

**You're like the  
last human  
being alive**

# Outside


**Insights into loneliness and isolation for  
blind and vision impaired people**



**Report by Fight for Sight / Vision Foundation based on research by  
Dr Mhairi Thurston and Craig Dunlop at Abertay University**

# Contents

<b>Foreword, Marsha de Cordova MP</b>	<b>01</b>
<b>Executive Summary, Eleanor Southwood, Director of Social Impact</b>	<b>03</b>
<b>Research methodology</b>	<b>05</b>
<b>Meet the researchers</b>	<b>05</b>
<b>What are loneliness and isolation?</b>	<b>06</b>
<b>Key findings</b>	<b>07</b>
<b>The case for support</b>	<b>08</b>
<b>Section 1: Experiences of loneliness and isolation</b>	<b>10</b>
<b>Section 2: Internal and external barriers impacting loneliness and isolation</b>	<b>17</b>
<b>Section 3: Exploring intersectionality and lived experience, including data collation</b>	<b>24</b>
<b>Get in Touch</b>	<b>XX</b>



Seventy six percent of survey respondents said they felt lonely some or all of the time.

# Foreword by Marsha de Cordova MP



This report spotlights how vision impaired people in the UK experience loneliness.

It reveals that they are more likely to experience loneliness and isolation and to feel it more severely than the general population.

Internalising what they perceive society's views are of people who are vision impaired creates a vicious circle where many withdraw: they self-isolate, increasing feelings of loneliness. External barriers cause others to stay home due to the fear of navigating the

world, especially in new environments.

Sadly, some report that life becomes joyless and that they no longer live, but exist.

Feelings of loneliness and isolation negatively impact people's mental health, with feelings of acute anxiety and depression being common.

The World Health Organisation (WHO) has classified loneliness and isolation as a global health concern, which can impact people's health as significantly as

smoking 15 cigarettes per day.

This report is a call to action for government, decision-makers and organisations.

Practical support exists but is patchy, and, in some areas, blind and partially sighted people have little or no easy access to support at all.

There's a pressing need to find new ways to make it easier for vision impaired people to engage in activities and experiences that



improve wellbeing,  
reduce isolation and  
bring joy.

I know all too well  
from my own lived  
experience, and from  
speaking to my  
constituents how  
crucial access to  
emotional support is  
and having people  
who understand.

We need to ensure  
people have the skills,  
confidence, access to  
resources, tools, and  
connections to join in  
with activities crucial  
for wellbeing, like  
physical exercise,  
cultural activities, and  
work opportunities.

Marsha is MP for Battersea, Balham and Wandsworth and Chair of the All Party Parliamentary Group on Eye Health and Visual Impairment.

She has a proud history of working in the voluntary sector for over 10 years before becoming an MP.

Marsha was born with Nystagmus and is registered blind. She has dedicated much of her life to campaigning for disability rights and is passionate about equality for all.

We are grateful to have her as a member of our Social Impact Grants Assessment Panel (SGAP).

# Executive summary



What is loneliness and isolation like for people who are vision impaired? It's a tricky question to

experience of vision impaired people, specifically. Like all groups who share a characteristic,

**“We fund discoveries that prevent and treat sight loss and inform and accelerate social change for anyone impacted by vision impairment.”**

answer for several reasons.

People who are lonely or isolated are, by definition, less engaged and less visible in our communities.

Similarly, data that captures experiences tends to do so for disabled people but doesn't explore the

blind and partially sighted people are not a homogenous group, and there is little work to date which explores how other aspects of identity and intersectionality interact with the experience of loneliness and isolation for vision impaired people.

## Eleanor Southwood Director of Social Impact

Eleanor joined Fight for Sight/Vision Foundation in 2023 where she leads the organisation's grant making and impact work.

She brings significant experience in public policy, social change and organisational transformation, with experience in the public, private and voluntary sectors.

She also brings an in-depth knowledge of the landscape for blind and vision impaired people, gained in over a decade working in the sector and informed by her own lived experience.



We must capture this information.

