

# Campaign update

Autumn 2009

Welcome to your autumn edition of Campaign update, a quarterly newsletter for RNIB's campaign supporters' network. In this edition, we'll update you on our "What would you lose?" campaign. We will also fill you in on our new campaign for accessible health information, on our goal to meet audio description targets and a new pilot project into accessible textbooks for children.

Our regional and local campaigns update will focus on the work our campaigns staff and volunteers are doing in their communities. Your regional campaigns officer can give you more information about any of the stories in the update.

## If you do one thing!

We want to give campaign supporters lots of ways to get involved and campaign with us. So for each story we include suggested actions for you to take to support that campaign. We hope you'll pick and choose depending on your interests and concerns.

If you only have time to do one thing this time, please read the enclosed campaign briefing extra on accessible health information, and contact us for your "Losing Patients" notification letter.



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## “What would you lose?”

**RNIB’s new campaign will ask the public and key decision-makers to consider what it really means to lose your sight.**

Finding it difficult to go to the pub on your own; being too scared to leave the house after dark; losing touch with friends. These are just some of the difficulties you told us you faced when you were losing your sight.

“I remember just after diagnosis, I had lost my job, my income, my identity as a teacher, my driving licence, 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.”  
Mhairi Thurston, Dundee.

“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...”  
Sharon Sutton, Stoke-on-Trent.

For most sighted people, the idea of losing your sight is too scary to comprehend so we push it to the back of our minds. Many of us may never have considered the day-to-day implications of sight loss and how it would affect our independence, confidence and personal safety.

RNIB’s “What would you lose?” campaign aims to tackle this ignorance by pushing sight loss up the public and political agenda. The campaign will increase awareness of sight loss issues and it will ask the public and key decision-makers in local authorities, health bodies and government to consider the impact of sight loss on people’s everyday lives.

“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, Mansfield.

Dealing with the diagnosis and finding the support you need early on, is one of the key issues that many campaign supporters have told us about.

Our new campaign report called “Lost and found”, published on 16 September, talks about the shock, frustration and the isolation we feel when we’re first diagnosed with an eye problem. It highlights the ignorance that surrounds sight loss and the failure of health and social care services to give people the personal support they need at this critical time.



The report also presents research on the inadequacy of services to help people get on with their lives. Crucially, the “Lost and found” report calls on UK and devolved governments, local health and social care bodies to deliver appropriate support and services to help people find their lives again after they have been diagnosed with sight loss.

“Coping was almost impossible and when 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 suffered these bouts of depression less frequently...”  
Ollie Natelson, Finchley.

The “Lost and found” report makes it clear that there is life after you lose your sight. However, this cannot happen without people receiving appropriate and joined-up support and services. We 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 wants a better deal for blind and partially sighted people works for change, and the campaign will also aim to recruit a new generation of supporters.

## Campaigning at a national and local level

MPs will get their first taste of the new campaign during the UK Party Political Conferences in September and October. This will be followed by a range of actions at a regional and local level. In the first year, we will be working to:

1. make sure patient information in eye clinics, GP surgeries and hospitals is provided promptly and in the patient’s preferred reading format (for example, large print, braille, audio or electronic formats).
2. ensure that high-quality information, advice and support services are routinely available to everyone who experiences sight loss.
3. make sure that counselling and emotional support is available to everyone who loses their sight. This should include a spectrum of support, from peer support to counselling.

## Take Action!

**Share your experiences.** If you’d like to consider having your own story featured in the media, we would love to hear from you. The initial aim of the “What would you lose?” campaign is to raise awareness of sight loss issues through personal stories. We don’t just want to tell people how tough it is when you lose your sight, we also want people to know that there is hope and support – be it from RNIB or other sources. So if you’re willing to share your experience of losing your sight, the difficulties you’ve encountered or how you’ve overcome these difficulties, please contact Bill Alker or another member of the media team on 020 7391 2223 or email [bill.alker@rnib.org.uk](mailto:bill.alker@rnib.org.uk)

**Visit RNIB’s website.** If you have access to the internet, you can read the “Lost and found” campaign report online at [rnib.org.uk/lost-and-found](http://rnib.org.uk/lost-and-found) directly from people who have experienced sight loss.

As the campaign develops, we’ll be providing campaign toolkits and national and local template letters that you can use to contact decision-makers about the campaign. There are lots of ways to keep informed about campaign progress. Developments will be featured in future editions of Campaign update and you can also visit our website at [rnib.org.uk/lost](http://rnib.org.uk/lost). Don’t forget your national and regional campaign contacts are always on hand to let you know how the campaign is developing nationally and if anything is happening in your area. Contact details can be found at the end of this update.

