

# Wales Council of the Blind Roundup

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## No. 33

# Sight loss and other conditions



(Photo: Maggie Woodhouse with James, who has been wearing bifocals since he was two years old. Maggie's article is inside this issue.)

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**The next edition of Roundup** will focus on the socio-economic factors that are connected to sight loss.

# Editorial.

This edition of Roundup is the first to focus exclusively on articles on a particular theme with additional material from WCB's work and its member organisations. Regular readers might notice that there are none of the usual news items and opportunities. These are now dealt with in the monthly Sylw Bulletin, which is based on the fortnightly Sylw e-Bulletin. Subscribers to print and audio versions of Roundup will also be receiving the monthly Sylw Bulletin. We hope you find them both interesting and useful.

This Roundup edition is looking at ways in which sight conditions may arise from, or are complicated by, other conditions. We have a number of articles on this from various experts and some pointers to further information.

Our next edition will be looking at the socio-economic connections to sight loss. Please let me know of any useful sources of information on this by emailing [richard@wcb-ccd.org.uk](mailto:richard@wcb-ccd.org.uk)

## WCB News

### **West Wales branch of Your Voice: a Shared Vision**

At the meeting in December, there were talks from Bowel-Screening Wales, Transport for Wales, and Mid and West Wales Community Fire Service.

Fire Safety is a crucial topic for our sector, particularly where mobility and visual acuity have an impact on dealing with a fire, should it occur in the home. Your regional Fire Safety service will do a free check on your home and discuss your safety requirements and fire escape strategies with you. They also fit, free of charge, smoke alarms and give out extension cables with multiple sockets to replace any dangerous multi-way adaptors you might be using. Such adaptors should not be used as they overheat and can cause fires. Every month, the service in Mid and West Wales fits 300 alarm systems.

Dan Kempton told the group about the types of hazard to be aware of in the home. Overloading multiple sockets and adaptors is a risk – the limit is generally 13 Amps, so it is unwise to combine the likes of kettles, irons and toasters on the one extension cable. Ideally, they should all be served by individual wall sockets.

Candles are in increasingly popular form of decorative lighting, but they pose a significant risk of fire when used incorrectly. They are often left unattended at open windows where a blowing curtain can catch light; tea lights are placed around acrylic baths without the correct holders – he even cited a case where a tea light burnt through the top of a television causing a serious fire; Yankee Candles have been known to explode and send shattered glass in all directions.

He also suggested switching off appliances at the mains because they often draw power even when they are not in use. This makes economic sense as well as reducing fire risks.

Also, remove the cardboard wiring diagram often found on plugs around the pins – this is a fire hazard.

Charging your mobile phone under your pillow overnight is a risk.

Dan pointed out that you lose your sense of smell when you are asleep and children under about 9 years don't hear alarms in their sleep. However, for people with hearing difficulties the service will fit vibrating and strobing alarms.

The fire service will note people with impairments on the database that they use in the event of a call-out. So, if someone is confined to bed, the officers will know that they have to put on breathing equipment to aid them in performing a rescue.

So, any mobility problems, sensory impairments and such like will go into the occupant's record and be printed out in the event of a call-out. Obviously, you need to let them know if you require any additional support in this way.

Dan talked about how the team will run through your fire escape plan with you. If children are present they make it fun for them as well, getting them to draw diagrams of the house and so on.

Escape routes are not always ideal and can provide their own hazards. For instance, a first floor window opening onto a single floor kitchen roof is dangerous if the fire has taken place in the kitchen. These sorts of risks will be assessed by the visiting fire safety officer.

Speed is of the essence. If the house is full of smoke you have about six breaths you can take. So you need to get out fast, keeping as low as you can. Therefore, it is essential that you leave your keys in the door at front and back. In the door is preferable because other people who may be visiting will not know where to find the key if it is a secure place, especially if visibility is hampered by smoke.

If you are in a bedroom and smoke is coming in under the door, push some cloth along the base of the door to limit the smoke. Place your hand on the back of the door and if it is warm, don't open it. Open a window and shout for help!

Dan said that in the event of a call out, a fire rescue team would be with you within 6-8 minutes.

For more information contact your local Fire and Rescue Service:

**Mid and West Wales Fire and Rescue Service:** Carmarthenshire, Ceredigion, City and County of Swansea, Neath and Port Talbot, Pembrokeshire and Powys.

Fire Service Headquarters,  
Lime Grove Avenue,  
Carmarthen,  
SA31 1SP.

**0370 6060699**

<http://www.mawwfire.gov.uk>

**North Wales Fire and Rescue Service:**

Anglesey, Gwynedd, Conwy, Denbighshire, Flintshire and Wrexham.  
Fire and Rescue Service Headquarters,

Ffordd Salesbury,  
St Asaph Business Park,  
St Asaph,  
Denbighshire,  
LL17 0JJ.

**01745 535 250**

<http://www.nwales-fireservice.org.uk>

### **South Wales Fire and Rescue Service:**

Blaenau Gwent, Bridgend, Caerphilly, Cardiff, Monmouth, Merthyr,  
Newport, Rhondda Cynon Taff, Torfaen and the Vale of Glamorgan.

South Wales Fire & Rescue Service Headquarters,  
Forest View Business Park,  
Llantrisant,  
CF72 8LX.

**0800 169 1234**

<https://www.southwales-fire.gov.uk>

### **Bowel Screening Wales.**

Public Health Wales is responsible for the bowel cancer screening service. The risk of cancers of the colon and rectum, the low part of the digestive system, increase with age. A colonoscopy can identify polyps that require removal. Early identification means a better chance of successful treatment.

Bowel cancer is the fourth most common cancer. It occurs more in men and can be either lifestyle-related or genetic. In terms of lifestyle, it is connected with diet, drinking and smoking.

278,000 people were invited for screening - only half agreed to take part. People in richer, more affluent areas were more likely to take part – those in poorer areas, where the risks are highest, were less likely to.

From the exercise there were more than 200 referrals and more than 1000 polyps were surgically removed.

Participants in the scheme were given a self-administered kit to allow the laboratories to test for blood in the faeces. Three samples were taken over a ten-day period. Each kit was barcoded for identification purposes.

