





SOCIAL CONNECTIONS AND SIGHT LOSS

RESEARCH FINDINGS

Research by Royal Blind and Scottish War Blinded into links between vision impairment and loneliness Royal Blind is Scotland's largest vision impairment organisation. We provide educational, care and transcription services for blind and partially sighted people of all ages. Our vision is to see a community in which blind and partially sighted people, including those who have other disabilities, are fully included and lead fulfilling lives.

We operate only in Scotland and care for, educate and employ blind and partially sighted people from across the country, with occasional referrals from the wider UK.

Our sister charity is Scottish War Blinded, which provides free support for all veterans with sight loss, no matter if they lost their sight during or after service.

FOREWORD

The Scottish Parliament and Scottish Government have taken forward important work to focus minds on how we challenge loneliness in our society. This is a chance to improve the lives of hundreds of thousands of people in Scotland. It's also an opportunity to improve the lives of many people living with sight loss.

At the start of our work to research the links between loneliness and sight loss we believed we would find strong evidence showing that many vision impaired people have faced social isolation. Our findings have borne that out, suggesting that around two thirds of vision impaired people have experienced loneliness because of their sight loss.

Our research shows that vision impairment can lead to loneliness at every stage of life, from making it difficult to make friends at school, to sight loss leaving older people unable to get out and about. We have found this from speaking to the people who use our services: pupils at the Royal Blind School, parents of young adults we support in residential care, residents in our specialist care homes, and members of Scottish War Blinded.



Mark O'Donnell

We are pleased that this research shows our services are effective in helping vision impaired people overcome feelings of loneliness, but with the number of people with sight loss increasing there will be a greater requirement for support in the future. The impact of sight loss must be part of the national discussion we are having on tackling loneliness in our society.

There is much we can do to improve this situation, and that is why the Scottish Government's consultation on loneliness is welcome. We hope it leads to initiatives such as more community transport schemes for people with sight loss and action to ensure people with vision impairment can take part in local groups and activities.

Individual attitudes are important as well. Our research showed that many people with sight loss want more of us to make an effort to ensure we don't exclude them from conversations and activities, and this is something we can all do.

The Scottish Government's national strategy is a groundbreaking initiative to tackle loneliness and isolation in our country. We look forward to playing our part in making it a success.

The need to highlight the impact of loneliness on vision impaired people.

RESEARCH

"My child was four and a half when he lost his sight. It was very scary for him, he would not come out of his room unless I was with him."

Scotland has led the way in considering the impact of loneliness and social isolation on society. In 2015 the Scottish Parliament's Equal Opportunities Committee carried out a groundbreaking inquiry into age and social isolation. This inquiry highlighted research that loneliness can increase the risk of death by almost 10 per cent, is estimated to be as bad for people's health as smoking 15 cigarettes a day and has been linked to depression and mental health problems.

The Scottish Government responded to the report of the Equal Opportunities Committee by announcing it would conduct a consultation on developing a national strategy to tackle loneliness and isolation. At the same time, the cross-party UK Loneliness Commission, initially established by Jo Cox MP with Seema Kennedy MP, began its work involving a range of partners including charities working with disabled people. The Jo Cox Commission published its findings in 2017.

The Scottish Parliament inquiry had initially focussed on loneliness as it affects younger and older people. However as the conversation around loneliness developed, many other characteristics other than age began to be discussed. Royal Blind and Scottish War Blinded recognised the Scottish Government consultation was an opportunity to raise awareness of how sight loss can contribute to feelings of loneliness. We have seen how social isolation has affected many of the vision impaired people we support, and that one of the key benefits for people accessing our services has been the chance to build connections and friendships, including with other people living with sight loss. Royal Blind and Scottish War Blinded are also keenly aware that the rising number of vision impaired people in Scotland means more services will be required in the future to ensure people with sight loss do not face social isolation. Today there are around 188,000 people living in Scotland with significant sight loss, but this number is projected to double over the next two decades, to almost 400,000.

We wanted to deepen our understanding of these issues through learning more about the views and experiences of vision impaired people in relation to loneliness and social isolation. To take this work forward, we conducted a survey of almost 300 vision impaired people using our services, and Scottish War Blinded also held a focus group along with the Age Scotland Veterans Project.



"Losing one's sight is devastating. Being unable to jump into the car and visit family and friends at will leads to a feeling of isolation and loneliness."

The findings of this survey were published in our submission to the Scottish Government's consultation "A Connected Scotland: Tackling social isolation and loneliness and building stronger social connections." They have also informed this report and the recommendations we have made, which we see as key interventions to reduce the number of people in Scotland who are not only living with sight loss but too often are facing loneliness as well.

