

Help someone find  
their life again **RNIB**

# Lost...

Before you read this report, we'd like to ask you a simple question. **What would you lose if you lost your sight?**

"I miss my friends whom I've not contacted for a long, long time... What can I say to them?"  
Ollie Natelson

"I hit a brick wall... You just don't know what to do with yourself"  
Sharon Sutton

"Nothing, nothing, nothing will ever prepare you for not being able to see"  
Sue Townsend



# and found

There is life after you lose your sight. However this cannot happen without people receiving decent, appropriate and joined-up support and services.

RNIB wants to reach more people losing their sight, to improve statutory services across the UK, and to create a more inclusive society. We can only achieve this if everybody who shares our concern and passion for a better deal for blind and partially sighted people works for change.

**Help someone find their life again.**

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Andrew Kaye

# Foreword

by Sue Townsend, author of the *Adrian Mole* diaries

Since being registered blind I've found out from talking to friends and family, and anyone that will talk to you honestly, that going blind is one of their greatest fears.

But nothing, nothing, nothing will ever prepare you for not being able to see. It's as simple as that. But I'm not going to pretend it's not a huge loss, in fact, it's a calamity. I refuse to pretend that it's not a calamity.

My optician alerted me to the fact that he could no longer prescribe me reading glasses unless the lenses were like bottle tops. I was diagnosed with diabetic retinopathy and my GP referred me to the Royal Infirmary.

One day the registrar said to me "Did you drive yourself here?" I said "No." He said, "Good because you wouldn't be able to drive yourself back. You're partially sighted."

That was it. I got up and walked out and made another appointment and I was shocked. When my sister came to pick me up, because of the drops and the laser treatment I couldn't see her car. And she was beeping the horn and shouting, and I couldn't see her. When I eventually got in the car I was so shocked I could hardly speak and I said to her "I think I'm partially sighted!" and I can still remember the feeling which was wanting to ask an awful lot of questions and not knowing who to ask and then wanting to forget all about it. And get on with things.

It's bloody hard work not being able to see because you're constantly having to make sense out of incoherent shapes. You're constantly having to interpret the world rather than just be in the world.

It doesn't mean to say that I'm going to wallow in self pity and not do anything and lie about wailing. I'm not going to do that and I haven't done that. I do feel bereaved and I do feel as if I'm undergoing a mourning process.

I know that I am not alone in my experiences. There are more than two million blind and partially sighted people living in the UK, all with their own story to tell. There is no magic cure for blindness, but there are things that can be done to make life easier for blind and partially sighted people. RNIB aims to do just that and this is why I am fully lending my support to this campaign.



# Introduction

## “What would you lose from your life, if you lost your sight?”

Every week in the UK, hundreds of people who have been able to see begin to lose their sight. Some are children, some are in work and many are retired. This report from Royal National Institute of Blind People (RNIB) gives a glimpse into the everyday lives of people who have lost their sight. Their stories reveal the realities of living with sight loss and the frustration and isolation that often follows. Research confirms that the personal experiences shared in this report are also those of many thousands of others.

In this report, people speak about the ignorance and misunderstanding of blindness and partial sight by friends, family, professionals and the public at large. They talk about their own feelings of depression and despair. However, despite their inner turmoil, their resilience and determination to get on with their lives shines through.

## Services in short supply

People talk about the shock when they had to face up to their blindness or partial sight, when medical treatment had nothing more to offer and the eye doctor told them “nothing more can be done”. People speak out about the failure of health and social care services to give them the personal support that they needed at this devastating time.

As people get to grips with what is happening, they highlight the inadequacy of support to help them get on with their lives. They talk about the challenges they have within their homes, the battle to get out and about, the difficulties with staying in work and the struggle to maintain hobbies, interests and a social life. Services are in short supply: services which should provide emotional support; services which should assist the use of remaining vision; and services which should teach new, safe and independent ways of doing things.

Losing your sight is a crushing experience and there is no magic wand that can restore the joys and riches of seeing. Nevertheless, this report makes clear that there is life after sight loss. There are new friendships to be made, new skills to be learned, new doors which can open and unexpected experiences to be discovered. However, none of this can happen without people receiving decent, appropriate and joined-up support and services.

## Making a difference

Is it too much to ask to get the help and support you need to adjust to losing your sight and to live independently? RNIB doesn't think so and the majority of the public agree with us.

Whether you are a national politician or an elected councillor, a chief executive of a health body or local authority, an eye doctor or social worker or a member of a voluntary organisation you have a crucial role to play in improving services to people losing their sight.

We at RNIB, which includes our associate charities, Action for Blind People and Cardiff Institute for the Blind, play a major part in improving and extending help and support to people losing their sight, and over the next five years we want to do even more. As well as improving and extending our own services, we will continue to play a lead role in delivering the UK Vision Strategy, a radical agenda for improving eye-care and sight loss services, through collaboration with government bodies, health and social care, professionals and other voluntary organisations.

We at RNIB want to reach more people losing their sight, to improve statutory services across the UK, and to create a more inclusive society. We can only achieve this if everybody who shares our concern and passion for a better deal for blind and partially sighted people works for change.

# Day one: The shock – visiting the eye clinic

## What would it mean to you to be told you're losing your sight?

What would it be like to lose this most precious sense? What impact would that have on your life? For most of us it is extremely difficult to imagine since the fear of it happening pushes it to the very back of our minds.

You would imagine people would help. You would imagine that services would be available to you so you could learn how to adjust to losing your sight. When you first hear the news in the eye clinic that your sight loss is irreversible you would imagine being given the necessary support to come to terms with this dramatic, frightening change. You would imagine...

## Judith Robson, 55, Stockton-on-Tees, Teeside

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When Judith lost her sight it panicked her, as it seemed to happen quite quickly. She made an appointment at her local eye hospital.