However, this kit was quite difficult to use, so a new one is being issued that only needs a single sample. It is much more sensitive and is able to distinguish between animal and human blood (animal blood may be present as a result of certain food being eaten).

The testing is automatically offered to people between 60 and 74 and they are hoping to reduce this to 50 by 2021. People over 75 can opt in to the service. The results are available within two weeks. If nothing is found you will be invited again in 2 years time.

For more information contact:  
0800 294 3370 (Monday - Friday 8am - 5pm)

Bowel Screening Wales, Unit 6 Greenmeadow, Llantrisant, CF72 8XT.  
Website: <http://www.bowelscreening.wales.nhs.uk/home>

## **Transport for Wales.**

Now that the rail contract has been awarded in Wales to replace the former Arriva Trains Wales franchise, representatives of Transport for Wales spoke to the group to outline some of the changes afoot, including how TPW intends to address certain accessibility concerns.

There are some 2,000 people working for TfW, running around 1,000 rails services each day.

However, the rolling stock is currently up to 30 years old, so new trains will be coming which will be fully compliant with disability legislation and guidelines. 400 new carriages have been ordered to refresh the service throughout Wales.

Also, £40 million is being spent on upgrading stations with a further £15 million on improving access. There shall be better parking facilities, WiFi, priority seating which is easier to find and with dedicated room for Assistance Dogs – the seats reserved for dogs would bear yellow reservation cards so that they are left free. More lifts

will be installed and platforms will be raised where necessary to enable level access onto the train from the platform. The orange wallet – sometimes used by people with sight loss to indicate to others that they may require certain adjustments in interaction and service – will be properly recognized by TFW staff.

One of the group raised the problem of travelling from Swansea to Aberystwyth. This is a long journey that requires travelling to Crewe, then taking a train across to Aberystwyth. Welsh Government is looking at the feasibility of reopening the Carmarthen to Aberystwyth line, making that particular journey considerably easier.

## **South East Wales branch of Your Voice: a Shared Vision**

### **Transport for Wales**

Representatives from Transport for Wales also attended the South East Wales event.

The group identified some concerns, which included TFW staff not fully understanding what concessions are available for disabled people and instances of Passenger Assistance failing to deliver.

Geraint Morgan from Transport for Wales informed the group that an Accessibility Panel has been set up to enable disabled passengers to report issues and consult on and contribute to future enhancements to the service.

Welsh National Opera and Transport for Wales were keen to work together to support people with sight loss to travel with confidence and agreed to organise and assist people on a trip to the Millennium Centre.

### **Welsh National Opera**

Members of the Welsh National Opera's 'Sightline' team spoke about their audio description service and Touch Tours. They are committed to ensuring people with sight loss experience the spectacle of opera by providing live audio descriptions and a pre-show touch tour.

Several props and costumes were available for members of the group to hold and feel, similar to what would be provided during a pre-show Touch Tour to enable people with sight loss to familiarise themselves with the set, props and costumes.

For further information about upcoming performances and booking information, visit: [wno.org.uk/take-part/access-performances](http://wno.org.uk/take-part/access-performances) or call: 02920 635000.

## **Vision Support – Putting VI People in the Lead**

Email: [information@visionsupport.org.uk](mailto:information@visionsupport.org.uk)

Telephone: 01244 381515

Vision Support is a Regional Charity established in 1876 and recognised as one of the leading providers of local support and services to people of all ages who are blind or living with vision impairment in North Wales, Cheshire and Halton.

Our charity is actively involved in several partnership activities and projects in Wales and England, including the opening of an innovative sensory centre in Halton, which provides professional rehabilitation services for people with sight and/or hearing loss.

During 2018 Vision Support developed a new Community Empowerment model to support national priorities which include promoting empowered and resilient communities. Being resilient generally means having the capacity to cope with adversity whilst empowerment focuses more on **how things can be done and who does them**, rather than what is to be done. Helping to build resilience in local communities or communities of interest involves empowering people and encouraging local leaders to come forward. An example of this is the Denbighshire Sight Loss Stakeholder event that was led by the Chair of Denbighshire VI Voices and the group's members.

We want to make sure the people who benefit from Vision Support's services and projects take the lead and get more involved in their design, development and delivery. Everyone is different, but we believe people with a vision impairment know best about the services they want and have the skills and experience to help deliver them. We also want to make sure we have a good knowledge of the work of

other organisations and we develop relationships with them to reduce duplication and make the best use of resources.

A psychology student from the University of Chester has worked with Vision Support to develop our community empowerment model further and below is a summary of what we have been doing and some initial findings and feedback. Over the next year we will be holding Sight Loss Stakeholder events in each of the counties where we provide services and once these are completed, Vision Support will produce a final report so we can share what we have learnt and what actions we have taken or plan to take.

**Please note, all are welcome at the Sight Loss Stakeholder events but places are limited. Please do let us know if you would like details of future events in your county, or you would like to make a provisional booking.**

Vision Support is also setting up a Steering Group with vision impaired representatives from each county served by our charity. The Steering Group will make recommendations to the Board of Trustees after reviewing information from our engagement and empowerment process. Please contact Vision Support if you are interested in becoming a member of the Steering Group.

### **Vision Support's Community Empowerment Update**

- Vision Support wants its services to be led by the people who are going to benefit from them – people with sight loss.
- We want people with sight loss to be more involved in the planning of the services they receive and in choosing future projects for us to try and find funding for.
- It is important we talk to people regularly to find out how well we are performing and where we can improve.
- We also believe in empowering and supporting individuals, so they use their skills and experiences to help other people with sight loss.
- We developed a community empowerment model to help make this happen.

- Since June 2018, Vision Support has facilitated 9 focus groups in Chester, Halton, Rhyl, Mold, Llandudno, Prestatyn and Wrexham with a total of 92 service users attending, as well as a number of volunteers.
- We also carried out a survey, which could be completed on-line, or in other formats and 42 surveys were completed from service users in Anglesey, Conwy, Denbighshire, Flintshire, Wrexham, Chester and Cheshire West.
- In November 2018 we held our first Sight Loss Stakeholder event in Denbighshire with over thirty people attending for round table discussions.
- The second Sight Loss Stakeholder event was held in Flintshire and was a joint event between Vision Support and Cambria College Business Students.
- We have conducted research into a range of issues impacting individuals with sight loss, such as unemployment, social isolation and digital communication.
- This research consistently supports the issues being raised by our service users.