METHODOLOGY

The survey was conducted through questionnaires and interviews amongst both young and older people using Royal Blind and Scottish War Blinded's services. Where pupils and young adults were not able to respond themselves, parents were invited to respond to the questionnaire.

This was also the case for the carers of some older service users, but the great majority were completed by people with sight loss themselves. Although the statistics we have compiled are drawn solely from the survey, a joint focus group was also held by Scottish War Blinded and the Age Scotland Veterans Project, and the findings of the focus group will be discussed later in the report.

90% The vast majority of respondents had some experience of loneliness.

Nearly two thirds (60%) of respondents said their sight loss had directly contributed to feelings of loneliness. Only 9.6% had neither experienced loneliness nor accessed services to overcome feelings of loneliness.

Many of the drivers for loneliness amongst those surveyed are the same as those for other groups in society: problems accessing transport, bereavement and a lack of community facilities. However the survey indicates there are causes of loneliness which result specifically from vision impairment and participants in the survey have expressed a wish for more services to tackle these issues.



identified in the survey were:

01. Problems with mobility and accessing transport 02. Other problems including health issues 03. Vision impairment making it hard to make friends.

The four top interventions to help overcome feelings of loneliness were support from Royal Blind and Scottish War Blinded services, equipment to help with vision impairment, and contact with family and friends.

Among the interventions most supported by those who responded to the survey are better support to access transport, more specialist vision impairment support services, and more befriending services.

RESULTS

Ouestion 1:

Has your vision impairment ever contributed to feelings of loneliness?

60.1% (169) YES

39.9% (112) NO

Of those respondents who answered "no" to question 1, 85 respondents answered further questions to indicate they had received assistance to overcome feelings of loneliness. This indicates other aspects of their life had resulted in feelings of loneliness, and also that without access to these services and other forms of support they would experience loneliness.



vision impairment has contributed to feelings of loneliness: 169 (60.1%)

impairment has not contributed to feelings of loneliness and they have not accessed services to overcome feelings of loneliness: 27 (9.6%)

Respondents indicating vision impairment has not contributed to feelings of loneliness but they have accessed services to overcome feelings of loneliness: 85 (30.2%)

Question 2: If you have ever experienced loneliness, what has contributed to that?

01 Unable to get out and about/access to transport:

53.7% (151)



02 Other problems including health problems:



"Isolation is felt when you are alone and aware that younger, sighted people are leading active lives involving their families and acquaintances."

Over 90% of respondents said that either their vision impairment had contributed to feelings of loneliness or they had accessed services to overcome feelings of loneliness.

RESULTS (CONTINUED)

Ouestion 3: Which, if any, of the following has helped you overcome feelings of loneliness?

01 Support from Royal Blind/Scottish War Blinded services:



02 Equipment to help with vision impairment:



03 Talking with friends and family over the phone:



04 Local community groups and activities:



05 Support to use technology like smartphones and tablets:



06 Video or audio calling online friends and family ie Skype/ Facetime:



07 Spending time on social media – Twitter, Facebook, online forums:



"The new Scottish War Blinded centres are fantastic, we need more!"

"I get involved in groups and activities in the care home."

MEET MONTY

William Montgomerie, aged 61 of North Ayrshire, served 35 years in the forces, beginning his career aged just 15 at the Scottish Infantry Depot in the Bridge of Don before moving onto the 1st Battalion Argyll and Sutherland Highlanders.

His service took him to Germany and Cyprus, as well as tours of Northern Island. He finished his service in 1977 and joined the Territorial Army as part of the 23rd Special Air Service Regiment (Reserve).

But he was forced to retire early from service with the Territorial Army, and from his civilian job as a Firefighter at Prestwick International Airport, after suffering a blow to the head by an aircraft door which caused a brain injury, mental health problems, and subsequently a series of heart attacks.

"I was only 43 and I was forced to stop working and to retire from service," said William who is known as Monty to his friends. "It was a very dark time. I became very depressed, in part as a direct result of the head injury, and in part because I felt that I was no longer of any use to society. I had gone from working and having the camaraderie and companionship of the TA to being on my own. The injury also caused me to have flashbacks of the things I'd seen in service - it felt like my head was a malfunctioning junction box.

"I have glaucoma which is stable for now. Before I joined Scottish War Blinded, I had carers and help, but I live alone so I was completely alone for most of the time – my family and friends are mostly abroad. I was receiving help but that stopped due to cuts. I fell through the net and I was very depressed.

"The biggest danger of loneliness is how it makes you feel about yourself. The reality is that you might only speak to your Alexa

device for days at a time – wishing her a Merry Christmas and no-one else. It can make you feel suicidal.

You're thinking to yourself, 'what's the real reason I'm here? What is the point of my life'. I think it's something a lot of lonely people have to deal with at the moment."