Loneliness and isolation are as severe a threat to public health as cigarette smoking, obesity and physical inactivity.

For Fight for Sight / Vision Foundation, knowing how experiences of loneliness and isolation impact people who are vision impaired is vital to our mission.

We exist to Save Sight. Change Lives.

We fund discoveries that prevent and treat sight loss and inform and accelerate social change for anyone impacted by vision impairment.

We invested in commissioning this groundbreaking evidence from Abertay University to accelerate that social change. The evidence we've gathered will inform the programmes we fund, the partnerships we build and the infrastructure we support.

We'll monitor the impact of the work we fund and build on this evidence base to influence change within the sight loss sector and beyond.

Our goal is that anyone affected by sight loss has access to ways to increase the joy and connection that make loneliness and isolation less likely. I am grateful to Dr

Mhairi Thurston and Craig Dunlop for their diligence in collating information in a literature review, for the sensitive way they approached designing the online questionnaire, and for conducting a series of interviews with people who are blind and vision impaired.

This report explores trends in the lived experience of loneliness and isolation for people who are blind and vision impaired. With moving first-hand accounts from interviewees at its heart, this report creates a compelling case for change, and we hope it will inform and inspire action from our partners, the wider sector and beyond.

# Methodology



We commissioned the research from Dr Mhairi Thurston and Craig Dunlop at Abertay University. It comprised:

- A literature review of existing research and information
- In-depth interviews with 18 blind or vision impaired people
- A survey with 162 responses.



## **Craig Dunlop**

Craig has worked as a Research Assistant at Abertay University since May 2023.

He is a fully qualified counsellor and registered member of the British Association for Counselling and Psychotherapy (BCAP). Craig has previously worked in housing and homelessness as well as in the tourism industry.



## **Dr Mhairi Thurston**

Mhairi is a Senior Lecturer in counselling at Abertay University and a Senior Fellow of the Higher Education Academy.

She is an accredited, registered counsellor with the British Association for Counselling and Psychotherapy (BACP). Her research interest is the social and emotional impact of acquired sight loss.



# What do we mean by loneliness and isolation?

Although they may overlap, we have followed academic consensus in this report by treating loneliness and isolation as separate phenomena.

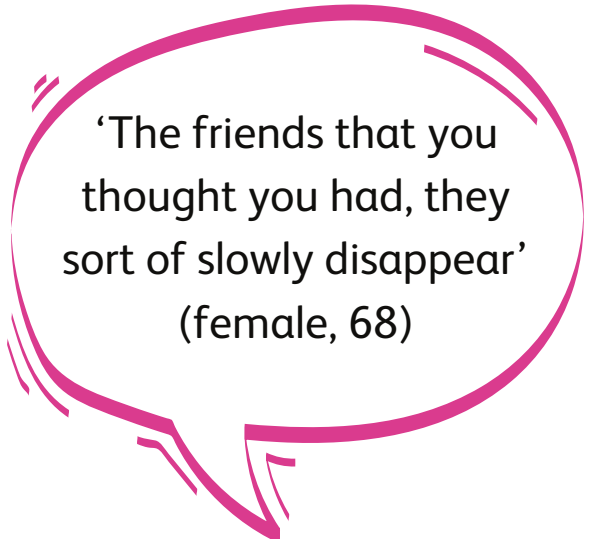
## What is loneliness?

Loneliness describes a subjective, painful feeling that someone experiences when they recognise a difference between how they would like their social and/ or intimate relationships to be and how they are.

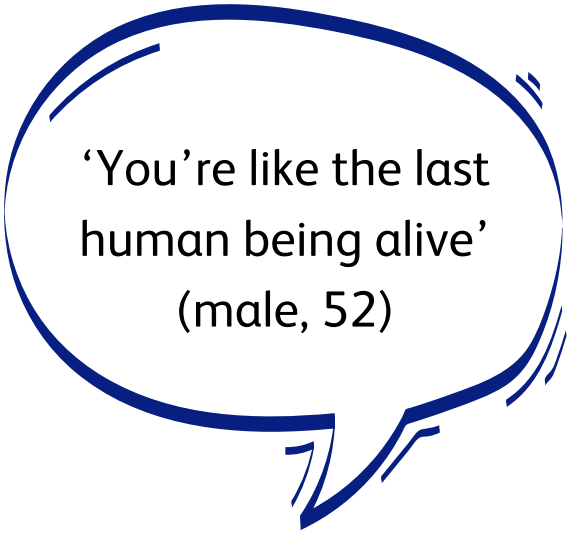
## What is isolation?