## **Survey Findings**

- Most people who completed the survey were over 65
- There were more female respondents than male
- Nearly all respondents were registered sight impaired or severely sight impaired
- Social groups/activities were very popular with 85% attending
- Reasons for not attending were transport problems, busy doing other things, not well enough, lack of assistance and not having sufficient sight
- High rates of satisfaction were reported for social/activity groups, rehabilitation services and the mobile unit
- Home visiting and welfare rights services also had high rates of satisfaction, but these are only available in Cheshire
- People were less satisfied with digital training with issues relating to the length of waiting lists and wanting more sessions and on-going support rather than the quality of the training itself

- With the exception of social groups, almost half of respondents had not used services such as rehabilitation and the mobile unit

### **What should Vision Support consider developing?**

- The main suggestion made by service users was around social groups/activities – 20 individuals requested an additional group or sport or supporting general groups to be more inclusive
- Another request made by a number of respondents was communications between service users and Vision Support should be increased, with more regular contact and home visits.
- Service users would also like more digital training that ideally is ongoing, as technology and the internet are developing at a continuous rate.
- Other suggestions include emotional support, increased sight loss awareness and help with getting out and about. For example, 6 individuals requested help with getting to and from social groups and the shops.

### **Sources of information**

- The most common source of information was word of mouth, with 67% of service users identifying this as their main source of information, with talking newspapers and social services/rehab workers being relatively common as well.
- Only one service user identified search terms that they would use to find out about things when searching online, suggesting that the internet is not a frequently used information pathway for people with sight loss aged 75 years old and above.

### **Other comments/suggestions**

- A number of service users suggested we encourage people to pass on information as word of mouth was the most common source of information – either from friends or family, people managing the residence they live in, and social services/rehabilitation/ECLO workers.
- A few individuals revealed they would not know what to search for if they were using the internet, which may explain why very few people find out about Vision Support online.
- Transport and employment were both raised as issues through the surveys and focus groups, supporting the findings of previous research.

## **In Summary**

- The focus groups, survey and research all evidence there are still major issues relating to information and communication for people with sight loss.
- Lots of information is online but people, particularly older people, are not keeping pace with digital advances and specialist training sessions are insufficient for their needs - there are not enough of them and they are not long enough. Feedback strongly suggests people still want face-to-face services and there is an over reliance on digital communication.
- People enjoy social groups and want more activities, but transport continues to be a major issue and it is difficult to find volunteers to run the groups.
- Mainstream groups and activities are also not as accessible as they could be if some minor adjustments were made, although some activities such as VI football do need to be specialised.
- For people who find it too difficult to go out, the home visiting service in Cheshire is particularly valued as is the welfare rights and mobile unit service.
- For those of working age, employment and training opportunities are reported to be a major issue with employers reluctant to employ people with sight loss and training is not as accessible as it could be.
- There is a lack of emotional support and access to specialist counselling services.

## **Feedback from the Denbighshire Sight Loss Stakeholder Event Issues Raised and Comments:**

### **Accessibility (Locations and Transport)**

- The location of Prestatyn centre – lack of parking and rural routes
- Kinmel Bay – difficulty getting to the main stretch to use public transport.
- Transport service in Dyserth was cancelled as it was not being used but now people are struggling

- Transport is expensive
- Local transport is spread thin – bus routes have been cut.
- Transport and knowing where to access it.
- Train ticket machines are inaccessible – people threatened with fines.
- Obstacles in the street.
- Abergele Eye Hospital is hard to get to.
- Only 3 buses to get to Abergele Hospital from Rhyl - more direct routes needed.

## **Services**

- Social services – didn't hear from them until 6-8 weeks after initial contact and had to chase them up.
- Services need to be more personal/meaningful – not just ticking boxes.
- Town council does not give any donations towards community transport e.g. Dial-a-ride.
- Not knowing about services was identified as a primary concern.
- Alienating language used in correspondence/communication from organisations/council/etc.
- Rates of certification of vision impairment are dropping; consultants are reluctant to issue certificates – makes it difficult for people to access services if they do not have a certificate.

## **General**

- Barriers to volunteering – people don't want a lot of responsibility.
- Assumption that everyone is online/using the internet/technology.
- Ignorance/lack of understanding.
- Technology described as 'double-edged sword'.
- Signs in shops are too small, e.g. in supermarkets.
- Electric cars are too quiet.

## **What would be useful/suggestions/solutions?**

### **Information packs containing:**

- Contact details of organisations.
- A timeline of what to expect and when to hear back from people, and who can offer support in the meantime.
- List of community transport services by area/public transport contact details.
- Information on how to register immediately and avoid being passed from person to person.
- More explanation about what's being done initially.
- Information on what benefits you are entitled to.
- More information surrounding what 'partially sighted' means when first assessed.
- Could be provided by an optician/GP when initially approached to avoid people slipping through the gaps.
- More information needed around where and how to access services/who to contact.

### **Environment/Transport**

- Involving people with sight loss in the planning of e.g. new hospitals, signing, layout, at all stages to ensure accessibility. Town planning/council plans.
- Set prices for public/community transport.
- Ticket machines in train stations need to have audio.
- Training for the staff on train platforms that help people on and off trains.
- Training for bus companies.
- Accessibility information in health boards – should be better tailored to the individual.
- Necessity for easy-to-identify info/support services in shops/libraries etc. – front desk service rather than roaming staff.
- Health board highlighted ability to record specific communication needs as an issue.

## **Awareness**

- Making issues part of the cultural/societal conscious – community/group-led.
- Put information packs into libraries – can advertise groups.
- Importance of education/awareness.
- People going out and into schools to increase awareness – needs to be continuous throughout education so that people don't forget.
- Engage with different groups of people – outside people with sight loss.