William joined Scottish War Blinded in 2017 and began attending our new activity hub in Paisley, the Hawkhead Centre, after it opened in October. He said: "It has changed my life. Having people to socialise with and activities to do makes a real difference and you take that feeling home with you and it lasts you through the week. I miss the camaraderie and feeling of family of being in the forces and I have found that here. It was like coming home for me.

"I think looking after your mental health has a big effect on your body too. I still have symptoms of angina but my heart feels happier and I feel better in myself.

"It has been great being at the centre from the start because we've all gelled so well together, the staff and the members. And we've a lot to learn from the staff - but they listen to us too. We've got a lot of collective knowledge and the people here have experienced a lot in life so they take our advice."

MEET LEWIS

Royal Blind School pupil Lewis Shaw has spoken out about how his experience of being the only vision impaired pupil in a mainstream school caused him to feel lonely. Lewis was born without sight.

Through hard work and determination, he was able to achieve two As and a B in his exams at his mainstream school.

Lewis has spent an additional year studying at the Royal Blind School in Edinburgh to help him develop the vital life skills he will need to thrive during his three years at the University of Stirling.

Lewis remembers his early primary school fondly, saying that he made friends easily and doesn't remember struggling in class. He was able to learn arithmetic with ease and it was only when he began to study fractions and more complex mathematical and scientific concepts that he began to find that he was unable to access his classes.

He said: "In primary school I was accepted by my class and I made friends easily. Everyone wanted to be my friend because I was quite interesting to them because I was blind. Back then I remember enjoying going to school. I had lessons I preferred more than others –



I liked art and music more than maths or science, but at that stage I didn't really feel excluded.

"When I went to High School everything changed for me. My old friends from primary school deserted me and I suddenly found I was being excluded. It was horrible and I felt very lonely and excluded. I tried to join a music club at one stage but whenever I spoke up I felt I was being ignored. I could see that I wasn't going to be included properly so I left after one week.

"It got to the point where my old friends were making mean comments about how I wouldn't ever be able to get a job. I felt really angry and had an argument with them and I ended up having to move tutors."

Lewis is looking forward to attending university in September and hopes one day to have a career in politics.

He added: "I was expecting to go to the University of Stirling to study Politics in September but I felt that I just wasn't prepared because I didn't have the right life skills. I had visited the Royal Blind School in my 5th year to visit a pupil who was skilled in the BrailleNote. I felt at home here straight away and everyone was so friendly, I wanted to move here immediately. Everyone is very friendly and welcoming here. I could tell straight away that everyone is happy and I have found it very easy to make friends. It has made a big difference to me."

FOCUS GROUP

In March 2018, Scottish War Blinded held a joint focus group on loneliness and isolation with the Age Scotland Veterans Project at Scottish War Blinded's Hawkhead Centre in Paisley. The group was facilitated by Doug Anthoney, the Age Scotland Veterans Project Lead Officer. Loneliness and isolation among older people has been a key campaign for Age Scotland, who have highlighted research showing that 100,000 older people in Scotland feel lonely all or most of the time.

lssues arising in the focus group

Participants highlighted a range of issues and challenges which contributed to loneliness among people with sight loss, and spoke about their own experiences, both positive and negative.

Veterans talked about the challenges of transitioning from military duty into civilian life and felt more support was required at that time. They also expressed a desire to **retain a link with** the forces and regiments they had served in, and felt that the services could do more to stay in touch with veterans. While there was discussion about how loneliness affects veterans specifically, members of the group also talked about broader issues in loneliness and social isolation, particularly for people with sight loss. More support from **local authorities** to help people live independently was thought to be important. Better signposting to services like those provided by Scottish War Blinded was also an important issue for the group, and the difference that support makes along with access to equipment to help with vision impairment was emphasised. Two participants spoke about their experiences of the link between **loneliness** and mental health issues. It was also felt that we needed to have a **friendlier society**, and that people generally were not as willing to engage each other in conversation as they used to be.

"A lot of people don't interact now. You're losing conversation. On the train, people don't interact – they're on phones and tablets. I live alone so there's a lack of conversation at home."

"If someone gets taken to hospital and then it transpires they have vision impairment and they're ex-service that should trigger an automatic alert for Scottish War Blinded so they can be made aware of the Centres and so outreach workers and resource workers can give them support. We shouldn't be finding out about places like this by chance."

TIMES OF LONELINESS

Can you give an example of a time when you experienced loneliness?

> "I found it very difficult when my sight got worse and I was unable to do my job which I had done for over 30 years. There was no-one to turn to so I could talk over what was happening to me."

"Some children were nasty at my old school."

