needed. Yet again 2024 was another successful year, with very positive outcomes. We would like to thank everyone who has donated or funded the service, as without this generous help we could not continue.

## **Enter One Lottery and help Suffolk Sight**

Being part of One Lottery means that with your support Suffolk Sight can help to generate regular sustainable funding.

This will enable us to continue to help adults and children with a visual impairment to live full and independent lives – but we couldn't do it without you.

Buying a ticket through One Lottery means that we can continue to grow and provide our services.

So, whether you buy 1 ticket or 10 tickets, thank you.

To buy your tickets go to:

<https://www.onelottery.co.uk/support/suffolk-sight>

**Good luck!**



**Suffolk Sight**

## Raising the profile of Suffolk Sight

In the last edition of Suffolk Sight News, we announced the creation of the role of ambassador for Suffolk Sight and that Trisha Wynn and Colin Presland were the first two to undertake this exciting role. We can now share with you that we have a further two people who are going to join them in this important work.

**Oliver Wray**, is our first Suffolk Sight Junior Ambassador. We asked Oliver why he wanted to become a Junior Ambassador:

"I was born with a condition called x-linked congenital stationary night blindness (CSNB). I am short-sighted and registered as partially sighted.



Oliver Wray.

I am so honoured to be the first Junior Ambassador for Suffolk sight. I want to promote our lovely group called Suffolk Sight Juniors that is hosted every first Saturday of the month in Stowmarket.

I want to make young people aware of how to overcome sight issues and become confident to get help if you're struggling.



Meg Staff.

I want to make my Mum and Dad proud of what I have accomplished"

We are very excited to welcome you to our team, Oliver!

**Meg Staff**, who currently co-leads the Bury VIPs Club, and was instrumental in getting the Bury Winter Beer Warmer up and running, is looking forward to going out into the community to increase awareness of the good work that Suffolk Sight does and already has a number of presentation sessions set up with local organisations.

## **Information is power – community is empowerment.**

Navigating the world with a visual impairment can be challenging, but there are fantastic resources out there, like radio programmes, engaging podcasts and supportive Facebook communities, that can keep you informed and connected. Here we dive into some gems that can help get you started.

### **RNIB Connect Radio**

A radio station broadcasting 24 hours a day, providing insights into living with sight loss. Programmes, interviews and features cover a broad spectrum of topics, including the latest campaigns, eye conditions, accessible technology, talking books, mental health and blind sports.

Listen on the RNIB Connect Radio website, via smart phone radio apps, on your TV (Freeview channel 730), or by asking your smart speaker to play RNIB Connect Radio.

### **RNIB Tech Talk**

Many of the programmes broadcast on Connect Radio are available to listen to in podcast form, including Tech Talk – a show that discusses all types of accessible technology for blind and partially-sighted people. Find out about new products, from specialist items to off-the-shelf solutions, and hear from the people who make them.

Listen to episodes via the podcast section of your device, or by asking your smart speaker to play RNIB Tech Talk podcast.

### **In Touch**

A long-standing programme broadcast on BBC Radio Four, Tuesday evenings at 8.40pm, airing news, views and information for people who are blind or partially sighted. Also available to listen to as a podcast on BBC Sounds or just ask your smart speaker to play In Touch podcast.

### **My Macular and Me**

Delve into the world of macular disease with the Macular Society podcast. Hear from eye-care professionals as they provide expert insight on the latest developments in research and evolving

treatments, as well as sharing first-hand stories and exploring the support available for those living with sight loss. Listen via the podcast player of your choice or from your smart speaker.

### **Henshaws YouTube Channel**

Charity Henshaws support people living with sight loss and a range of disabilities to achieve their ambitions and to go beyond expectations. They have produced a series of useful videos sharing tips, tricks and tech for living with sight loss and disability.

### **The Blind Life YouTube Channel**

Another useful YouTube channel focussing on assistive, accessible tips and independent living by a visually-impaired content creator, Sam Seavey.