## **Communication**

- EqIA (Equality Impact Assessment) – identifying who their stakeholders are.
- Communicate more with Vision Support over the phone/face-to-face.
- Build a degree of autonomy and independence when it comes to organisations communicating with service users.
- Partnership/communication highlighted as something that makes services more effective.
- Organisation needs to engage more – with each other and service users.
- Groups syncing in together with transport – e.g. booking dial-a-ride together.
- Vocal information should be provided at first point of contact in hospital/doctors surgery, NOT just signage – important.

## **General**

- Blue Badge applications are set to go online in the New Year.
- Benefit applications highlighted as an issue – online applications necessary.
- Blue Badge face-to-face appointments highlighted as a big success – one-to-one support
- Domiciliary information /signposting advisor – like talking points/Single Point of Access but one-to-one in the home.

- Resources for confidence-building identified as a community need – would ECLOs be able to help with this?
- Standardisation of register card – more recognition/durability (card that shows you are registered with VI).
- Register though SPOA – makes things easier having a single number to call.

## **Next Steps**

Vision Support will be organising Sight Loss Stakeholder Event Days in the counties where it provides services. Once these have been completed Vision Support will produce a feedback report that will identify actions both ourselves and our partners can take to make improvements. If you want to become more involved in making change happen, please contact us about joining Vision Support's Steering Group.

## **Storm WCB**

### **Sex and Sexual Health**

Our latest Storm Event was at the end of February with our Cardiff group and was held in the Public Health Wales building.

The event's theme was Sex and Sexual Health and we had a couple of things happening during the event. To start, Mared and I ran a quiz to see how much people really knew and then showed an informative video called 'Consent, it's as simple as tea', offering a cup of tea as a metaphor for asking someone for sex. For example, if someone said 'yes' to tea last Saturday, it doesn't mean they want tea all the time. Whether it's tea or sex, consent is everything.

This was followed by 3 people from Cardiff YMCA who talked through all the different safe sex and contraceptive options, allowing everyone a chance to see them all close up. They also gave everyone the challenge of putting a condom on a model properly. We also had two members of staff from the STI and Sexual Health clinic in Cardiff talking through the process when you visit the clinic. A really valuable discussion started around accessibility in the clinic. We spoke about things like making the signage more accessible, how could we tackle

the issue if people can't see the signs, and the possibility of making the forms large print or digital.

Lastly, we were joined by Arielle and her colleague from Promo Cymru who wanted to work with the group to collect feedback on the material that they use to promote their Meic service. Meic is the helpline service for children and young people up to the age of 25 in Wales.

# Sight Loss and other conditions

Sight loss can sometimes be part of a larger set of medical conditions. It may go unnoticed because the other condition takes precedent or it may be caused by another condition. First, here is a brief look at some of those relationships.

## Stroke

Ana Palazon, Director of the Stroke Association Cymru, said: “Up to two thirds of people experience some changes to their vision after stroke. Having trouble with your vision can be distressing and it can affect the rest of your recovery ... Problems with vision can sometimes be missed, so if you think you or someone you know has visual problems after a stroke, talk to your doctor.” (Stroke Association website, 2015).

A mini-stroke (transient ischaemic attack or TIA) can cause symptoms such as visual disturbance, although these symptoms usually disappear quickly. A TIA is a warning that you are at risk of a full stroke. Read ‘Steve’s Story’ below.

## Multiple Sclerosis

‘Many people with MS have a problem with their vision at one time or another. It’s often an early symptom, although problems can occur at any time.’

<https://www.mssociety.org.uk/about-ms/signs-and-symptoms/eyes-and-sight>

The two most common eye movement problems in MS are double vision (diplopia) and involuntary eye movements (nystagmus). John Sanders’ article below gives more on this.

## **Sepsis**

Some sepsis survivors experience a variety of physical, psychological and emotional problems while recovering, including changes in vision. This is known as Post Sepsis Syndrome (PSS) and usually lasts between 6 and 18 months, sometimes longer. (UK Sepsis Trust website)

## **Dementia**

<http://www.visionuk.org.uk>

<https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/sight-hearing-loss>

The Alzheimer's Society has a factsheet on 'Sight, perception and hallucinations in dementia'.

Vision 2020 has a factsheet on dementia and low vision and another that gives advice on cataract operations for people with dementia.

## **Cancer**

'Some cancer drugs can affect your eyes and your eyesight. Changes can include cataracts, eye infections and eyesight changes.' (Cancer Research UK website). Various types of cancer, including brain tumours, nasal, nasopharyngeal and sinus cancer can cause sight problems.

## **Diabetes**

Info from Diabetes UK and Wales Diabetic Retinopathy Screening Service.

## **Learning Disabilities**

People with learning disabilities are at increased risk of sight problems. Seeability has info and factsheets. More below.

## **Down's Syndrome**

Read Maggie Woodhouse's article below for a detailed overview.

# **Multiple Sclerosis (MS) and topsy-turvy vision impairment**

Most of us have heard of Multiple Sclerosis (MS). However, unless we have personal experience of this condition, we tend to think of it as mainly affecting the muscles, control of our limbs and mobility. What is less well known is that MS often affects vision too.

The National Multiple Sclerosis Society estimates that at least half of those with the condition experience disruption to their vision at some stage. The MS Society adds that vision disturbances can occur at any time and are sometimes an early sign that a person has MS before other symptoms become apparent.

The three common vision conditions linked to MS are optic neuritis, diplopia and acquired nystagmus. Optic neuritis is a temporary loss or disturbance of vision and can be painful. Diplopia means double vision where you see two of the same object or person, usually side by side or one above the other. If you have acquired nystagmus and MS your eyes move involuntarily and so does the world around you.

## **Serious impact**

How vision is impacted varies widely. Some with MS have no problems with their vision at all or are only slightly or occasionally affected. However, for others having optic neuritis, diplopia or acquired nystagmus seriously reduce their quality of life and mental wellbeing, even to the extent of making people feel suicidal.

These three conditions can limit your ability to do everyday things like work, drive, walk, read or even watch television. Their impact is, however, sometimes under-estimated. The author has heard from people with MS who have been told by professionals that they will “simply have to learn to live with nystagmus.”

Why vision impairment associated with MS is sometimes sidelined is hard to say. It may be because the vision aspects of MS are less obvious than some of the other symptoms. Or it may be because people with optic neuritis, diplopia and acquired nystagmus can still see and, to put it bluntly, probably don't fit the stereotype of being blind or vision impaired.