“(After the first appointment) they said they would phone on the Monday or the Tuesday, and they didn’t. They said they had taken my phone number down wrongly... the next time I went in for an appointment my right eye had ‘gone’. I couldn’t see the Snellen chart.”

Although the nurses insisted everything was going to be fine, Judith didn’t feel so confident. She wasn’t offered any information on her eye condition or what it meant to lose one’s sight. Although she wouldn’t have been able to digest what was going on that evening, she would have liked to have been able to take a leaflet away with her so she and her husband could refer back to it in their own time.

### “There was nothing”

“As far as the medical profession goes, there was nothing. When I went back to the waiting room, they gave me a cup of tea and left me with my husband.”

No one in the eye clinic spoke to Judith about her feelings or offered any practical advice on what to do now her sight loss was permanent.

“I was left for a while on my own... there needs to be something in eye hospitals soon after diagnosis; that has to change.”

### “Left to rattle along”

Judith soon experienced the symptoms of depression, and although she’s not sure



whether that was the result of medication she was given at the time, she felt like her family had been left alone to “rattle along” and do everything by “trial and error”.

Six years on and things are getting a little easier. Judith has got in touch with the council to find out how she can register as blind and get the help she needs. Assisted by Blind Voice UK, her local society, she now feels ready to do things she had given up. She is learning new skills, including reading braille, and she is growing in confidence as she undertakes mobility training.

“Before I lost my sight I was just an ordinary Mum. But I still am. You are still the same person. Just one bit of you has changed, that’s all.”

## Other experiences in the eye clinic

**“At the beginning there was basically nothing – nothing at all. The eye hospital’s (attitude) was ‘you’ve got an eye problem. Bye. Sort it’.”** Andy Stowe, 53, Mansfield.

**“Even in that panic, no one put forward what I would call a kind hand. The medical staff do a lot of good things, but what they forget is that you’re not a car that’s having a wheel taken off and a replacement put on. You have got feelings. I think that’s what they don’t connect with.”** Linda Kelly, 59, Catford.



**“(The consultant) said ‘you can be registered as partially blind at any time.’ It was at that point that I actually realised this is really serious, and he said, ‘I don’t think you’ll have any sight left in about three years’ time.’ I could think of better ways of being told – not quite that bluntly... I have never had any empathy from anyone.”** Heather Giles, 54, Maida Vale.

## Facts and figures

- Being diagnosed with an eye condition can cause a wide range of reactions. It can be an extremely confusing and uncertain time and in many cases it is emotionally traumatic.
- One of the key things a number of people who have lost their sight express is a dissatisfaction with how ophthalmologists or other staff communicated the news that nothing more could be done to help them (Endnote 1).
- Sight loss is associated with a higher than normal risk of depression (2).
- 70 per cent of blind and partially sighted people said they wanted someone to talk to about their fears and concerns after being told they were losing their sight. Only 19 per cent were offered this opportunity in the eye clinic (3).
- A survey of registered individuals reveals that after diagnosis only 8 per cent of blind and partially sighted people were offered formal counselling by the eye clinic, either at the time or later (4).
- Nearly a quarter (23 per cent) of blind and partially sighted people leave the eye clinic not knowing, or unsure of, the name of the eye condition that caused them to lose their sight (5).

## What must change

Poor quality or non-existent personal support at the eye clinic should not be viewed as the fault of individual professionals. There are systemic problems, which lead to people not being offered the helping hand they need at this critical time. Local health and social care services are failing to deliver support to people losing their sight. Patients need time and emotional support to absorb difficult news and an opportunity to discuss their concerns when they have taken the news in. Only a small minority of eye clinics have support workers, who help people to adjust to losing their sight and refer them to vital services.

### A better approach

#### Patient support services

Support workers can play a vital role in eye clinics. Their job is to give people the support they need when their sight loss first becomes a problem. For a younger person, this might mean help with keeping a job, referral to a counselling service and support with financial problems. For an older person, this might mean giving information on their eye condition, providing a listening ear, referral to peer support groups and benefits advice.

At Sussex Eye Hospital, an eye clinic liaison service is being delivered by Action for Blind People. Kerry Leask has provided this service for more than five years. She supports on average 55 new patients a month and deals with over 100 enquiries. The work is jointly commissioned by Brighton and Hove City Primary Care Trust (PCT) and the local authority, which means Kerry enjoys excellent relationships with both the eye care and social care teams.

Most of her clients are older people who have just been told that they are losing their sight. Most are too shocked to take things in and Kerry's presence in the clinic means she can sit with them and provide a sympathetic ear – listening and supporting. She also makes sure that they do not leave without getting information on the local and national services that are available. Perhaps most importantly, Kerry stays in touch with people to check that things actually happen and they are not left alone. For those facing the most severe depression, Kerry is able to refer to a trained counsellor.

The Eye Clinic Liaison service provided by Kerry in Brighton is highly valued. The people she supports get quicker access to other services, such as low vision aids. The local sensory services manager has described her presence as "essential" to the effective focusing of her rehabilitation team. Kerry makes sure people do not fall between the gaps in the health and social care system.

## Other experiences with patient support services

A service user on the Action for Blind People website has said, **“It is great to have a single point of contact; an expert that knows how and where to get help from more than one service at one time” (6).**

**“It was comforting to know that somebody was interested and knew how I felt.”** Jane Pritchard, Cardiff.

It's not just qualified Eye Clinic Liaison Officers (ECLOs) that perform this important role. A number of voluntary organisations provide personal support in their local eye clinics, staffing an information desk or providing other forms of help.

### **RNIB will:**

- We will make sure that more people losing their sight receive the information, advice and emotional support they need at this critical time.
- We will work with others to increase the opportunities for peer support, enabling people losing their sight to provide mutual support to each other.

### **RNIB calls on:**

- The UK and devolved governments to take a strong lead in improving patient support in hospital eye clinics, opening up access to information, advice and emotional support and counselling for people losing their sight.
- Local health and social care services to work together to commission and deliver information and support in the eye clinic to those losing their sight.