### **Facebook**

As well as keeping up to date with Suffolk Sight news on our own Facebook page, there are other very useful pages and groups that provide information, advice, and discussion. The most popular amongst our team include RNIB Connect East of England, the Suffolk Guide Dog and VI Forum, and the range of VI Talk groups, which cover interests such as, gardening, cooking and travel.

### **My Life - How I See It**

The world is not always built for kids like 13-year-old Eleanor, who has a visual impairment, but she wants to change that. Follow her trailblazing challenge to audio describe a live show at the National Theatre, usually done by sighted people.

While juggling her own journey to gain independence, Eleanor must prove to herself and her parents that she is ready to take her next big steps.

Available to watch with audio description on BBC iPlayer.

You can follow Eleanor on Facebook  
<https://www.facebook.com/eleanorsvoice>

Image taken from Eleanor's Facebook page.



## New Monthly Walking Group

We're delighted to announce a new walking group for our members.

The group will meet on the first Wednesday of every month from April to September. The walks will be free to join and will be approximately 3 to 4 miles in length. Locations will vary every month. All dogs are welcome

Walks will be led by Steve Giddings, who is a Suffolk Sight trustee and an experienced walker himself.

For more information about locations of future walks, please call 01473 611011 or email [info@suffolksight.org.uk](mailto:info@suffolksight.org.uk).



Image shows the group meeting in Debenham. They are getting ready to set off for their first walk on a glorious April morning.

## Game Day Vision

Game Day Vision are empowering visually-impaired individuals to access live sporting and cultural events with confidence

Andrew Birch, Managing Director of Game Day Vision CIC, explained: "My mission is to enhance the mental health and overall well-being of visually-impaired individuals by facilitating their attendance at live sporting and cultural events.

We are very excited to announce that our sighted-guide service is ready to use across Suffolk.

Our fully-trained sighted guides are now available to accompany anybody who feels like they need sighted reassurance when attending a live sporting event, or perhaps a trip to a local theatre or concert.

Our service is completely free and is created and managed by people from the blind or low-vision community, so we understand what it is like to sometimes not be able to live your life as you perhaps once did before.

Please get in touch if you have any questions. We are available and would love to hear from you."