Nonetheless, all three conditions add to the strain and tiredness experienced by people with MS. Having a vision problem on top of other MS symptoms undoubtedly eats away at your already limited reserves of energy, stamina and confidence.

## **Few easy answers**

Optic neuritis is possibly the most common eye condition associated with MS and often responds well to treatment with steroids. However, there are no easy fixes to diplopia and acquired nystagmus. Glasses and contact lenses probably won't help because the damage is behind, not in, the eyes. Drugs such as baclofen and gabapentin also help some people with acquired nystagmus, but not everyone. And the side effects of these drugs are often not worth any small gains.

What people actually find helps them most is having a good understanding of the effects of diplopia and acquired nystagmus in particular. Part of that comes from talking to others with these conditions so that they feel less isolated and can share experience and advice.

## **Making changes**

Simple strategies make an important difference. Knowing for example that your vision may be more disrupted at certain times of day or when you're tired is both reassuring and means you can plan activities with a greater chance of success. Similarly, it helps to know if looking in certain directions aggravates your diplopia or acquired nystagmus.

Making changes at home helps too. Installing grab rails, reducing trip hazards, improving lighting and contrast are simple but effective modifications. Low Vision Aids (LVAs) make some tasks easier and are available free in Wales. Local charities specialising in vision impairment and high street optometrists can advise on adaptations and equipment.

People in Wales can also tap into extra support at the moment thanks to an MS Society project called "My MS, My Rights, My Choices". The project offers befriending and emotional support, courses on symptom management and mindfulness among other topics, as well as

individual advice and advocacy on employment, benefits, housing and social care.

Finally, one of the biggest frustrations for people with MS is that family and friends don't always realise how difficult and draining it is to live in a topsy-turvy world. Thankfully, technology in the shape of Simulation Specs and virtual reality goggles now allows anyone to briefly get some idea of these conditions. A few minutes of having your world turned upside down soon helps you understand how distressing it is for those who face such confusion on a daily basis.

Facebook page is at <https://www.facebook.com/msscymru/posts/my-ms-my-rights-my-choiceswe-are-delighted-to-announce-that-our-my-ms-my-rights-/1640531325981254/>

John Sanders  
February, 2019

# Steve's story.

*Rehabilitation Officer, Ian Moran, tells us about his work with Steve, whose vision was badly affected by stroke.*

I worked with Steve for just under 6 months and got to know him really well over that period. I would like to thank him for letting me share his story so openly. It explains some of the difficulties he has experienced over the past 6 years. Steve's story highlights how working in partnership can get the best outcomes for people. Each person we work with has their own individual needs and concerns. This is Steve's story.

## Background

Steve is an aquatic caretaker and fish keeper. He did it as a job and as a hobby for many years, even travelling to South America to rescue fish. He said that his wife used to go crazy at him because he had turned the living room, garage and spare room into an aquarium. His passion was the source of most arguments

6 years ago Steve had a TIA (small bleed on his brain) and lost all useful vision in his right eye. At the time he was working and was the main carer for his wife who was very ill from cancer.

Steve told me that it was a difficult time for him but said that he was able to manage with the loss of this vision. He said that his main priority was to stay strong for his family. He hid his health and vision problems from them to avoid them any further worry.

Steve said that shortly after his TIA his wife passed away. He had support from his family and from a McMillan family support worker. He said that he couldn't have got through this without them. He eventually told them about his health and what he had been hiding from them. He did have good vision in his left eye and said he could manage to continue to do everyday tasks.

Steve's son moved away and his daughter had finished her first year nursing in Newport. Steve said that this was a difficult time because he was not used to living alone. He said that he now started to spend more time meeting friends to play skittles.

2 years ago Steve had another TIA and lost a substantial amount of vision on the left hand side of his good eye.

## **The impact**

This had a massive impact on Steve's life.

Steve had to give up his job because it was felt that it would be too unsafe for him to continue to work.

He was scared to go out. He explained that because he was now living alone he had to go out shopping and attend hospital/GP appointments by himself. He said that this caused him a great deal of anxiety and he was at a very low point in his life. He had several falls and knocks when he did attempt to go out. He was bumping into people and becoming disorientated. He was spending all his savings on taxis and was starting to struggle financially.

The drop in vision meant that he could no longer read his bills and was struggling with all near tasks. He told me that he was struggling to look after himself but more importantly to him he was finding that he could not look after his fish.

He told me that he was burning himself and cooking was extremely difficult. He had become very isolated. He was unable to use his phone to contact his friends and family and had to rely on them calling him.

## **Steve slipped through the net**

Steve didn't really understand what had happened with his vision. He was being passed from hospital to hospital and from Ophthalmology to Neurology and was confused about what he was being told and about what had happened.

By chance he was out in Cardiff with his daughter after going to the Heath Hospital for an appointment. They walked past RNIB/CIB offices and saw somebody with a cane going in. His daughter persuaded Steve to go in and ask for help and where he could get a cane.

Cardiff Institute for the Blind contacted our first response team and referred him for a specialist assessment from a Rehabilitation Officer.

Steve was a high priority because he lived alone, was experiencing falls and burns and had become isolated.

He was allocated to me and I first visited early last summer. When I asked Steve what his main goals were, he said "he needed to get out and take back control of his life."

## **What we did**

We referred him to his high street optometrist to check eye health, assess functional vision and access the Low Vision Service.

Steve was issued with a hand magnifier, UV shields and monocular. The optometrist identified the extent of his visual field loss and shared his low vision record card with me.

We carried out low vision training using his magnifiers and explored different strategies to avoid his field neglect on the left hand side. We also looked at tracking and tracing exercises using his monocular. His UV shields made a huge difference and reduced the glare he was getting. They also helped with transitioning from light to dark areas.

This was an early success for Steve and he was now able to access text and could read his correspondence, cooking instructions on packages and organise his own medication.

We then started to look at more practical solutions for him in the kitchen. Steve had already been cooking but had burnt his arms on his oven. We looked at how to reduce these risks and I encouraged Steve to repeatedly practice while the oven was switched off. This eventually became muscle memory.