# Month one: Returning to a different world – home life

## What would you lose from your home life if you lost your sight?

Our homes are where we are meant to feel comfortable and relaxed – “at home”.

When we lose our sight we don't always experience home life quite like this. Of course our home lives are as varied as anyone else's – there are highs and lows. But too often we experience a deep sense of frustration, even isolation.

We need more than bricks and mortar to build a warm, secure home environment. For a house to become a home, we need a few key ingredients, especially as we adjust to and go through the transition of sight loss. What won't help create this atmosphere is struggling to make a basic meal. Or finding there aren't any books on the shelves to read. Certainly what won't help is finding it difficult moving from room to room concerned that every next step we take could lead to a fall. What will help is to know local support will be available; being pointed in the right direction and feeling someone cares.

## Sharon Sutton, 43, Stoke-on-Trent, Staffordshire

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**“I couldn’t go out in the dark. It scared me.”**

When Sharon’s eye condition worsened she felt she could no longer do the things she enjoyed. She wanted to give up.

**“I hit a brick wall... you just don’t know what to do with yourself... (all I was doing) was sitting around and perhaps listening to the TV.”**

**“I was struggling at home”**

**“My son was very angry... I had a home visit, but then I didn’t hear anything for months, which left me gutted.”**

Sharon explains how she received very little support from health and social services during this period.

**“I was offered nothing. I panicked, because I couldn’t run my home, even cook a meal, and they were the really scary times. I was frightened if I went out... I got hold of the council to get some help because I needed extra lights in the house to make my life easier and that has been very difficult”.**

RNIB showed Sharon how to adapt her house so it was easier to undertake household tasks. Now Sharon is trying to receive a Direct Payment from her local council so she can buy-in the support she needs to remain independent. However, despite beginning cane training she is still waiting for her Direct Payment to be sorted out, stalling her efforts



to go out more frequently and join a gym. She keeps busy promoting greater awareness of the health risks posed by living with diabetes and is an Expert Patient, supporting others living with the condition.

**“I feel a bit guilty”**

Sharon doesn’t want to feel dependent on her son and parents, but going out alone can often leave her in a state of panic and “on edge.”

**“I feel a bit guilty about relying and depending on my family... my son feels so responsible - he feels trapped (as a carer). (Losing sight)... spoils your relationship with your family... my son says I’m a totally different person now. I stay at home a lot.”**

## Other experiences of home life

**“It wasn’t anything to do with the hospital treatment that upset me. It was the fact that afterwards I was cut loose... that nobody picked me up afterwards... which is where the horror story really started.”**

**Chris Atkins, 54, Wellington, Somerset.**



**“I love reading. I get the Talking Books from RNIB – the CDs – I love those... It’s getting out that door (that is difficult)... I have to push myself to go. It’s like crossing a line... it’s a blind thing.”** Ann Murphy, 76, Chorlton.

**“I remember just after diagnosis, I had lost my job, my income, my identity as a teacher, my driving license, my social network, my house, my independence and I had sunk into a deep depression, whilst struggling to look after a new baby and two toddlers. Although my physical needs were catered for, in terms of offers of low vision aids and rehabilitation, it felt as if my emotional needs were overlooked.”** Mhairi Thurston, Dundee.

**“My wife found it difficult. She wanted me to be positive and consider the cup half full, but I kept insisting that the cup was half empty. Coping was almost impossible and when (I was) alone I would cry out of despair and horrible loneliness. As the weeks stretched into months, I began to see a different world – full of possibilities and (I) suffered these bouts of depression less frequently...”** Ollie Natelson, 68, Finchley.

**“Some people do really struggle... you get things come through the post, ‘fill this form in – do this – do the other’ and really you could do with help to do it sometimes.”** Mary Craddock, 76, Redditch.

## Facts and figures

- Reactions to a sensory loss, especially sight, can resemble reactions to bereavements (7).
- Sight loss is often concurrent with other health and mobility problems and social changes associated with ageing (8).
- Some areas have seen surprising falls in the numbers of new people registering with their councils as blind or partially sighted, causing concern that some eye hospitals are failing to refer people to social care services.
- 20 per cent of people say they do not recall receiving any visit from social services in the year after they registered as blind or partially sighted (9).

- The percentage of people reporting that they received a visit from social services within six weeks of their appointment at the eye hospital ranged from 88 per cent for the best local authority to 14 per cent for the worst (10).
- 17 per cent of people that register with their council reported that they received no help or information at all in the year following registration (11).

## What must change

A number of UK and devolved government initiatives have been launched in recent years, with the objective of enabling disabled people to lead independent lives (12). These are all positive and a number of progressive policies are now being implemented. However, the area you live in too often determines the levels of support you receive. Across the country, health and social care services need to take action to ensure people feel properly supported in the weeks after they are told their sight loss is permanent or worsening.

### A better approach

#### Rehabilitation Services

Rehabilitation describes the range of services and support which help people to live with sight loss, through providing information, skills, training and specialist equipment. There are already some places in the UK leading the way in providing this support.

Many of these services are provided by voluntary organisations. MertonVision is just one example of a local society of blind and partially sighted people that supports people soon after diagnosis. Their aim is to work with people soon after they lose their sight, supporting them with whatever services they need to live independently (13).

MertonVision has a contract with the London Borough of Merton Social Services to provide rehabilitation and mobility training for people with sight loss in Merton. The rehabilitation officer who is employed by MertonVision carries out personal assessments on behalf of Merton Social Services.

Following their assessment, the person is offered information and practical advice regarding sight loss. The rehabilitation officer may also advise on, or provide, equipment. Some people will also be offered skills training, usually tailored to meet their personal needs. Skills training can cover reading and writing, getting around inside and outside, and daily living tasks. Referrals can be made to other services such as counselling, occupational therapy, the community alarm scheme and social care.