To find out more, please contact Andrew Birch on 07538 031005

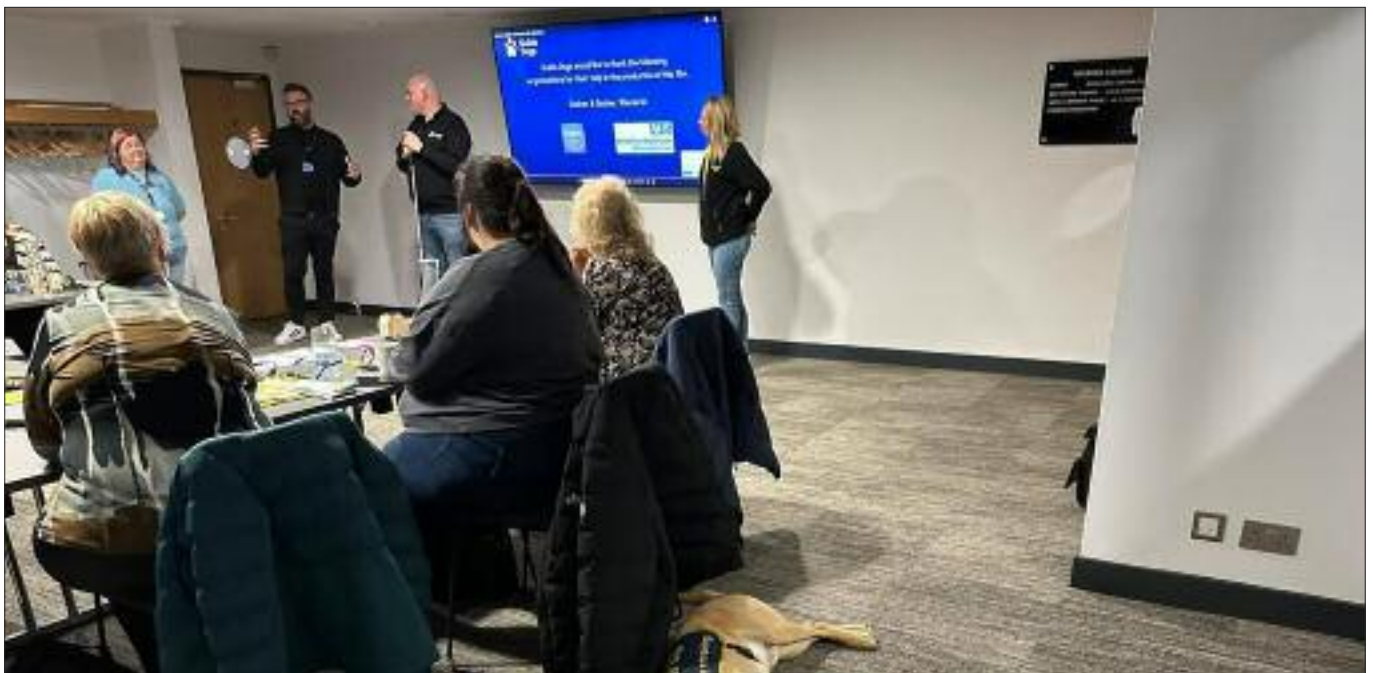


Image shows an event at Ipswich Town Football Club to train sighted volunteers. There were also guide dog puppies in training too.

# Outreach across the county

We're delighted to now offer monthly drop-in sessions with our Community Workers, at various locations across the county.

Our team will be available to give personalised advice and support including:

- Daily living and independence – aids and adaptations
- Low vision – magnification and assistive reading (with referrals to our low-vision specialist where appropriate)
- Financial matters – benefits, grants and concessions
- Tech solutions – gadget advice and demonstrations
- Social opportunities and befriending service
- Advice about services that can help you get out and about safely

## Haverhill

Venue: The Link, 45A High St, Haverhill, CB9 8AE

The drop-in sessions will take place on the third Wednesday of the month on the following dates:

21 May • 18 June • 16 July

Time: 1.00pm–3.00pm

At this location we will also be offering assistive technology support, with one of our volunteers, at the same time.

Whether it's staying in touch with loved ones, shopping online, or accessing services, we can offer help and support.

Bring along your device and find out about the latest apps to make life easier for people living with visual impairment

Our drop-in sessions are for everyone, whatever your ability.



Image shows the poster for the Haverhill event.

## **Lowestoft**

Venue: Disability Advice North East Suffolk, 161 Rotterdam Road, Lowestoft, NR32 2EZ

Our team will be available on the second Tuesday of the month, on the following dates:

13 May • 10 June • 8 July • 12 August • 9 September  
14 October • 11 November

Time: 10.00am–1.00pm

## **Newmarket**

Venue: Brampton Manor Care Home (in the lounge area on the ground floor), Fordham Road, Newmarket, CB8 7AQ

Starting 14 May 2025 and then on the second Wednesday of each month, on the following dates:

11 June • 9 July • 13 August • 10 September • 8 October  
12 November

Time: 10.30am–12.00pm



Image shows Brampton Manor Care Home, the venue for the drop-in sessions for Newmarket.

# Eye conditions explained – this edition's is Retinitis Pigmentosa

Raj Hanspal, Consultant Ophthalmologist, Clinical Director of Newmedica Suffolk, and Suffolk Sight trustee, has kindly written this article explaining Retinitis Pigmentosa.



Retinitis Pigmentosa (RP) is a group of rare, genetic disorders that involve a breakdown and loss of cells in the retina, which is the light-sensitive tissue at the back of the eye.

## What is Retinitis Pigmentosa?

RP is a progressive disease that affects the retina's ability to respond to light, leading to a gradual decline in vision. It often starts with night blindness and loss of peripheral vision, eventually leading to central vision loss.