## Campaign launch for accessible health information in Sheffield



Eighty people packed into Sheffield Royal Society for the Blind on July 17 to launch “Losing Patients” – a new campaign to help blind and partially sighted people secure accessible information from the NHS.

Local MPs Nick Clegg and Richard Cabourn gave powerful speeches of support, following an impassioned testimony from Sheffield resident Sarah Bryan, who struggled to get medical test results in a format she could read.

### Take Action!

This edition of Campaign update includes a campaign briefing extra all about the Losing Patients campaign. In it, you can find out more about Sarah’s experience, main findings of the campaign research and how we can work together to end the injustice of inaccessible health information.

## Campaign Voice

“I am Pauline Cooper and am a volunteer campaign coordinator with RNIB. I am registered blind and have a guide dog called Emily.

I moved to Wellingborough in 2008 and soon afterwards registered with the local GP clinic not far from my home. Unfortunately, on asking for my medical records in an accessible format, I was told this wasn’t possible and couldn’t someone read the information to me.

I obviously wasn’t going to accept that. I knew the law and my rights and the fact that the clinic has to provide me with information in an accessible format – large print in my case. So I spoke to and then wrote to the practice manager asking for large print information as otherwise the clinic would be breaching the Disability Discrimination Act. The practice manager didn’t sound convinced until I told them that I was seeking legal advice (through RNIB), then things changed.

I got an apology in large print and now get all my letters in large print and the clinic staff know that I need an accessible format and offer to ring me with the results of tests or provide information in my preferred format.

It wasn’t easy but because I knew my rights and the law it meant I wasn’t going to take no for an answer. It is really important that people ask for these things as without asking we’ll never get the service we deserve.”

# Calling parents of blind children. Where's my child's book?

It is no secret that if pupils are not given textbooks, they will not get a proper education. Yet thousands of blind and partially sighted children get their textbooks after their sighted classmates, often in the wrong format, or in some cases not at all. RNIB research in 2006 showed that less than one in forty maths or science books are available in large print at key stage 3.

### Does this sound familiar?

We've long been campaigning for accessible textbooks along with other "Right to Read Alliance" members. Teachers have told us they need a proper system that helps them meet the needs of pupils who find it difficult to read standard print. After years of campaigning by RNIB and our allies, the government has now recognised the issue. Some textbook publishers provide electronic versions of textbooks so that accessible versions can be created easily, and the government is now funding a pilot project in England that builds on this approach. Progress has been painfully slow, and we know that every week that passes children are missing out, so we're pursuing this vigorously across the UK.

The pilot scheme starts this September and will run for a year. There will also be an additional year of analysis of the results and a report to suggest the best long-term solution. Whilst it progresses, we'd like to help parents and blind and partially sighted pupils to improve the current system in



their area and ensure that teachers and schools understand their needs. If you're the parent of a blind or partially sighted pupil, we have some "top tips" that you might want to give to your child's teacher(s). These give practical advice on common sense steps teachers can take when providing information. We've also started working with organisations specialising in this field such as the parent's organisation, "LOOK", and the National Blind Children's Society (NBCS)

### Take Action!

Contact your regional campaigns officer for your copy of the practical "top tips" briefing and advice on how to ensure that teachers and schools understand the needs of blind and partially sighted pupils. Contact details are listed at the end of this Update.

## Crucial campaigning opportunity to influence audio description targets

At the moment, broadcasters are only required to audio describe 10 per cent of their programming but we want more. You may recall that in May's Campaign update we reported on our very successful February parliamentary reception on audio description. We also said that OfCOM wanted to wait until it completed its 2009 "Access Services Review" before deciding whether to recommend an increase of the Audio Description (AD) target to 20 per cent. This review has now been announced. OfCOM intends to consult widely to "assess the costs to broadcasters and the benefits to users of an increase in the audio description quota".

After months of sustained campaigning, the review represents a not-to-be-missed opportunity for blind and partially sighted people to influence OfCOM's

recommendations in favour of an increase to 20 per cent.

We're concerned that certain sections of the media will argue that in these times of financial hardship it is too expensive to increase the AD target. There is a real danger that OfCOM listens to these arguments. So if you've supported the AD campaign in the past, or if you're a new campaign supporter and would like to find out more about the benefits of AD and why it's so important we achieve an increase of 20 per cent then please get in touch.