People are also invited to a course that enables them to meet with others who have recently lost their sight. This provides an opportunity to visit MertonVision's resource room, which includes specialist equipment. The local Primary Care Trust funds a Low Vision Aids service at MertonVision. The optometrist and rehabilitation officer work together to carry out personal assessments and provide magnifiers and training in how to use low vision aids.

As the rehabilitation service is based within MertonVision, people have access to their other services, such as adult education, computer training, art and crafts, tai chi, exercise classes, benefits advice, help with filling in forms, and a lively social calendar.

For those who are housebound, the rehabilitation worker can refer to the home visiting service which provides trained volunteers for reading, dealing with post, escorts to events or shopping or just some friendly company.

The partnership between social services and MertonVision means that they can offer a comprehensive and sensitive service to local people with sight loss.

## **RNIB will:**

- We will increase the reach of our information, advice and specialist product services to support more people to live independently.
- We will increase access to braille, audio and large print books and magazines, including our much-loved Talking Book Service.

## **RNIB calls on:**

- The UK and devolved governments to deliver reforms that enable people who lose their sight to speedily access care and support. Social care assessments should be sensitive to the needs of people who lose their sight.
- Local health and social care services to modernise and extend low vision services so that people who lose their sight maximise the use of any remaining vision.
- Local social care services to deliver rehabilitation support, which equips blind and partially sighted people to live independently in their own homes.

# Month three: At a crossroads — getting out

## What would you lose from your everyday life, if you lost your sight?

Everybody struggles with “life’s little complications”. Everybody wants shopping and commuting to be less stressful. But getting out of the front door and heading into town can be a huge ordeal when you lose your sight.

Losing our sight need not mean we stay at home all day long. With the appropriate training and support we can get out-and-about, use public transport and carry on with our lives as normal. But at the beginning it’s rarely straightforward. In fact it’s sometimes a real effort.

It’s not a case of wanting to proudly and stubbornly “carry on” as if nothing has changed in our lives. We generally want expert training in the use of a white cane. We would like someone to help build our confidence so we can meet new people and go along to social events. At this critical stage in our lives we do want rehabilitation, but it is usually our cash-strapped councils that say, “no, no, no”. There are lots of things we could learn, but it would be a lot easier if we didn’t have to face it all on our own.

## Andy Stowe, 53, Mansfield, Nottinghamshire

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When he first lost his sight, Andy's confidence levels dropped and he found it difficult to get out and about on his own. He didn't receive any visits from social services and he didn't get any mobility training.

### **"Moving out of people's way"**

"I was so conscious I had my stick; moving out of people's way, feeling I was a nuisance rather than a normal person. I was moving more slowly, being more cautious, staying alongside buildings so that I wasn't going to get in people's way".

He began to receive help from a disability information and advice helpline and things slowly started to improve. Andy tries to remain stoical, but using public transport and going into town can still prove frustrating

### **"There are certain places I don't go to anymore"**

"All the buses from here go into town, but I would have trouble flagging down the right bus on the way home; finding the right bus number".

"There are certain places I don't go to anymore – like the card shop, with its halogen lighting. When it's my wife's birthday, I normally have to stand outside and give the wife money to get her own birthday card".



### **"An extra little bit of help"**

Since contacting the helpline, Andy has grown in confidence and he enjoys spending time with his grandchildren. He doesn't like to ask for help and his first instincts are to try and do things independently, especially around the house. But he recognises that there were certain things it would have been helpful to know soon after losing his sight.

"An extra little bit of help and advice right at the beginning would go a long, long way."

## Barrington Chambers, 39, Bristol

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When Barrington was first told he was losing his sight, he believes he was in a state of denial.

**“It was devastating... thinking I would need somebody to guide me around.”**

He moved in with his aunt and cousin, and this slowly helped him to rebuild his confidence. At first, Barrington spent a lot of time listening to the radio, thinking about life but his cousin encouraged him to do things he wouldn't have thought of doing on his own.

**“We would go to the cinema together and my cousin would hold my hand and describe what was taking place on the screen”.**

### **“How can you play blind cricket?”**

**“I loved football and cricket. I used to have my own ball and bat, and I was introduced to the Bristol Blind Cricket Association. My initial reaction was to wonder, ‘how can you play blind cricket mate? When you can't see the ball?’ But I played for five years and I had never been to Lord's before. Yet as a visually impaired person I ended up at Lord's playing in a final. We won a few”.**

Adjusting to sight loss hasn't always been straightforward.

**“I didn't go back to the pub for a long time. Because I would have to depend on my cousin. That was the hardest thing – I couldn't go to a pub on my own. Pubs, restaurants – they're a ‘no-go’ area for me.**



**Things are 60 per cent better now but family still say they think I shouldn't go to certain places.”**

### **“Someone to sit down and talk with”**

Barrington is positive about the future but he remembers the time he lost his sight as a traumatic period in his life.

**“If you're a single person and you're living on your own and your doctor says to you, ‘you may lose your sight’ the first thing you're going to do is cry your eyes out. You need someone to sit down and talk with you to comfort you then, not just to leave you and say ‘we'll see you within three months’.”**

## Other experiences of getting out and about

“I got into such a state when I got to town... I couldn't remember which bus to catch to get back. I stood for two hours and my son rang me, and I asked, 'which bus do I catch to get home?' Twenty minutes later he turned up in town and told me which bus to get... I felt gutted... I've got a bus pass, but I only ever used it once". Sharon Sutton, 43, Stoke-on-Trent.

“Shopping? I was a right shopaholic... and I had to give that up. Having to have somebody explain everything that's in the shop - it takes all the pleasure away". Judith Robson, 55, Stockton-on-Tees

“I bump into people, crash into trees and lamp posts, bash into bollards, knock over little old ladies, tread on children and pet dogs. In the bus or on the train I sit on people's laps when I think the seat is vacant and occasionally go into the women's loo by mistake... it sounds hilarious - and sometimes it is! I've got past the embarrassment stage and just laugh as I say I'm blind." Ollie Natelson, 68, Finchley.