## Symptoms

- **Night blindness:** Difficulty seeing in low light or darkness.
- **Peripheral vision loss:** Gradual loss of side vision, creating a 'tunnel vision' effect.
- **Central vision loss:** In advanced stages, central vision may also be affected.
- **Difficulty adjusting to light changes:** Trouble adapting from bright to dim environments.

## Causes

RP is caused by genetic mutations that affect the retina's ability to function properly. These mutations can be inherited in a variety of different patterns.

## Diagnosis

- **Eye exams:** Comprehensive eye exams, including visual field tests and retinal imaging, are essential for diagnosing RP.
- **Genetic testing:** Identifying specific genetic mutations can help confirm the diagnosis and provide information about the inheritance pattern.

## Management and Treatment

There are currently no treatments that can slow or stop the progression of RP. However, there are several clinical trials of potential therapies underway. Several strategies can help manage the condition:

- **Regular eye exams:** Monitoring the condition and detecting changes early.
- **Low vision aids:** Devices such as magnifiers and special glasses can help maximize remaining vision.
- **Gene therapy:** Newer treatments aim to address the underlying genetic causes of RP. For a small minority of patients with a mutation in the RPE65 gene there is a gene therapy called Luxturna that is available on the NHS.

## Living with Retinitis Pigmentosa

Living with RP can be challenging, but there are resources and support available to help patients maintain their independence and quality of life:

- **Support groups:** Connecting with others who have RP can provide emotional support and practical advice.
- **Rehabilitation services:** Vision rehabilitation specialists can help patients adapt to vision loss and learn new skills.
- **Assistive technology:** Tools such as screen readers, voice-activated devices, and navigation aids can enhance daily living.

If you or someone you know is experiencing symptoms of Retinitis Pigmentosa, it is important to seek medical advice and explore available resources such as those offered by Suffolk Sight to manage the condition effectively.

## Diabetic Eye Screening

In our last newsletter, we included Diabetic Retinopathy as our focus on an eye condition.

Diabetic eye screening is an important part of diabetes care. The NHS offer screening as it helps to prevent sight loss.

Screening can detect retinopathy before you notice any changes to your vision.

Diabetic eye screening is not part of normal eye examinations with an optician. Screening does not look for other eye conditions. You should continue to visit an optician for regular eye examinations as well.

Suffolk and North East Essex Diabetic Eye Screening Programme (SNEE DESP) are the diabetic eye screening provider in your area.

Should you wish to book, amend, or cancel an appointment call 01473 954800.

You can also follow the team on Facebook at <https://www.facebook.com/SNEEDESPP> for a list of venues, and other useful information about the service.

We're delighted that the Engagement Team will be attending our Equipment and Information Day on 11 June.

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## Visit from Jack Abbott MP

After the general election in July 2024 we reached out to all of our MPs to raise awareness of who we are, what we do and the many issues facing our members.

We were delighted to receive an invitation to meet with Jack Abbott, MP for Ipswich, and he met with staff members, Wendy and Kate, and trustee, Carolyn, at our Tower Street offices.

Leah the guide dog did her best not to grab all the attention and we were able to discuss the ongoing issue of businesses still refusing access to guide dogs; the lack of buses; money issues, including the accessibility of contactless card payments; concerns over changes to Suffolk Libraries; potential changes to benefits and the long waiting times for Access To Work applications.



Image shows Jack and Carolyn Allum with Leah, Carolyn's guide dog.

We also talked about the lack of free earwax-removal services, which some of our members have raised with us. Finally, we asked for Jack's support in bringing audio-described performances to The Regent Theatre in Ipswich.

We're grateful to Jack for giving us his time and gamely trying on our Simi-specs, which attempt to simulate various eye conditions.

## **Why do gifts in wills matter to Suffolk Sight?**

In my role as chief executive of Suffolk Sight, I have a lot of contact with other organisations and it has been noticeable how, over the last couple of years, a number of charities had to cease operations because they ran out of funds. On paper, Suffolk Sight looks to be reasonably well off, but in reality, without any significant income we can only continue for a few years. We are all working hard to raise funds in different ways but the honest truth is that legacies are the lifeblood of our charity. A gift in your will is a very special way to be remembered and your kindness would allow us to continue making life better for people with sight loss.