Isolation is an objective, observable fact. Someone is described as isolated if they don't engage with others or don't have the resources to cultivate such engagement.

Researchers used the recognised UCLA-3 Loneliness Scale , which ranges from 1-9, to identify levels of loneliness and isolation among survey participants and interviewees.

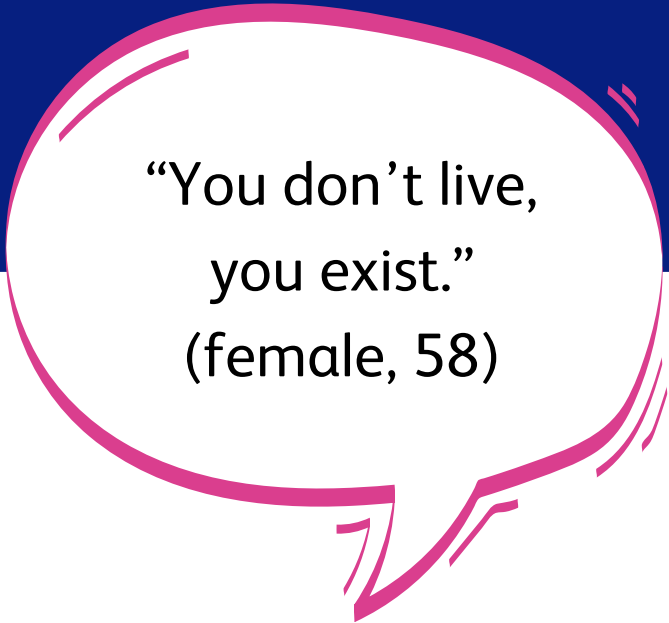


'The friends that you thought you had, they sort of slowly disappear'  
(female, 68)



'You're like the last human being alive'  
(male, 52)

# Key findings



“You don’t live,  
you exist.”  
(female, 58)

Survey respondents were three times more likely to report feeling lonely some or all the time than the general population.

**76%** of survey respondents said they felt lonely some or all of the time.

**25%** of the general population feel lonely some or all of the time.

**44%** of interviewees scored an 8 or a 9 on the loneliness scale.

**26%** of survey respondents scored an 8 or a 9 on the loneliness scale.

People reported that they did not see or speak to anyone for days, that they felt unable to take part in the things that had previously brought them joy and connection, and that they accepted chronic loneliness and isolation as a part of life.

While we understand these emotions and their underlying causes, we do not accept a future where this continues.



# The case for support

**Our report identifies areas where we can and will invest in change. Our report identifies the need for:**

- A more holistic, consistent approach to emotional support at the point of diagnosis and for ongoing support with anxiety and depression related to vision loss, including better link up between primary and secondary care.
- Renewed efforts to ensure that vision impaired people can connect with others and have access to tools and resources to gain confidence and mitigate the risks of internalising real and perceived stigma about what it means to be vision impaired.
- A better appreciation of how life events, including national events like pandemics and lockdowns, might be made harder for someone with vision loss.
- Creative, flexible and practical ways for vision impaired people to get out and about, even whilst real external and internal barriers exist.
- New and sustainable solutions that make it easier for people to build confidence, resilience and social and practical skills for handling the everyday difficulties of blindness or vision impairment, including digital skills.
- More granular data that specifically focuses on blind and vision impaired people, along with a deeper understanding of the ways that different identities and aspects of intersectionality impact how blind and vision impaired people experience loneliness and isolation.