“You get a lot of crooked taxi drivers... the fare is usually £5.50 to £6.00, but he drove me back and charged me £15... (he then said) 'so much for you, and so much for the dog'!" Ann Murphy, 76, Chorlton.

“I miss my friends whom I've not contacted for a long, long time...what can I say to them? I can't look at their pictures or read a story to them or go to the cinema (with them)... I find meeting new people difficult... I cannot see their faces, nor recognise them if they move away. I cannot judge their body language nor gauge their mood from facial expressions that I cannot see.”

Ollie Natelson, 68, Finchley.

“The biggest thing I had to give up because of my sight loss is singing. I always sung in choirs... semi-professional choirs. The point at which I realised I could no longer read music was horrible.” Heather Giles, 54, Maida Vale.



## Facts and figures

- Registered blind and partially sighted people are more likely to live alone compared with the general population (14).
- The majority of people aren't offered support to help them get out and about, such as mobility training.
- Feelings of isolation are most marked in the younger age groups.
- 43 per cent of blind and partially sighted people say they would like to leave their home more often (15).
- Nearly half (48 per cent) of blind and partially sighted people feel "moderately" or "completely" cut off from people and things around them (16).
- In the year after registration, less than a quarter (23 per cent) of people who lost their sight say they were offered mobility training to help them get around independently (17).
- 15 per cent of blind and partially sighted people say that they do not do any leisure activities outside of their home (18).

## What must change

When people lose their sight they are all too often unable to tap into immediate support. They shouldn't have to rely on kind offers from strangers and loving relatives and friends but should be offered expert help that enables them to get out independently and gain the confidence and skills to do everyday tasks, such as shopping, controlling money and using public transport. At present, such support is patchy and fragmented. Health and social care services shouldn't allow people losing their sight to "fall through the gaps." Instead, they should ensure that after diagnosis, people get the right support to enable social inclusion, including mobility training.

### A better approach

#### Personal budgets

Personal budgets in social care are designed to increase independence, choice and control.

When Cindy started to lose her sight she says she pretended that everything was all right. In fact, she was becoming very depressed.

Cindy has young children and finally sought help from her local council, Barking and Dagenham in London. She was given direct payments to enable

her to get help with housework. She was a bit happier, but things were still difficult.

“I’d get frustrated easily – little things like not being able to feed my baby properly, or doing things around the house.”

Barking and Dagenham Council then asked Cindy if she would consider receiving a new form of assistance from the council – a care budget. This enabled Cindy to decide how best to meet her own needs.

Cindy wrote her own care plan and she found that she was able to pay for things she had previously been unable to do. For example, she was able to attend a mother and toddler group for the first time with support to help her supervise her children. She was also able to attend college to learn how to use a computer with a screen reader; purchase a laptop and software to make a computer accessible to her; and pay for friends to help her, rather than employ strangers. She found that her new arrangements also worked out cheaper, allowing the budget to stretch further.

Someone supported her throughout the process, overseeing the care plan to ensure her needs were being met. As a result, she felt much happier and has much more flexibility and independence.

Cindy believes all disabled people should have choice and control. “Why should anyone with any sort of disability not be able to do things that other people take for granted?”

## **RNIB will:**

- We will increase awareness of local and national services that support blind and partially sighted people to get on with their lives.
- We will increase opportunities for peer support so blind and partially sighted people can share experiences and learn from each other.

## **RNIB calls on:**

- The UK and devolved governments to deliver reforms that enable people who lose their sight to speedily access rehabilitation services, including mobility training.
- Local social care services to ensure people who lose their sight receive care and support services, which enable their full inclusion, including personal budgets.

# Month six: Opportunity knocks – working life

## What would you lose from your working life, if you lost your sight?

Work: it's a hard slog, isn't it? Fewer of us seem able to "clock in" and "clock off", work for eight hours, and do the regular "nine to five". Life these days can feel like a constant struggle to balance work, family life and our own lives. There's simply too much to do.

Of course, there are those who don't struggle with such concerns, like people who lose their sight. We have other things on our minds, like how to keep or find a job.

It is not the latest restructure that senior management is proposing which usually keeps us awake at night. It's the prospect that no matter what our qualifications, what our contribution, the world of work remains shut off to us – out of reach. It can be a hard slog, work. But it's a harder slog still when employers cannot see beyond your impairment.

## Ollie Natelson, 68, Finchley, London

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When Ollie started going blind he found it extremely difficult to cope.

### **“Was I to sit on street corners?”**

“Was I to sit on street corners, cloth over my eyes and a begging bowl in front? What could I do in life – a switchboard operator or piano-tuner – or perhaps weaving baskets? Oh, it all seemed so black and despairing. My mind was in constant turmoil and agitation.”

Ollie was a Science lecturer, but his eye condition had already caused him to retire, aged only 61.

“I would have been unable to continue teaching Chemistry and Physics. Already by then I was making mistakes that were personally embarrassing – but laughed them off. I poured liquid into test-tubes and kept missing – right in front of my students.”

Losing his sight had a significant impact on Ollie.

### **“Being thrown on the scrapheap”**

“For years afterwards, I would spontaneously burst into tears – in the street, on the bus, the train, at home, in bed. It was an awful period of my life. Here I was, a highly trained scientist, being thrown on the scrapheap.”

With his wife’s support, Ollie began feeling hopeful again. With a friend, he joined a local group of blind people. Meeting like-minded



people, with similar interests in culture, Ollie received a tremendous boost. He is an active campaigner, typing reports on saving wildlife and opposing planning applications. Ollie is also active in his local community, giving guided tours around his part of north London.