### Take Action!

We have a short briefing about the OfCOM consultation, including the main points we need people to make in response to the review. It is available from the campaigns team. Email [campaign@rnib.org.uk](mailto:campaign@rnib.org.uk) or telephone 020 7391 2123.



# Defending Attendance Allowance

In July 2009, the Government published a social care Green Paper, Shaping the future of care together to address the challenge of growing demands on England's social care system.

One of the proposals in the paper is that Attendance Allowance (AA) should be abolished and the money used to help plug the gap in funding for social care. We agree that this gap needs to be plugged – but not at the expense of AA. We're very strongly opposed to the loss of this important benefit.

We'll tell the Government very clearly why this measure would be very bad news for blind and partially sighted people. We'll join with other organisations in campaigning against its abolition and we'll be collecting evidence on the difference that AA makes to the lives of people with sight loss.

### Take Action!

Tell the Government your views. The Green Paper consultation closing date is 13 November 2009. If you get AA yourself, or know someone who does, say what you or they spend it on and what you'd miss out on if it wasn't there.

You can let the Government know your views by

- emailing [careandsupport@dh.gsi.gov.uk](mailto:careandsupport@dh.gsi.gov.uk)
  - going to the website [www.careandsupport.direct.gov.uk](http://www.careandsupport.direct.gov.uk) or
  - writing to the Care and Support Team, Room 149, Richmond House, 79 Whitehall, London, SW1A 2NS
- Please copy us into what you say by emailing [gfmister@rnib.org.uk](mailto:gfmister@rnib.org.uk) or writing to Geoff Fimister, Campaigns team, RNIB, 105 Judd St, London, WC1H 9NE.

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## Regional and local campaigns update

**Our regional campaigns officers have been working hard around the country. Here's a round-up of some of the work taking place (if you'd to like contact your regional campaigns officer about these or other issues, you can find contact details at the end of the Update):**

### Essex cars on pavements

Essex access forums, groups of disabled people from across the county, and others have been working to stop cars parking on

– and blocking – pavements, but little had happened. Until now...

As this issue affects blind and partially sighted people, Diane Stedman, the Essex volunteer campaign coordinator, was keen to get involved and make something happen. She met with local councillors, a police officer and other interested groups and everyone agreed that action was needed.

Hundreds of instances of people prevented from safely walking to their local shops,



doctors or other locations, due to cars parking on the pavements, were raised. In one example, a lady in a wheelchair was prevented from going to vote as cars continually parked across pavements, blocking her way to the polling station.

At the meeting, it was agreed that a leaflet would be produced and it would be funded by Essex County Council. The leaflet will be put on all cars that are found to be illegally parked on pavements; it will highlight the impact of their action and state that if they do it again, they will face a fine. The police will then follow up any persistent offenders, fining them if they don't find somewhere else to park.

In addition, councils and others across Essex will be writing to the new chief constable of Essex police to call for increased powers for community support officers (PCSOs) to issue fines to illegally parked cars. This is something the PCSOs and local people want because it'd make it a lot easier to effectively tackle parking on pavements.

The campaign starts in October and if successful it will be rolled out across Essex and beyond.

### **Northampton pavements, footpaths and waste collections**

In January, Northamptonshire Association for the Blind (NAB)'s Viewpoint magazine published a letter from campaigner Arnold Civil. In the letter, he highlighted problems with footpath and pavement damage and the hazards of household waste collection, wheelie bins and recycling boxes left on the pavement. Northampton north MP, Sally Keeble, responded to the letter from Arnold by raising the issues with Northamptonshire County Council, highlighting areas where tree roots created a major hazard for blind and partially sighted people. She also mentioned the problem of overhanging trees and shrubs.



Working with NAB and RNIB, Arnold met with Northampton Borough Council Waste Operations Team to discuss recycling and waste collection. Arnold highlighted the problems faced by blind and partially sighted people, such as the haphazard way bins and boxes are left on the kerbside and the amount of rubbish following collections. The council team acknowledged the issues and stated that where bins were left out for extended periods the council would fine people.

Arnold suggested that wheelie bins should have a bright reflective strip or markings as a visibility aid for all. The council team agreed to talk to bin manufacturers to incorporate these in new bins, while NAB and RNIB would look for funding for reflective stickers for existing bins. As a result of the meeting, all the information provided by the Waste Operations Team will now be available in audio – either on CDs or on the council’s website.