## How we'll deliver change

Fight for Sight / Vision Foundation is responding to this need by funding collaborations, programmes, projects and ideas that explore the issues and deliver innovative, and practical solutions.

Our support includes gathering insight and impact so we can scale learning and influence the sector and broader ecosystem to drive change that improves lives.



“You just become a shell of the person that you were.” (female, 58, diagnosed at 31).

## Section 1

# Experiences of loneliness and isolation.

The case for change.



# Loneliness and isolation

People who are blind or vision impaired are more likely to experience feelings of loneliness and isolation and experience it more keenly.

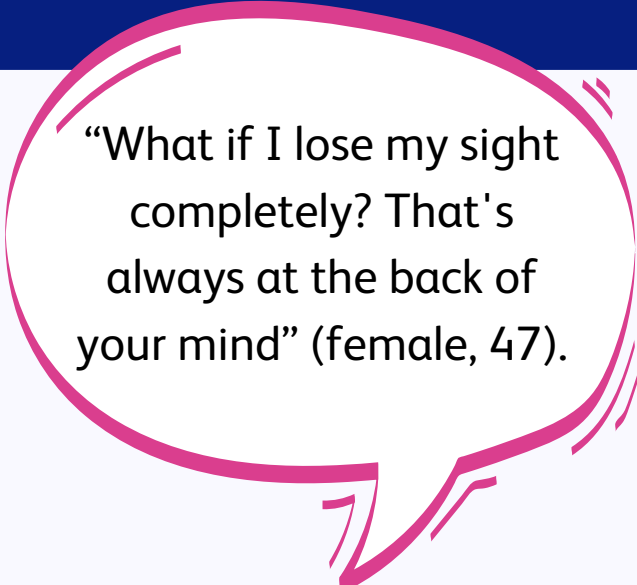
Interviewees directly associated their loneliness or isolation with being blind, vision impaired or losing sight.

Feelings of loneliness resulted from a lack of emotional support.

We found feelings of loneliness and isolation led to anxiety, depression and negative self-image, perpetuating a vicious circle of self-isolation.

## **Lack of information and emotional support**

There is a lack of consistent, adequate emotional support and information, particularly at the point of diagnosis, which can heighten feelings of loneliness and isolation.



“What if I lose my sight completely? That's always at the back of your mind” (female, 47).

People spoke of a sense of abandonment by medical professionals.

## **Anxiety and depression**

Interviewees expressed an almost universal experience of anxiety. Some expressed grief for the way life was previously and frustration around considerations that living with vision impairment brings.

Anxiety about the future was a particular theme among people who were progressively losing sight. With each change in vision, people adapt to the new situation and anticipate what further vision loss might mean for them.

## Losing sight of self: a vicious circle

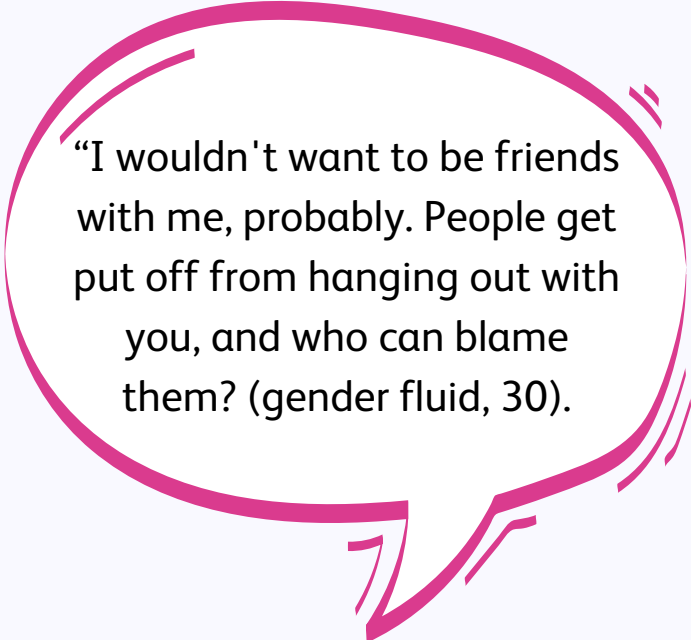
A diagnosis of sight loss can mean people lose a sense of self.