Steve has qualifications in computer science and had been an iPhone user for several years. We looked at changing the accessibility settings on his phone and how to switch 'voice over' on and off. Steve picked this up extremely quickly. He was now able to make calls, send and receive emails, text messages and access his social media. Steve downloaded traveline Cymru app and was again able to plan routes and track his bus. Later on in the intervention Steve would use the GPS to assist with orientation.

We started a mobility program. Steve was very nervous when going out and it was essential that he use a long cane to increase safety. The main issue he had was he felt that he needed to look down at the floor to see what was coming up. This had a negative impact on his posture and was the main reason for the falls and the knocks he was having.

We started off learning techniques that he would need to identify what was happening with the ground and practiced straight line travel. Encouragement was needed to keep his head up to make best use out of residual vision and improve his posture. Steve picked this up extremely quickly. The program progressed to controlled and uncontrolled road crossings.

Steve knows his local area very well so not too much work was needed in orientation. We started to look at the different routes Steve needed and built these into our sessions. Steve confidence started to increase and I started to pull back as he no longer needed instruction.

The routes started to become more complex and we looked at bus and rail travel. I again started to pull back and would meet Steve at the end of his journeys.

Steve was now able to travel independently using public transport to pick up his live bait for his fish. This saved him over £35 in a taxi fare.

After several months and numerous sessions Steve had met all the outcomes identified in his assessment. He told me he looked forward to our weekly sessions and didn't even mind the rain.

Before I ended my involvement, I referred Steve back to Cardiff Institute for the Blind. They had recently employed a community development officer. Steve said he wanted to start swimming again. Carys and Kristian from CIB undertook awareness training with the staff and she accompanied Steve to his first few sessions. She also encouraged Steve to attend some of their groups.

I visited CIB offices about 3 months after ending my involvement with Steve. They showed me some of the pictures they had taken over the past few months. It was with delight that I seen Steve playing walking

football in one, riding a bike in another and a group picture in the pub with Steve in centre sharing a laugh with other members.

As a rehabilitation officer, we visit people with varying degrees of vision impairments, The emotional impact that a loss of vision can have must not be underestimated and a certain level of resilience and acceptance is needed by people for positive outcomes to be achieved, We are invited into people's homes to address problems that are of a personal nature and in some cases this can be distressing for people to face. It is important that we recognise, not only what vision has been lost, but also recognise what impact this has had on a person's identify.

### **Steve's story so far...**

Steve is now meeting up with his friends again to play skittles. He uses his monocular and tells me his game hasn't dropped.

He is accessing the local leisure centre to go the gym and go swimming.

He attends an under 50's group in Pontypridd. (Steve is an honorary member because he is a bit older).

He's enjoying cycling.

He volunteers and fundraises for McMillan and completed the Llantrisant walk independently to raise money for them.

He goes to Newport on the train to visit his daughter and travels all over the Rhondda to meet friends.

He is now a proud grandfather and ...

He's continuing to look after his fish - he now has another hospital tank in his living room!!!

The rehabilitation process did not fix Steve. He still has the same challenges everyday that he did before I met him. He still gets anxious about going out at times and things do knock his confidence back. What work we did together was to give Steve the tools to take these challenges head on.

On behalf of Steve and myself we would like to thank Cardiff Institute for the Blind for referring into our service and supporting him to get back into the community, Davies and Jones opticians in Talbot Green for assessing Steve and providing us with the clinical and functional information we needed, and McMillan for helping Steve get through the loss of his wife.

Finally, I want to thank Steve for letting me share his story.

*Ian Moran, Rehabilitation Officer*

## **Down's syndrome and sight loss**

People with Down's syndrome are described as 'visual learners'; that is, they are more reliant on their vision to understand the world around them, than are typical people; and that is saying something when you consider that vision is supposed to contribute to 80% of ordinary people's learning. Children with Down's syndrome, once considered to be 'uneducable', are now achieving more and more, because teachers are aware that they learn in a different way to typical children; they need to be *shown* rather than *told*. What this means, of course, is that a visual impairment will have a greater negative impact on someone with Down's syndrome than on a typical person. However, it has long been recognised that people with learning disabilities, including Down's syndrome, are much more likely than the general population to have eye and sight problems.

### **Long and short-sight and astigmatism**

In developing countries, the most common cause of visual impairment is uncorrected refractive errors (that is, long, short-sight or astigmatism). It many come as a shock to readers (and it should, because it's scandalous) that for people with a learning disability in the developed world, the major cause of poor sight is the same, that is, needing spectacles and not having them. The UK and Down's syndrome are no exceptions. Recent studies in special schools throughout the UK have shown that about 50% of pupils need spectacles and only a quarter to a third of those that need them, have them.

The situation is improving. Most areas now have healthcare pathways so that all young children with Down's syndrome are referred to their local hospital for eyecare and are prescribed spectacles if needed. The problem comes later, when the children are older and are discharged from the hospital. Many parents are unable to find suitable eye care in the high street, or they take their child for an eye test once and the experience is so negative (some parents describe it as 'horrific') they are too embarrassed or distressed to try again. Their children then go without spectacles.

Help is at hand. More optometrists are developing the skills required to see children with special needs, as our professional associations are prioritising training in this area. Very recently, a Facebook Group called 'Optometrists working with people with Down's syndrome' has formed, so that we can connect and exchange ideas. As I write this, there are 138 members (not all are optometrists or opticians; we have some orthoptists, teachers and others on board). Very soon we will have a database of eye care professionals with expertise in Down's syndrome, available to parents, so watch this space!

## **Near focusing**

Those of us who are over 40 will know that we lose the ability to focus on near tasks as we age – we find ourselves holding the newspaper further and further away. This is a natural ageing process caused by the lens in our eye getting stiffer and unable to change focus. And, of course, this will happen to anyone with a learning disability as well. In the general population we come to rely on 'reading specs'. But we use near spectacles (or bifocals/varifocals) for lots of other things as well – sewing, drawing, looking at photos, using our phones; the list is endless. Almost all people with Down's syndrome will be doing many near tasks in middle age and will benefit from suitable spectacles.