"At the bowling club I can attend but not take part, and have had to resign after 40 years. I go to the football but can't see the match, so can't discuss the game with friends afterwards."

> Bereavement was frequently cited as a time of loneliness.

> > "Still feeling effects of my wife's death. Feel lonely and isolated at times due to ill health, age and not being able to get out without assistance."

Participants in the survey were asked if they could give an example of a time when they had experienced loneliness. The isolating effects of sight loss were frequently referenced by respondents to the survey.

Mobility problems were also identified as leading to isolation:

and friends."

"It can be very hard for our child to travel on trains due to the noise and size of his chair."

> Respondents also talked about the emotional impact of loneliness:

"Loneliness moves along on invisible waves and can kill."

> "When there has been no contact with anyone for over two weeks but you can hear others laughing, having fun outside. Some people don't know how to talk to blind people - so ignore."

"I'm unable to have my independence to go on a bus for shopping or visiting family

THE SCOTTISH GOVERNMENT DO?

WHAT COULD

"Communications in large print about local activities."

"As a family we found that there were not enough places for visually impaired people to get together with others of their own age, we were only able to attend a few through Royal Blind."

Respondents highlighted the need for a multi-agency approach

' It would be good if the Scottish Government had an understanding of the impact vision impairment can have on mental health. It is also not unusual that young people may also have more than one disability so some form of cross over between charities or better multi-agency working would be really helpful." Participants in the survey were asked what they thought the Scottish Government could do to ensure those with vision impairment do not feel isolated or lonely. There was a large amount of support for more services like those provided by Royal Blind and Scottish War Blinded:

> "Setting up specific blind/deaf centres for focused help... rather than leaving it to social work services general group."

More specific support from local authorities for those with vision impairment was also proposed

"Funding for local authorities for more sensory impairment specialists."

"Address delays in registration, send out awareness help packs from the council's vision impairment team."

There was also a great deal of support for more **befriending services**

"Someone to visit and speak to me. Someone to give respite to my wife, even just for half an hour to go to the shops."

ROYAL BLIND AND SCOTTISH WAR BLINDED RECOMMENDATIONS

With the number of people with sight loss projected to double over the next two decades in Scotland, Royal Blind and Scottish War Blinded have called on the Scottish Government's new national strategy on loneliness to include specific actions to support people with vision impairment.

There are many interventions which could challenge loneliness among people with sight loss, but we are proposing three key recommendations:

More specialist support for vision impaired people to help tackle loneliness

The survey highlighted the importance for people with vision impairment of services and activities which are accessible and tailored to the needs of people living with sight loss. Respondents argued for **more services at a local level** which supported people with sight loss and brought them together, provided both by local authorities and the third sector. The need for **additional specialist provision in public services** was also often cited. Where pupils were not able to access adequate specialist support in schools this had been a factor in causing them to feel excluded within their school community.

More provision of vision impairment awareness training in communities and public services

Our research has emphasised **vision impairment awareness** is vital in a range of settings – for health and social care staff, to ensure they provide the right support for people with sight loss receiving treatment; for social care staff, so they can provide care which meets the needs of a vision impaired person and detect signs of sight loss; and in communities so that stigma which remains around vision impairment can be challenged. We believe there needs to be a **renewed focus on the provision of vision impairment awareness training,** and that this should continue to be an important strand of activity in of the Scottish Government's See Hear Strategy and also a key aspect of the new loneliness strategy.

New community transport initiatives to support people with sight loss

The difficulty of accessing public transport was raised by many respondents, both through reductions in local provision and vision impairment and other disabilities making it difficult for some to use public transport. Taxi card schemes can benefit many people with sight loss, but many have been scaled back and we believe that **community transport can play an increasing role in the future.** We urge national and local government to work with community transport providers to develop **new services for people with sight loss.** We believe these services should be part of the concessionary travel scheme to ensure people are not prevented from accessing them if they are on low incomes.

REFERENCES AND THANKS

The report of the Scottish Parliament Equal Opportunities Committee on Age and Social Isolation: www.parliament.scot/S4_EqualOpportunities Committee/Reports/FINAL_Report.pdf

The Scottish Government Consultation "A Connected Scotland": https://consult.gov.scot/equality-unit/connected-scotland/

Jo Cox Loneliness Commission: https://www.jocoxloneliness.org/

Statistics on Vision Impairment are from the Scottish Vision Strategy 2013-18: https://www.rnib.org.uk/sites/default/files/ Scot_Vision_Strategy_refresh.pdf

Royal Blind and Scottish War Blinded would like to express our sincere thanks to everyone who took the time to take part in our survey and share their views with us on this important issue for people living with sight loss.

You can read our submission to the Scottish Government's consultation "A Connected Scotland" at: http://bit.ly/royalblind-loneliness



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