Many interviewees expressed views that suggested they had internalised negative or discriminatory views about blindness or vision impairment.

Diagnosis impacted people's view of their ability to date, and parental roles. They believed they would become reliant on others and be unable to work or travel independently.

Internalising these views heightens feelings of loneliness and isolation, causing some people to withdraw from society and increase their isolation. One male, aged 52, said: "You know Homer Simpson on the couch? That's what I've become because there's nothing out there that I can do".

Internalised stigma led to a sense that romantic



"I wouldn't want to be friends with me, probably. People get put off from hanging out with you, and who can blame them? (gender fluid, 30).

relationships were unlikely and an assumption that friendships would disappear because of a perceived need that individuals would require levels of help that others would find unacceptable.

## Life events: transitions

Being vision impaired also makes it harder to deal with life transitions and events such as moving home or relationship breakdowns.

People found it hard to adjust following bereavement and experienced anxieties about how they'd manage logistics if a sighted partner were no longer able to help.





Fifty percent of our survey respondents said they spend less time in activities outside their homes following the pandemic than before.



Our interviewees also expressed concerns about how they would continue to use their existing coping mechanisms and approaches if their health started to decline or if they became frailer and more vulnerable in older age.

There was a sense that these life challenges would be compounded by blindness or vision loss.

One woman, age 62, said: “The break-up of my marriage was particularly difficult ... the thought of having to forge a life by myself was particularly hard. I ended the marriage, but that took so much courage. I probably would have ended it earlier if I hadn't been visually impaired.”

## **Lockdown learnings**

The Covid-19 pandemic and associated restrictions were hard for blind and vision impaired people. Unique challenges were created by social distancing rules for people whose primary

means of getting information about the world and interacting with it is through touch.

Participants spoke about feeling extremely guilty for asking others for help, the incredibly negative impacts on mental health and increased feelings of not belonging and being different.

The impact of Covid-19 and associated restrictions remain, and our research suggests that blind and vision impaired people are struggling to rebuild their pre-pandemic lives. 50% of our survey respondents said they spend less time in activities outside their homes following the pandemic than before.

This was particularly the case for working people who missed the social aspects of being in an office. This has had a knock-on effect on people's levels of confidence.

# Delivering change

We are committed to reducing experiences of loneliness and isolation among blind and vision impaired people.

We will fund and support work that:

- Improves how primary and secondary care responds to blind or vision impaired people, e.g. using social prescribing that connects people with local community activities and shared interest groups. We're supporting calls for a national eye care strategy and an eye care support pathway that ensures access to psychological and clinical support.
- Creates opportunities for connection and confidence building. We've funded mentoring services for young people and opportunities for people to build emotional and practical confidence about life with vision impairment.
- Increases access to activities that are proven to reduce anxiety and poor mental health, including sports and physical activity, access to nature and creative and cultural activities.
- Explores the specific role of blindness or vision impairment in life events. For instance, we have funded work exploring experiences of Domestic Violence and Abuse that revealed that assumptions are made when blind and vision impaired people seek help or may be potentially at risk. >> [Read the report in full.](#)
- Continues to build the evidence base for what works, e.g. by measuring the impact of our funded activity on participants, organisations and local infrastructure and the wider ecosystem, enabling others to replicate success.



We will continue to fund work that supports opportunities for connection, such as Jamie's Farm, pictured.

“I just sit in at home where I feel safe. I won't go out on my own because you never know what you're going to encounter” (female 66)

## Section 2: Inside/Outside: internal and external barriers impacting loneliness and isolation



# Internal and external barriers

Our research showed that blind and vision impaired people face substantial barriers that prevent them from engaging with the world around them as they would wish to.

## External barriers

External barriers include inaccessible environments such as venues, unreliable buses, unmanned train stations and cluttered streets. Fear of other people's attitudes was another factor impacting people's willingness to go out and about.