However, Ollie still feels his is a restricted life.

### **“I want to do something different”**

“Losing my sight sapped my confidence to work or to seek employment. So I used the excuse – ‘Oh, I’m retired’. But really I’d loved to have continued teaching. Instead, I sit and type out reports. Reports, reports. They tell me these reports are wonderful. But it is lonely. I want to do something different.”

## Other experiences of working life

**“(At first) I tried to limit myself in my job – by about fifty per cent. In the end I couldn’t go on any further... I couldn’t do the job I used to do... I want to teach engineering, even part-time. Someway, somehow.”**

Barrington Chambers, 39, Bristol.

**“In a professional situation I particularly avoid carrying it (white cane) because I don’t want to be stereotyped and people to have pre-conceived opinions on what I can and can’t do professionally.”** Heather Giles, 54, Maida Vale



**“At the time I was a workaholic... and I thought, being an engineer and losing my sight, ‘what other work can I do?’... (Receiving an award for ‘Player’s Player’ at work) showed me, that for other people, my visual impairment wasn’t a problem.”** Andy Stowe, 53, Mansfield.

**“Everything, everything takes longer... it takes ages... so I have to just learn if I want to continue doing my work... I have to accept I either do less or I take longer than my colleagues to do certain things... the choices I have made at the moment about my career are somewhat influenced by my eyes.”** Heather Giles, 54, Maida Vale.

## Facts and figures

- Onset of sight loss can have a significant or profound effect on individual levels of confidence in the workplace.
- Blind and partially sighted people say factors blocking them from finding a job include the availability of suitable jobs, information about jobs, training and support on offer and levels of individual confidence (19).
- There is a clear cost benefit case for retaining a newly disabled member of staff, instead of terminating their contract and recruiting and then training a new replacement.
- When asked about the main reason for leaving their last job, a quarter of registered blind and partially sighted people said it was mainly due to the onset of sight loss or deterioration of an existing eye condition (20).
- A fifth of blind and partially sighted people of working age describe themselves as long-term sick or disabled. Nearly three-quarters of this group say they left their last paid job because of either their health or their sight loss (21).
- A blind or partially sighted person has to get a degree merely to have the same job prospects as a person that left school with no qualifications (22).

## What must change

Far too many people fall out of employment once they lose their sight. Employers often don't know what is possible or what government help is available. The person losing their sight is devastated by the experience and unaware of the possibilities. The Access to Work scheme provides assistance to both employers and those losing their sight. However, awareness of this and other important services remains worryingly low. One thousand additional people with sight loss every year start to claim Employment and Support Allowance. This figure is too high and we need government-funded employment services to support more people to stay in work after they have lost their sight.

### A better approach

#### South Lanarkshire Council

South Lanarkshire Council has 15,000 employees, and an annual budget of £538 million. The large and varied council area covers rural, upland and urban areas.

South Lanarkshire Council's positive employment practices have gone a long way to removing barriers that might have prevented blind or partially sighted people being part of the work force. Furthermore, they have worked hard to retain staff members who have become disabled.

Gill Bhatti, South Lanarkshire's Employee Development and Diversity Manager, emphasises that employers can actively retain staff members who lose their sight.

"We commissioned training in visual awareness for our staff, as we knew that often only small changes are necessary to allow employees to work differently. We have several blind or partially sighted staff and we do our best to make the necessary adjustments which allow them to stay in their job or to retrain in a new role with us, with appropriate training and support. Advice, training and funding are readily available and we have made good use of Access to Work and RNIB Scotland's employment practitioners."

One of those staff is Thomas Scotland, who worked for South Lanarkshire Council as a parking attendant. After his sight was affected by optic nerve damage, he was re-deployed as a clerical assistant. Thomas said, "I had never really used a computer, and was relieved to know that it could be adapted for me. I had to learn some new skills, and used the funding available from Access to Work to help make the change. It is reassuring to know that my employer was willing to keep me in a job as I have much more to offer."

## Helping people into work: social firms

A social firm is a business developed to provide employment opportunities for people who are severely disadvantaged in the open labour market. “Concept” is a developing social firm based with Action for Blind People in Birmingham, providing conference facilities and onsite catering. Its mission is to provide life skills training in cooking and healthy eating for blind and partially sighted trainees, enabling them to move into a career in the catering or hospitality industries. There is a core team of blind and partially sighted staff who provide support to trainees.

Concept trainee Kevin Johnson has benefited from working at Concept, helping him re-train and gain new skills.

“When I took the trainee post at Concept I had not worked in catering before so I didn’t have any conception of what to expect. I knew it would not be easy because I had worked in the manufacturing industry for the last 20 years. I am more motivated and the new skills and confidence I have gained in the last 12 months will help me with my future job prospects.”

### RNIB will:

- We will help greater numbers of people to keep their jobs after losing their sight and help others into work.
- We will provide workplace opportunities for volunteering, training and learning, which equip blind and partially sighted people for employment.

### RNIB calls on:

- The UK and devolved governments to give greater priority to supporting job retention for people who lose their sight whilst in work.
- The UK and devolved governments to ensure back-to-work support and employment services meet the specific needs of people with sight loss.

# Year one: A long way to go — public attitudes

**“The difficult thing isn’t living with other people, it’s understanding them”**  
Blindness (Jose Saramago).

## **What would you feel like if other people didn’t understand what you were going through?**

When we lose our sight we can’t fully anticipate on “day one” what will happen. We’re often too shocked to envisage how the next twelve months will unfold. We hope and expect people will care, show sensitivity and express solidarity. In many cases they will. But often, whether it’s born out of ignorance or something nastier, we end up feeling disabled by public attitudes. Patronised. Insulted. Overlooked. Let down. Tackling long-held cultural beliefs and educating people about what it means to be a blind or partially sighted person is no easy task. There’s a long way to go.