Whatever the size of your gift, it could make a huge difference to us. It's not difficult to do – all your solicitor or advisor needs is our registered charity name and number – and then you can forget all about it and get on with life; statistics show that people who make a will live on average 8 years longer than those who don't!

We realise that not everyone is in a position to make a gift of this kind but, for those that can, we would like to thank you in advance – your memory will live on in the work that you enable us to do.

**Steph O'Donoghue** *Chief Executive, Suffolk Sight*

# Sharing our fond memories of Mary Quinton, Roy Everett and Duncan Hodge.

## Mary Quinton

It was with great sadness that we received the news in late January that Mary Quinton had passed away after a short illness. Many of you will remember Mary more recently as an active member of the Ipswich club, where her quizzes and jams were legendary. Before Suffolk Sight existed in its current form, however, Mary had been a valued volunteer for Ipswich Blind Society and ESAB, running the macular group and coffee mornings before Covid put a halt to all activities.

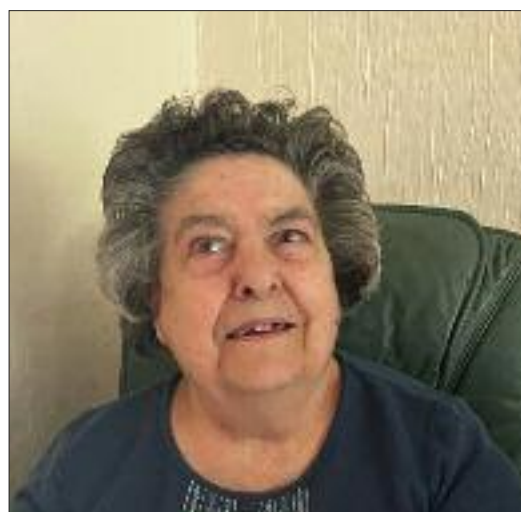


Image shows Mary Quinton.

Over the years, she had also been heavily involved with other organisations, including the MS club; joining after her beloved husband Sid was diagnosed with MS in the 90s, and for which she provided the catering.

I personally got to know Mary when working in the Tower Street office after ESAB took the reins. Here I discovered first-hand what an incredible cook she was (cheese scones and sausage pie, thank you very much!), and what made her company so very special. I learned all about her childhood on Dales Road during the war – the bomb and the brick dust, her roller-skating team of girls in the 50s, her work in the Royal George kitchen at Peachys and the Co-op, and her annual family knees-ups!

Despite having a large family (seven grandchildren and ten great-grandchildren) Mary still had enough room in her heart, and enough of a sense of humour, to allow me to adopt her. Ever since that time, she referred to herself as Grandma Mary.

Whether it was selling her jams for charity, or arranging a surprise homemade birthday cake to be delivered to a pitiful wretch going through the trauma of turning forty alone in the deepest depths of lockdown (that was me!), Mary's first thought was always for others.

A rallier and a natural carer, Mary's warmth and positivity left an indelible mark on everyone she met. She will be hugely missed by us all... and especially me. Sweet dreams, Grandma.

**Clare Burman**, *Access Technology Advisor*

## **Roy Everett**

Roy passed away peacefully on 1 October last year at the age of 94. He was a member of Ipswich Blind Society, and then Suffolk Sight for more than 20 years. He served on the Board of Ipswich Blind Society for five years and was chairman of the Men's Visually Impaired Club for eight years. He was a keen bowler and as his eyesight worsened, he joined the Constable Bowls Club, a club for the visually impaired.

In his working life he was a well-respected electrician and one of his achievements was the installation of the floodlights at Portman Road, the Ipswich Town football ground.

He will be sorely missed by Phyllis, his wife of 71 years, and their six children.

**Malcolm Ford**, *Ipswich Men's Visually Impaired Club.*

## **Duncan Hodge**

As we went to print with this newsletter, we were also very sorry to hear of the passing of Duncan Hodge, one of our beneficiaries and a former trustee.