## Internal barriers

Respondents identified a lack of confidence in the skills, tools and resources to improve their situation.

Maintaining resilience and optimism in the face of these barriers is a struggle and prohibits access to activities that enrich life experiences, such as sporting activities.

## Other people's reactions

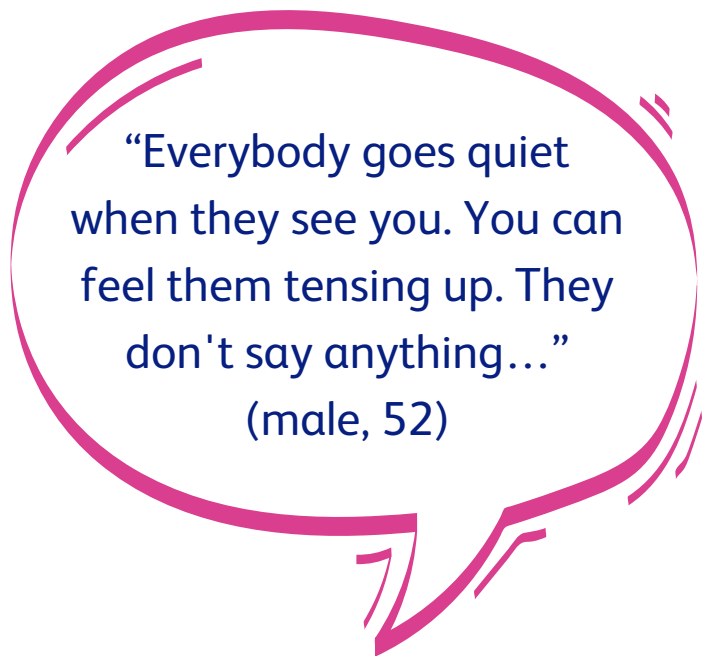
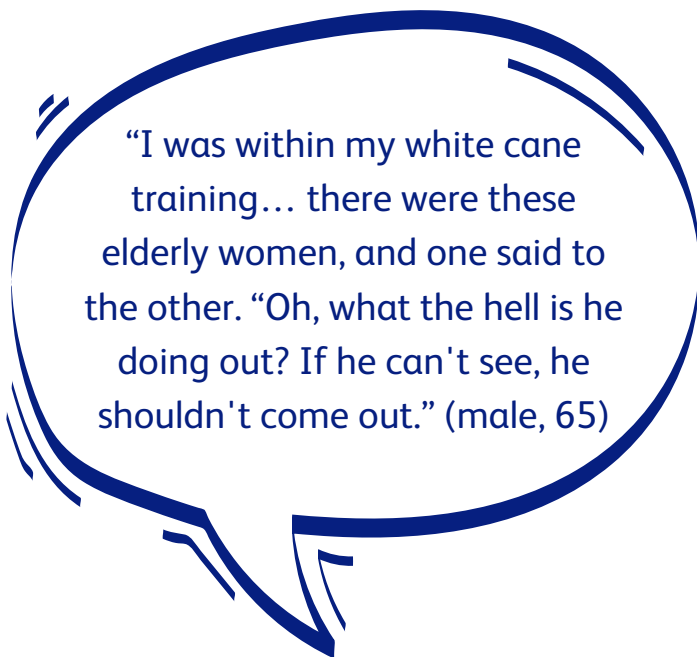
The responses of others frequently prevented interviewees from feeling able to get out. People described situations ranging from an apparent awkwardness and reluctance to engage to examples of overt discrimination and bullying behaviours. Even where these experiences were on the lower end of the scale, their persistence and frequency created a situation that participants found wearing.



A familiar feeling expressed by interviewees was the sense of feeling alone, even among others, because of being left out, ignored, or feeling that they didn't belong.

One risk factor that feels particularly pertinent is discrimination.

Our research participants reported frequent examples of both direct and indirect discrimination, including bullying and harassment.



### **Low confidence and vulnerability**

Another barrier was participants' low confidence in their skills to navigate new surroundings: commonly, people expressed anxiety about safety; people felt vulnerable and feared getting lost.