## Mary Craddock, 76, Redditch, Worcestershire

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“If you don’t ask for help, you don’t get offered any”.

Mary describes herself as a positive person that is fortunate to receive great support from her children. However, she recognises not everyone can rely on family. She thinks public attitudes about blind and partially sighted people have a long way to go.

### “People ignore people”

“A lot of people just think about themselves and they don’t care. If (blind and partially sighted) people go shopping on their own a lot of people take no notice of you”.

Mary acknowledges that you will always find people willing to help, but people that have lost their sight often have to be proactive in seeking out help.

### “They just look away”

“You do get those that do care. For example, there are all the volunteers. Some people are very helpful. Some people if they see you crossing the road with a white cane will stop the car. Other people will just not take any notice. They just look away.”

“There could be more help available in the stores. My daughter Debbie goes shopping with me. I do lead quite an active life thanks to her.”



Mary accepted her sight loss fairly early on and now enjoys Talking Books, learning braille and going to the theatre with Debbie.

“The library is very helpful. They will sort out different books that I haven’t read. I didn’t have a clue about using a computer, but once a week I go to the Bradbury Centre and learn how to use the computer.”

Mary has just five per cent of her vision remaining. Last time Mary went to see her consultant, he informed her it was quite possible that in the not-too-distant future she could lose her sight altogether.

“I try not to think about that,” Mary says. “I try to keep positive.”

## Other thoughts on public attitudes

**“I don’t expect anyone out there to know how I’m feeling. People can be very patronising. People treat you like you’re deaf and dumb as well, like you’re a child.”** Ann Murphy, 76, Chorlton.

**“At the risk of upsetting somebody, they say nothing. People try to be too politically correct - to avoid saying anything that might upset you... that one word: ‘blind’. It’s something you don’t want to say to people. I don’t like it as a word.”** Judith Robson, 55, Stockton-on-Tees.

**“I’m West Indian born. It was one of the most irritating things... people (from the community) approaching me, saying, ‘is that Barrington? What’s wrong with your eyes?’ We need people to go and teach kids about, not necessarily blindness, but blind people.”** Barrington Chambers, 39, Bristol.

**“People have always baffled me. People test out whether I can actually only see through one eye. I don’t want to be looked at as any different.”** Linda Kelly, 59, Catford.

## A long way to go

Disabled people’s rights have improved over the last fifteen years, with advances in legislation and in Great Britain with the establishment of a Government Office for Disability Issues. Legislative change and advances in public policy are extremely significant, but without cultural change – until the public’s understanding of sight loss improves – people who lose their sight will continue to feel disabled.

### Poor public understanding

For many people who lose their sight, it’s the reactions of their family and closest friends and colleagues that matter most, at least at the beginning. Even when loved ones and friends do try to help, this can hinder independent living as they may over-protect, even limiting a person’s ambitions. This can slow successful adjustment to and acceptance of sight loss (23).

People who lose their sight face repeated conflicts between the wish to continue living independently and the need to accept help (24). Feeling that you can’t go out when you wish or that you are no longer able to do certain activities can precipitate feelings of hopelessness and isolation.

### The tag of “blindness”

Attitudes to blindness affect people in different ways. People may feel that losing their sight fundamentally changes their character in some way. People may internalise commonly-held negative beliefs about what it means to lose one’s

sight, or may be over conscious of others' views about blind and partially sighted people.

**"You're at the whim of everybody else and what they perceive as being beautiful, lovely and great."** Linda Kelly, 59, Catford.

It's sometimes the tag of blindness that affects people's adjustment to sight loss. Or people don't feel comfortable using aids that would mark them out as "blind".

**"Later when I considered 'Registration as Partially Sighted or Blind' it would just confirm to the world that I would be useless."** Ollie Natelson, 68, Finchley.

**"I'm embarrassed (about using my white cane)... because its telling people that I'm visually impaired."** Sharon Sutton, 43, Stoke-on-Trent.

Some people become anxious that changes to their sight could lead to changes in their identity.

**"I don't want me to be dominated by sight issues."** Heather Giles, 54, Maida Vale.

## **Need for greater awareness**

Some people comment that they don't obviously "look" blind or partially sighted and that this can cause complications in public.

**"Someone put a note on my car saying, 'what are you doing using a disabled parking pass - there doesn't look anything wrong with you?'"** Sharon Sutton, 43, Stoke-on-Trent.

**"People who think you've got a little bit of residual vision think you're a con-artist. It hurts like hell."** Chris Atkins, 54, Wellington, Somerset.

One of the most important issues for blind and partially sighted people is the need for greater awareness of sight loss amongst the public at large.

**"A young shop assistant passed the form I needed to sign to my wife, and asked, 'Will the client be able to sign it?'"** Andy Stowe, 53, Mansfield.

**"(What people think about going on trips or outings is) 'you can't see, so why do you need to do anything?' People need some sort of awareness training."** Judith Robson, 55, Stockton-on-Tees.

Perhaps most concerning is the complacency and indifference that means most people believe blind and partially sighted people are coping well. Many are but many people who lose their sight struggle at the beginning because they don't receive appropriate help and support. There is a commonly held belief that blind and partially sighted people will be fine as long as charities and local groups help them. The reality is these services often depend on voluntary income.

## Facts and figures

- Research suggests that a practical understanding of sight loss can be lacking amongst blind and partially sighted people's own families (25).
- Just under a quarter of people (24 per cent) have never had any contact with blind or partially sighted people (26).
- Nearly one fifth (18 per cent) of people who don't know anyone who is disabled do not consider blind people to be disabled (27).
- One in ten 18-24 year-olds pities blind people (28).
- Only around half of the public (51 per cent) would be very comfortable with their relative marrying a blind person (29).
- A quarter of 18-34 year olds surveyed by social researchers said they would not feel comfortable if a blind person were to move in next door (30).