Recent research has demonstrated that the problem of poor near focusing can happen even in children with Down's syndrome. In fact, it may be that as many as three quarters of children are unable to focus properly on near tasks, including their school work. In these children, the cause is not a stiffening lens; in fact we don't know what the underlying mechanism is. However, it's quite clear from a number of international publications, that if children with Down's syndrome wear spectacles for long or short sight only, most will remain visually

impaired for near tasks. Bifocals are the solution, and most children wear them perfectly happily and enjoy clear near as well as distance vision. Many hospital clinics now measure near focusing and prescribe bifocals, but by no means all. Some hospital clinics stick to their old ways and don't consider the children's needs at near, where, of course, they do all of their learning. It is vital that parents insist on the children's near focusing being measured and insist on bifocals if there is a problem, or demand referral to a clinic that does offer care for near vision.

## **Nystagmus**

Nystagmus is a continual 'wobble' of the eyes that is associated with visual impairment. It occurs along with most eye conditions that are present at or soon after birth, and it can also exist without an underlying condition – this latter form is called 'idiopathic', meaning no known cause. Nystagmus appears in about 15% of children with Down's syndrome; sometimes it spontaneously resolves in infancy. If it remains, it is, of course, associated with poor vision just as it is in typical children. However, in some cases (all too many, in my experience) parents are not given any information about nystagmus at their hospital visits, or even told that it affects the way their children see. In fact, some parents are told that wobbly eyes 'are nothing to worry about' in a child with Down's syndrome, and then, tragically, no compensation is made at school for poor sight. It is, therefore, essential that children with Down's syndrome and nystagmus are managed in exactly the same way as typical children with the condition; investigation for any underlying cause and referral to the educational support services.

## **Keratoconus**

This is a condition of teenage years and early adulthood, in which the cornea thins and grows abnormally into a conical shape causing distortions that cannot be corrected with spectacles. If it progresses, sight can be threatened by scarring of the fragile cornea. Keratoconus is common in Down's syndrome (1 in 10 as opposed to 1 in 1,000 in the general population) and used to inevitably lead to visual impairment. However, there is now a treatment, called collagen cross linkage, which comprises a one-off instillation of drops, followed by bathing the eye in UV light, which 'sets' the cornea and prevents

further growth. Some people with Down's syndrome can have the therapy under local anaesthetic; others who are unable to keep still enough during the procedure, will have a general anaesthetic.

The challenge in cross-linkage therapy is that it is only feasible in the early stages of keratoconus, while the cornea is still reasonably thick. The normal cornea in people with Down's syndrome is considerably thinner than in typical people, so identifying keratoconus early is much more urgent than in the general population. Because people with Down's syndrome are less likely to complain that their vision has worsened and thereby trigger an eye examination, it is imperative that families and carers arrange regular (at least annual) eye checks for teenagers and young adults with Down's syndrome, and that the optometrist is aware of the risk of keratoconus.

Cross-linkage therapy halts progression of keratoconus; it does not restore the cornea to a 'normal' shape. So following therapy, or in non-progressive cases, or cases in which therapy is not feasible, vision will be poor. In the general population, keratoconus is managed very well with contact lenses, and there are many examples of young people with Down's syndrome wearing lenses very successfully. Contact lens wear may require close supervision, but a young person should never be denied a trial of contact lenses on the grounds that they have Down's syndrome.

## **Cataracts**

Congenital cataracts are rare but are slightly more common in children with Down's syndrome than typical children. The treatment and prognosis, however, are exactly the same; removal of the cataracts if they are sight-threatening, at as early an age as possible.

Age-related cataracts are common in the general population and almost all readers will have an elderly relative or neighbour who has undergone cataract surgery. Research suggests that cataracts are just as common in people with Down's syndrome, but that they can occur at a much younger age. Regular eye examinations are therefore important throughout life. Cataract surgery may be a little more challenging for a person with Down's syndrome in that many will require a general anaesthetic and overnight hospital stay, plus close

supervision in the recovery period. Down's syndrome should never be a contra-indication for surgery.

## **Diabetic retinopathy**

Diabetes (both types 1 and 2) is more common in people with Down's syndrome than in the general population. Yet research suggests that diabetic retinopathy is *less* likely. Isn't it nice to report good news?

## **'Normal' vision**

Children with Down's syndrome who are fortunate enough to escape any of the conditions described above, or who are wearing the correct spectacles, still have vision that is poorer (both in detail and in contrast) than typical children. 'Normal' vision in Down's syndrome is not poor enough for the children to qualify as 'sight-impaired', but nevertheless, it is significantly reduced. This means that accessing the same materials in school or the workplace as typical people is a real challenge for people with Down's syndrome. Larger, bolder print and clear pictures are needed and it is essential that teachers and trainers are aware of the visual limitations. The Down's Syndrome Association includes advice on vision in Down's syndrome in all of its guidelines for parents and teachers.

## **Summary**

Although there are no eye conditions exclusive to people with Down's syndrome, children and adults with the syndrome are more likely to have eye problems than are members of the general population. No one is too disabled to have an eye examination, and there are many optometrists who have a real interest in helping people with special needs. Families and carers should ensure that people with Down's syndrome have an eye examination at least every year, so that they can have the best eyesight they can, and they can have early treatment, if they are unlucky enough to develop a sight-threatening condition.

*J Margaret Woodhouse, Senior Lecturer and Optometrist, School of Optometry and Vision Sciences, Cardiff University*

# Sight loss and learning disabilities

*We are very grateful to SeeAbility for allowing us to use the following information which has been taken from their website, <https://www.seeability.org>. SeeAbility is a charity that provides specialist support, accommodation and eye care help for people with learning disabilities, autism and sight loss.*

Eye care is extremely important for people with learning disabilities. Good eyesight enables us to learn, communicate and feel more confident, but the reality is that adults with learning disabilities are 10 times more likely to have serious sight problems. Children with learning disabilities are 28 times more likely so it's important for eye care to start at a young age.