For several participants, readiness to adopt mobility aids (e.g. a guide dog or white cane) was inherently bound up with their coming to terms with having a vision impairment. People frequently talked of feeling more comfortable when their vision impairment was not obvious and accepting assistance felt like giving in.



Some respondents attributed low confidence levels in managing social situations to the inability to pick up on visual clues, make judgements based on visual information or read nonverbal signals.

Several participants desired connections with others in a similar position. Whilst this was not for everyone, the opportunities for people to gain encouragement and tips from others and to share their experiences were clear.

## Technology and digital inclusion

Accessing technology and being digitally included were important ways to overcome loneliness and isolation. For example, engaging with supportive Facebook groups, meeting new people online, operating in a hybrid work situation or navigating new environments when out and about.

Survey respondents were keen to increase their confidence and skills, supporting the idea that current access to training, support and, in some cases, the relevant hardware is inconsistent. Access to technology – old and new – and being digitally included increasingly feels like a non-negotiable if blind and vision impaired people are to have equal access.

The current provision is neither sustainable nor widespread enough to meet demand. There is a wealth of organisations delivering training in digital accessibility, yet this is a recurring theme.

# Delivering change

Wherever they live, blind and vision impaired people should be able to access the means for getting out and about in the ways they'd like and on their terms. We will fund and support work that:

- Improves the options available to blind and vision impaired people to join in with activities they choose and engage with their local environments on their terms.
- Increases our understanding of the effectiveness of different solutions for people in different places and circumstances.
- Builds understanding of the ways that mindset and resilience interact with someone's experience of blindness or vision loss in a way that reduces chances of loneliness and isolation.
- Increases opportunities for people to build resilience, confidence, and social and practical skills that help when handling the tricky everyday realities of being blind or vision impaired, notably where formal training and support are lacking.
- Delivers evidence of what works for blind and vision impaired people to access both new and old technology in an affordable, sustainable way. We've supported work on a local level to increase digital skills and are keen to build on this.

In addition, we continue to support sector campaigns to increase the accessibility and predictability of public environments and transport but are equally keen to support ideas that people can make use of immediately, e.g. for parts of journeys where public transport isn't available.



# Can you help?



We all need connection. It's part of being human. Without it, mental health can suffer, and we feel depressed and anxious. Our research shows that people who are blind and vision impaired are more likely to experience loneliness and social isolation.

Seventy-six per cent of those we surveyed say they feel lonely some or all of the time; evidence shows their experiences rate the highest score on the loneliness scale.

People describe feeling like 'the last human alive,' that they don't live but exist. Covid dealt a significant blow in that many who rely on touch found it harder to navigate a world in lockdown where we all felt the loss of connection with family and friends.

The recommendations highlighted in this report all have a common thread: collaboration, connection, community; as no one organisation, community, or policy maker will alone enable the change.



Together, with funders from communities, individuals, companies, and funding organisations, we can collaborate to make significant funds available that will support ground breaking work across the four nations in delivering change. The change must be sustainable and build capacity, and this requires long-term commitment.

This is our open invite to funders to work with us to end disconnection, loneliness, and isolation and poor mental health for blind and vision impaired people.

Whilst we have a committed portfolio of funder relationships, having meaningful impact at scale requires a surge of investment from all over the UK to activate work in the heart of our communities, replicate success and demonstrate courage in innovative new approaches. We can only do this with your help.

Thank you.

Ranjeet Kharé

Director of Development

**Get in touch:**

Email us: [fundraising@fightforsight.org.uk](mailto:fundraising@fightforsight.org.uk)

Call us: 020 7264 3900

# An urgent need to Save Sight. Change Lives.

We are on the brink of treatments for multiple health conditions and diseases, yet research into preventing and treating sight loss only receives 1.5 percent of public grant funding. That's a meagre £9.60 for each person affected by sight loss in the UK – less than the hourly living wage.

With the help of our funders and partners, we can reduce sight loss and its impact.