Another meeting, this time with Northamptonshire County Council, addressed the issue of uneven pavements. The Highways Maintenance representative outlined the procedures and guidelines under which repairs are undertaken and stressed repairs are a matter of priority and finance. NAB agreed to promote the “Street Doctor” – how individuals can report pavement issues – and is going to work with the councillor responsible for highways to raise awareness of the need for householders to trim overhanging greenery.

### **Darlington’s support for “beep beeps”**

Roy Ruddick (regional campaigns officer for Yorkshire, Humber and the North East) has been assisting Noel Hemmings (a member of Darlington Charities of the Blind) to challenge the local authority over the removal of audible warnings from pedestrian crossings.

Following information from our advice team, Roy found out about the legislation and the latest Department for Transport guidance. This information was used to support Noel

at a meeting with the Highway Department and the Chair of the local disability group.

As there is overwhelming support for the restoration of the “beeps” (Noel’s survey was over 98 per cent in favour), the local authority has now agreed to carry out a Disability Impact Survey.



**The photograph shows Roy and Noel at one of the “silent crossings”.**

### **Out of touch in Newham**

A major campaign is underway in Newham – and it is the result of an anonymous tip off. We received a phone message alerting us to a change of council policy towards the use of tactile paving in Newham.

Crossings will no longer have tactile paving across the pavement, even though this is what alerts blind and partially sighted people to a safe crossing point. Instead, there will only be two lines of “bubble” tactile paving and it will be grey – the same colour as the rest of the paved area.

Further research by Mohammed Mohsanali, our volunteer campaigner in the area, also revealed that this had been done without

any consultation with disabled people. This was made even more frustrating by the fact that the Council said they made the decision because it inconvenienced people with mobility impairments.

So we wrote to the council's chief executive, requesting that the policy be suspended to allow a proper level of consultation to take place. We highlighted how important tactile paving is and how their policy would result in blind and partially sighted people being made less safe and therefore less likely to venture out alone.

We await the council's response. In the meantime the campaign would be helped considerably if residents of the borough were to write to their MP and local councillor to express concern about this policy and the harm which the new policy would cause.

### **Hazardous crossings in Warwickshire**

Continuing with the subject of tactile paving... Our legal officer, Anne Singh, was delighted to receive the following quick limerick from a campaigner in Warwickshire, who had been investigating options for improving the safety of crossings where he lives. His discussions with the local council in Warwickshire prompted this:

**A blind man, whilst walking around  
"Nowhere" were tactiles to be found  
The Council stated Oh! Mister  
We have no Corduroy nor Blister  
Only "Officers on the ground"**  
by Vaughan Rees, 2009

Thanks for your poetic efforts Vaughan – they made our day!

### **Good Practice in Sight in Oldham**

Our Action for independent living campaign aims to identify local authorities that aren't providing good services for blind and partially sighted people – and work to improve the services in that area.

As part of the campaign, we're working with Oldham local authority to analyse their service performance against the guidance laid down in our Good practice in sight guide. This guide illustrates how services for blind and partially sighted people should be delivered, in nine benchmark areas, including emotional support, referral and training. Oldham are beginning to look at how users can access emotional support and IT training and how referral routes into their services can be improved. We're hoping to undertake similar work with other local authorities across the North West, including Wirral in Merseyside.

### **Making the most of LINKs in Manchester and Wigan**

Two campaign volunteers in the northwest are becoming strongly involved in Local Involvement Networks (LINKs), which are charged with looking at health and social care provision in their local area. Volunteers in Manchester and Wigan are undertaking "Enter and View" training in order to be able to observe hospital and other health services and make recommendations on how they can be improved for people with sight problems. LINKs can be very useful contacts. It might be worth finding out about the LINK in your area.

### **Are you online?**

Help us save resources and improve our campaign communications: let us know if you're online and if you'd like to receive your Campaign update by email. From January, we'll be launching a new campaign e-newsletter which will make it easier to communicate campaign achievements and opportunities. Contact our campaigns hotline on 020 7391 2197 or email [campaign@rnib.org.uk](mailto:campaign@rnib.org.uk) to give us your current email address and postcode.

### **Get in touch**

#### **Central campaigns contact and enquiries:**

Campaigns hotline 020 7391 2123; email [campaign@rnib.org.uk](mailto:campaign@rnib.org.uk)

#### **Regional campaigns contacts:**

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