A sight test is the only way of keeping track of eye health and vision. Due to the increased likelihood of eye problems everyone with a learning disability should have an eye test every two years, particularly as there may be no obvious signs of poor eye health. Some people may need one more often. What makes matters worse is that many people with learning disabilities are not getting the eye care they need. SeeAbility's research suggests that a shocking 50% of people with learning disabilities have not had a sight test in the last 2 years. The charity has put forward the following suggestions to overcome the barriers that these people face:

- Prioritise having an eye test
- Plan for a successful eye test, for example by visiting the opticians in advance, and explaining what is involved.
- Ask for extra support at the opticians, who should make reasonable adjustments for people with disabilities.
- Support the individual to wear glasses – they may need time to get used to them.
- Make sure that you ask your optician whether you are eligible for free eye tests or basic glasses.

For more details information, read SeeAbility's guide, 'How to be eye care aware', which is available by searching at [www.seeability.org](http://www.seeability.org)

The following resources from SeeAbility are also relevant:

The 'Eye Care' section on the SeeAbility website:  
<https://www.seeability.org/looking-after-your-eyes>

'People with learning disabilities and eye care' leaflet:  
<https://www.seeability.org/Handlers/Download.ashx?IDMF=ec927cb9-7ea3-4cbd-8d33-626c695afc2e>

## **Dementia and sight loss**

Both sight loss and dementia are more common as people get older, and a recent study suggested that nearly one-third of people with dementia also had significant sight loss. This sight loss may be caused by an eye condition, such as cataracts, another health condition, such as stroke, normal ageing of the eye or the dementia itself. People with dementia may have visual difficulties (specifically problems with perception) but still have healthy eyes. These problems are caused by the effect of dementia on the brain. Dementia conditions which may have an impact on vision are: Lewy body dementia, posterior cortical atrophy, Alzheimer's disease and vascular dementia.

Because of the difficulty in differentiating between problems caused by sight loss and dementia, the Vision UK Dementia and Sight Loss Committee recommend that patients diagnosed with dementia should have an eye examination with a registered optometrist on diagnosis and should then have their eyes examined at yearly intervals.

It is possible to have an eye examination if you have dementia. Your optometrist (optician) should be able to adjust the eye examination to meet your needs, accurately measure your vision and prescribe and update any specs you may need. RNIB's factsheet 'Dementia and Sight Loss' has a useful checklist to help identify whether a person with dementia has a sight problem, and also some handy tips for visiting the optometrist. You can find out more and read the factsheet on RNIB's website: <https://www.rnib.org.uk/professionals-social-care-professionals-complex-needs-social-care/dementia-and-sight-loss>.

The Alzheimer's Society website also has some useful information:

<https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/sight-hearing-loss>.

## **Diabetes and eye problems**

Diabetes is the leading cause of preventable sight loss in the UK. Some people with the condition develop a serious problem with their eyes, diabetic retinopathy, which can lead to sight loss. However, if detected early enough, eye problems can usually be treated to avoid long-term problems.

If blood sugar levels and blood pressure are consistently high, you can seriously damage your blood vessels, which can affect the retina. However, there are lots of things you can do to keep your blood sugars and blood pressure in your target range, which will reduce your risk of developing serious problems with your eyes. The Diabetes UK website has more information on how to do this.

Diabetic Eye Screening Wales (DESW) is a free service established for all eligible people registered with diabetes in Wales to reduce the risk of vision loss due to diabetic retinopathy. If you are diagnosed with diabetes, you will be referred by your GP and should receive an invitation to attend screening within 3 months of being placed on the DESW register.

Retinal screening is a straightforward procedure that should take approximately 40 minutes. Photographs of the retina are taken using a specialist camera and then forwarded to a team of retinal graders who look for signs of diabetic retinopathy. On completion, results are then sent to the patient and GP. It is important to note that this screening process is not a replacement for regular sight tests that you should continue to attend.

In addition to the risk of diabetic retinopathy, diabetes makes you one and a half times more likely to get glaucoma and three times more likely to get cataracts. Both can lead to blindness, but can be detected during your regular eye test, which should be free if you have been diagnosed with diabetes. DESW screening should pick up any signs of a cataract developing, but not glaucoma.

The Diabetes UK website has more information about sight problems as a complication of diabetes:

<https://www.diabetes.org.uk/guide-to-diabetes/complications/retinopathy>

For more about Diabetic Eye Screening Wales, visit the Eye Care Wales website:

<http://www.eyecare.wales.nhs.uk/diabetic-retinopathy-screening-service-w>

# Power for Life

Western Power Distribution (WPD) operates the electricity distribution network in the Midlands, South Wales and the South West. Put simply, our role is to ensure the power network of poles and pylons, cables, wires and substations – the infrastructure that we all rely upon to live our lives to the full – delivers electricity to our homes and businesses around the clock.

## Power cut? Call 105 or 0800 6783 105

Sometimes power cuts can happen for reasons beyond our control. During a power cut we are able to help.

We know it can be particularly worrying if you rely on electricity for medical equipment or if you are elderly, very ill or disabled. If you depend on electricity for a reason such as using a nebuliser, a kidney dialysis machine, an oxygen machine, a ventilator – or any other reason – you should register with us.

WPD provides a FREE Priority Service Register, which helps us to identify customers who may need a little extra help during a power cut.

If you join our FREE Priority Service Register we can:

- Give you a direct number to call in the event of a power cut so you can get straight through to us.
- Agree a password with you before we visit you, so you feel safe.
- Provide special help, if needed, through the RVS (Royal Voluntary Service) or British Red Cross.
- Ring and tell you about planned interruptions to your electricity supply.
- Keep you as informed as possible in the event of an unplanned power cut.

To join, call **0800 096 3080**, or visit our website **[www.westernpower.co.uk](http://www.westernpower.co.uk)**

# Smell gas?

Staying safe in six easy steps

If you smell gas in your home or business, we're here to help. Here's what to do.

- 1 Call us immediately on Freephone 0800 111 999. We're available 24 hours a day, 365 days a year and will send out an engineer to make your property safe.
- 2 Turn off all your gas appliances and, if possible, switch off the gas at the meter (unless the meter is in the cellar or basement, in which case don't go in).
- 3 Open windows and doors.
- 4 Don't use any electrical appliances or switch lights on or off.
- 5 Don't smoke or use naked flames.
- 6 If there's a smell of gas in the cellar or basement, please wait outside or with a neighbour.



**YOUR GAS EMERGENCY  
AND PIPELINE SERVICE**



**WALES & WEST  
UTILITIES**