Despite advances in technology and the strengths in our communities highlighted through the pandemic, those living with sight loss only have a one in four chance of getting a job, are more likely to be lonely and are more likely to live on low incomes.

This can and must change.

## How you can help

Our grants are funded by voluntary income through individuals, families affected by sight loss, funding organisations, companies, and strategic partnerships. To meet the growing demand, we need and rely on your continued generous support.

**Visit us online:**

**Fight for Sight [www.fightforsight.org.uk](http://www.fightforsight.org.uk)**

**Vision Foundation [www.visionfoundation.org.uk](http://www.visionfoundation.org.uk)**

“I can’t possibly navigate in somewhere that I haven’t been before. I’ve always got to be with somebody. Somebody’s got to guide me all the time” (male, 66)

## Section 3: Exploring intersectionality and lived experience, including data collation



# The case for better data collection

Blind and vision impaired people are at increased risk of loneliness and isolation.

There's a close connection between these experiences and the psychological and practical impacts of being blind or vision impaired. Coping with inaccessible and unpredictable environments, anxiety about social interactions and getting around are major factors, as is inadequate access to the tools and resources to feel a sense of agency.

There is plenty of scope for better understanding the links between blindness or vision impairment and loneliness and isolation, and in commissioning this research, we have identified several areas where greater focus is needed.

## Improving data

Our literature review revealed gaps in national data reflecting the experiences of blind and vision impaired people in the UK. The UK government collects and publishes annual statistics: 2023 figures indicate that 6 % of the general population feels lonely most or all the time.

For people with a disability or long-term health condition, this increases to 13 %, but no statistics are collected on specific disabilities or health conditions.

There are common factors that are generally understood to increase people's vulnerability to loneliness and isolation. These include poor mental health, low income, unemployment, living in rented accommodation, and being younger, single or widowed.



Data collection, which explores the interaction between these characteristics for blind and vision impaired people, would clarify the picture better.

## Understanding intersectionality

Blind and vision impaired people are not a homogenous group. There are several areas in which this research is inconclusive because of sample size and demographics.

Research using larger sample sizes would enable more differentiation between groups and continue to build on the richness of the data. For example, a group that reports high levels of loneliness and isolation is younger people, and there is some recent sector evidence exploring the challenges they face, particularly when it comes to developing friendships.

There are also aspects of the experience of loneliness and isolation that seem to be particularly pertinent for blind and vision impaired people. For example, the ways that mindset, personal resources and resilience make it less likely that people experience very high levels of anxiety. Similarly, developing social competence and social capital is an important area, i.e., how people with little or no vision successfully navigate social relationships and build social networks.

Some experiences are under-researched.

We found no work exploring the experiences of people who identify as LGBTQ, and in-depth explorations within different ethnic communities are thin on the ground.

# Delivering change

There is an urgent need for greater granularity in collating data relating to blind and vision impaired people.

Our report shows that people who are blind and vision impaired are more likely to experience loneliness and isolation and to experience it more acutely.

However, it also gathers a breadth of experiences reinforcing the knowledge that people who are blind and vision impaired are not a homogenous group.

Experiences of blindness and vision impairment are likely to be nuanced and shaped by other life experiences, e.g. for people who are LGBTQ or are from a particular ethnic background. Understanding what this might mean for loneliness and isolation is essential for making sure people who experience additional disadvantages are not left behind.

It is unacceptable that these experiences don't form part of broader disability data. We will fund and support work that:

- Deepens understanding of the diversity of experience of blind and vision impaired people through respectful appreciation of direct lived experience. This report and our previous report on DVA are good examples.
- Focuses on understanding the interactions and nuances that arise from different aspects of identity and intersectionality, what this means for how people experience loneliness and isolation, and what works for mitigating it.

“The absence of consistent emotional support can turn a frightening experience into a profoundly lonely one.” Marsha de Cordova, MP

People don't approach you. It's like you're living in a world of one all the time.” (male, 52)

Connect with us:

[www.visionfoundation.org.uk](http://www.visionfoundation.org.uk)