Although he'd lived in Suffolk for many years, Duncan was a proud Scotsman from Bo'ness, who had many adventures travelling the world (and would often make us laugh with the stories he could tell!).

Despite losing his sight later in life, Duncan was always keen to be active and was on the board of trustees of WSVAB (later West Suffolk Sight) from 2012 to 2018, serving as Chair from 2015 to 2016, as well as using his cooking skills to fundraise for the charity.

Our thoughts are with his family at this sad time. Thanks, and safe hame, Duncan.

**Steph O'Donoghue**, *Suffolk Sight CEO*

## Welcoming Christine to our team of Community Workers

I've recently joined Suffolk Sight as a Community Worker and I'm excited to be part of the team. I've always been an advocate for Suffolk Sight through my role as the Co-ordinator for the Lowestoft Hand in Hand Club.

During the past twenty years I've had the pleasure of organising social activities for people with dual sensory loss.

Since 2019 I've volunteered with *Shout* which is a 24/7 text service for people in a crisis. I find it rewarding to listen, empower and support texters through a challenging time with their mental health.

I enjoy coastal walks, crafting, reading and spending time with my grandson, Patrick. My favourite film is *The Devil Wears Prada* and last year I went to London to see the musical version of the film.

Supporting people in the community is a real passion and I look forward to joining you all.



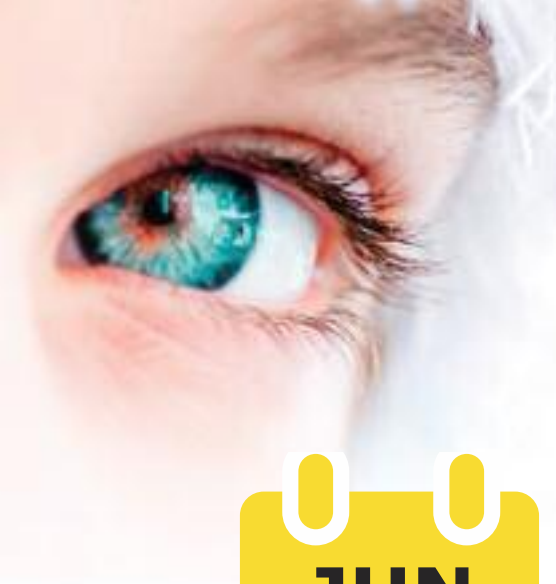
Image shows Christine Roe.

### Volunteering for Suffolk Sight

You can make a difference. We welcome the opportunity to involve volunteers in all aspects of our work.

We have lots of different roles, from social clubs to social media, fundraising, administration, transport and befriending. There are plenty of ways throughout the organisation that you can help.

Contact us and we can tell you about our opportunities and discuss how best we can support each other.



# Suffolk Sight Equipment and Information Day

**Wednesday 11 June 2025,  
10am–2pm**



**The Edmund Room  
(above Pilgrims' Kitchen)  
St Edmundsbury Cathedral  
Angel Hill, Bury St Edmunds,  
IP33 1LS**

Come along and try out the latest equipment and technology specifically designed for people with visual impairment.

We will be joined by some of the UK's leading suppliers:



**Advice and support will be available from local organisations including:**

**Newmedica, Sensing Change, SNEE Diabetic Eye Screening Programme and the Patient Experience and Engagement Team from West Suffolk Hospital**

**This is a FREE event and the venue is fully accessible.**



**Suffolk Sight**

**For more information please call 01473 611011  
or email [info@suffolksight.org.uk](mailto:info@suffolksight.org.uk)  
[www.suffolksight.org.uk](http://www.suffolksight.org.uk)**

**Suffolk Sight is a Charitable Incorporated Organisation Charity Number 1183608**

# **[www.suffolksight.org.uk](http://www.suffolksight.org.uk)**

**Suffolk Sight** is the sight loss charity for the county. Its purpose is to improve the lives of people who are affected by sight loss, throughout Suffolk.

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# **Suffolk Sight**