## What must change

Despite equality and human rights legislation, there is discrimination throughout society that excludes and marginalises blind and partially sighted people, often just through complete ignorance of what sight loss is and its impact on everyday life. Public authorities must take responsibility for tackling discrimination and promote positive attitudes towards disabled people, including those who are blind or partially sighted. In fact, everyone bears some responsibility – everyone can make small and reasonable adjustments to include blind and partially sighted people in society.

### A better approach

#### Sight loss awareness training

Training courses have a number of objectives, but perhaps the most practical aim is to give sighted people confidence in relating to those with sight loss.

The Cornwall Blind Association has an experienced trainer, who delivers tailor-made training courses for public and voluntary sector staff. The training covers sight loss issues and how service providers can most appropriately offer support to people that lose their sight.

Some of the benefits of sight loss awareness training include an improved understanding of disability rights and discrimination law; information on the practical and emotional effects of sight loss; and practical solutions for employers to help and support blind and partially sighted people in the

**continued overleaf**

workplace. At Cornwall Blind Association a blind or partially sighted person always works with the trainer and speaks about their own experiences.

Training sessions include a quiz, which considers some of the myths, and misconceptions people may have about blindness.

Customers have included the NHS, Cornwall Primary Care Trust and local Age Concerns. Staff feel that the course improves their understanding of sight loss and enables them to deliver a better service.

A staff member at Penwith District Council has said, "It has improved my understanding of how different life is for visually impaired people."

## **RNIB will:**

- We will work with public and private organisations to improve the accessibility of mainstream services to blind and partially sighted people.
- We will run a public awareness campaign designed to communicate the impact and realities of living with sight loss.

## **RNIB calls on:**

- The UK Government to ensure equality law places robust statutory requirements on public authorities to involve disabled people in the design and delivery of services.
- Public authorities and private organisations across the UK to promote positive attitudes towards blind and partially sighted people and ensure full and equal access to services.

# Conclusion – Together we can make a difference

Is getting the help you need to adjust to losing your sight too much to ask? RNIB doesn't think so and the majority of the public agree with us. Whether you are a government minister or an elected councillor, a chief executive of a health body or local authority, an eye doctor or social worker, a member of a community organisation or a concerned member of the public you have a significant role to play. Through the actions you take we can deliver improved services in every part of the UK to support people losing their sight. Together we can make a huge difference.

# Appendix 1: What must change

	<b>RNIB will:</b>	<b>RNIB calls on:</b>
<b>The eye clinic</b>	<ul style="list-style-type: none"> <li>• We will make sure that more people losing their sight receive the information, advice and emotional support they need at this critical time.</li> <li>• We will work with others to increase the opportunities for peer support, enabling people losing their sight to provide mutual support to each other.</li> </ul>	<ul style="list-style-type: none"> <li>• The UK and devolved governments to take a strong lead in improving patient support in hospital eye clinics, opening up access to information, advice and emotional support and counselling for people losing their sight.</li> <li>• Local health and social care services to work together to commission and deliver information and support in the eye clinic to those losing their sight.</li> </ul>
<b>Home life</b>	<ul style="list-style-type: none"> <li>• We will increase the reach of our information, advice and specialist product services to support more people to live independently.</li> <li>• We will increase access to braille, audio and large print books and magazines, including our much-loved Talking Book Service.</li> </ul>	<ul style="list-style-type: none"> <li>• The UK and devolved governments to deliver reforms that enable people who lose their sight to speedily access care and support. Social care assessments should be sensitive to the needs of people who lose their sight.</li> <li>• Local health and social care services to modernise and extend low vision services so that people who lose their sight maximise the use of any remaining vision.</li> <li>• Local social care services to deliver rehabilitation support, which equips blind and partially sighted people to live independently in their own homes.</li> </ul>

	<b>RNIB will:</b>	<b>RNIB calls on:</b>
<b>Getting out</b>	<ul style="list-style-type: none"> <li>• We will increase awareness of local and national services that support blind and partially sighted people to get on with their lives.</li> <li>• We will increase opportunities for peer support so blind and partially sighted people can share experiences and learn from each other.</li> </ul>	<ul style="list-style-type: none"> <li>• The UK and devolved governments to deliver reforms that enable people who lose their sight to speedily access rehabilitation services, including mobility training.</li> <li>• Local social care services to ensure people who lose their sight receive care and support services, which enable their full inclusion, including personal budgets.</li> </ul>
<b>Working life</b>	<ul style="list-style-type: none"> <li>• We will help greater numbers of people to keep their jobs after losing their sight and help others into work.</li> <li>• We will provide workplace opportunities for volunteering, training and learning, which equip blind and partially sighted people for employment.</li> </ul>	<ul style="list-style-type: none"> <li>• The UK and devolved governments to give greater priority to supporting job retention for people who lose their sight whilst in work.</li> <li>• The UK and devolved governments to ensure back-to-work support and employment services meet the specific needs of people with sight loss.</li> </ul>
<b>Public attitudes</b>	<ul style="list-style-type: none"> <li>• We will work with public and private organisations to improve the accessibility of mainstream services to blind and partially sighted people.</li> <li>• We will run a public awareness campaign designed to communicate the impact and realities of living with sight loss.</li> </ul>	<ul style="list-style-type: none"> <li>• The UK Government to ensure equality law places robust statutory requirements on public authorities to involve disabled people in the design and delivery of services.</li> <li>• Public authorities and private organisations across the UK to promote positive attitudes towards blind and partially sighted people and ensure full and equal access to services.</li> </ul>

# Appendix 2: Endnotes

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- (2) Evans, J.R., A.E. Fletcher and R.P Wormald (2007), pp. 283–288.
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- (7) Percival, J. and J. Hanson (2005), pp.189-205.
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- (9) Douglas, G., S. Pavey and C. Corcoran (2008) (a).
- (10) Please note that the figures regarding local authorities are unweighted.  
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