

# Campaign update

## Winter 2010

Welcome to your winter edition of Campaign update, a quarterly newsletter for RNIB's campaign supporters' network. This edition looks at progress made by the "Lost and Found" campaign to improve support at the time of sight loss, since its launch last autumn. We also report back on how you are helping to ensure that the accessible health information "Losing Patients" campaign really gains momentum and we have a round-up of national and regional campaign news and successes, plus lots more.

### If you do one thing!

Our campaign supporters are absolutely crucial to helping us achieve campaign success. There are lots of ways you can get involved and campaign with us, but if you only have time to do one thing this edition, please help us campaign for improved support at time of sight loss. Contact us for your own "Lost and Found" campaign pack which includes templates and a three-step guide to taking action. Find out more in the first story.

[rnib.org.uk/campaigns](http://rnib.org.uk/campaigns)



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## Lost and Found campaign

### Why are people left without information, advice and support when they first lose their sight?

- Fewer than one in ten blind and partially sighted people are offered formal counselling by their eye clinic when they are diagnosed.
- Nearly a quarter of blind and partially sighted people leave the eye clinic unsure of the name of the eye condition that caused them to lose their sight.

Being told that you are losing your sight can be emotionally traumatic. With the right support in place people can accept there is life after sight loss. Yet emotional and practical support to help people adjust to this enormous change is severely limited.

In autumn 2009, we launched a Campaign report called “Lost and Found” calling for improved support when patients are diagnosed in the eye clinic. Our mission is to make sure eye clinic patients are not left to face sight loss on their own. As supporter Andy Stowe, whose own experience contributed to the campaign report, says “an extra little bit of help and advice right at the beginning would [have gone] a long, long way” to help him accept the news he was losing his sight. In fact his confidence levels dropped and he found it difficult to get out and about on his own.

Momentum for the campaign is growing. Already MPs are showing great interest in



Mark Harper, MP, Shadow Minister for Disabled People visits the interactive RNIB stand at the Conservative Party Conference in October

the campaign. After we took an interactive display to last year's party conferences and the Houses of Parliament, many MPs decided to investigate the support available to eye clinic patients in their local area. Even the Chief Executive of the NHS has got involved, stating his concern that patients' needs aren't being met and that they are receiving inadequate services.

Now we have the recognition that there is insufficient support, we need local NHS organisations to prioritise improvements. Across the country only about 30 eye hospitals have a member of staff working in the eye clinic specifically to support patients after they see the consultant. To meet the needs of everyone being diagnosed, 100 more hospitals need to deliver these vital patient support services.

### Take Action!

A campaign resource pack is available which will give you the tools and templates to take three important actions to join the "Lost and Found" campaign:

- Ask your local NHS about its plans to support people who lose their sight.
- Call for an urgent investigation into care services.
- Ask local people what support they would expect and help raise public awareness of the issue.

Contact the campaigns team or your regional campaigns officer for a copy of the pack in your preferred format. Contact details can be found at the end of this update.

## Campaign Voice

Heather Giles, a volunteer campaigner, addressed MPs at a "Lost and Found" Parliamentary reception on 8 December. The reception highlighted areas around the UK that do not have vital patient support services in the eye clinic to support patients after they have received their diagnosis of sight loss. She tells Campaign Voice why she decided to support the "Lost and Found" campaign by speaking to MPs at the event:

"I've just been through the experience of moving from a sighted world into a visual impairment world and trying to find out how to access help and support in what was a difficult and complex journey. It's important for MPs to hear from someone who has recently done that journey. We have got to raise awareness of the need for good support when people are losing their sight. Without this, people are going to get lost literally and not have access to essential support."



Heather Giles addresses MPs at the "Lost and Found" Parliamentary Reception

## Losing Patients

**Our “Losing Patients” campaign is about empowering people to secure their own health information in accessible formats.**

To get this hot topic to hit home, we’re joining with local societies and associations of and for blind people to hold public meetings across the country. We want to bring the people who run our health services face to face with those of us affected by inaccessible health information.

In the autumn campaign update, we reported on the Sheffield Royal Society for the Blind launch of the campaign at which MPs expressed astonishment that blind and partially sighted people still could not get confidential health information, such as test results, in the format of their choice. Everyone agreed that the culture of giving blind people information in print should end. Since that launch, we’ve had two more hugely successful and well-attended events in Enfield, North London and Batley, Yorkshire. See page 14 for reports on these events.

As well as attending these events, Campaign supporters have been sending hundreds of requests for accessible information to their healthcare providers using RNIB’s campaign pack. At the time of publication, more “Losing Patients” events are planned including:

- Milton Keynes 19 January
- Nottingham 29 January
- Cornwall 5 February.

Events in North Lancashire, Worcester and the London borough of Merton are likely to follow.

### Take Action!

If you or someone you know struggles to get health information in an accessible format from your GP, hospital clinic or pharmacist, we urgently want to hear from you. Please contact the Campaigns team on 020 7391 2123 to share your experience and request a “Losing Patients” resource pack, which includes the template notification letter you can send to your own GP surgery, hospital or local clinic.



Mike Wood MP speaking at the Batley “Losing Patients” event.

## Campaign victory on bus passes!

From 1 April 2008 a new national concessionary travel scheme was introduced. This meant that every eligible older or disabled person in England can now receive free bus travel from 9.30am to 11pm, but it also gave local authorities the power to choose which extra elements of subsidised travel they implemented (also known as “discretionary elements”). As a result many areas have reduced the free travel available at other times, meaning that blind and partially sighted people are prevented from travelling before 9.30am, and free companion passes have been withdrawn in certain parts of the country. This change has also caused confusion for people travelling between local authority boundaries.

RNIB received a number of complaints about the effects of this change and decided to submit them to the Local Government Ombudsman, an independent body that looks at complaints about councils and other authorities.

The Ombudsman found in favour of all the complaints. He said the people affected were left with a “justified sense of outrage”. The finding was “maladministration causing injustice” and the Ombudsman requested that each of the seven councils pay the nine complainants £100 compensation each. Four of the councils have now reinstated travel before 9.30am and the other three councils have agreed to review their position on concessionary travel.

This Ombudsman decision is influential and a great result for campaigners. However, it cannot be used to challenge other local authorities who removed concessionary elements on 1 April 2008, because complaints need to be lodged within a year.

The report unfortunately does not force any other local authorities to respond or to change their policies, but it will be a useful future campaign lever.

### Take Action!

RNIB will be campaigning to get free companion passes added to the national concessionary fare scheme and to reinstate free pre-9.30am travel. If elements of your concessionary bus pass have recently been reduced, or are under threat, please contact Miriam Haywood on 020 7391 2123.

### Send a message to the Secretary of State for Transport

Sense have set up a link which allows you to send a message to the Secretary of State for Transport. It only takes two minutes to do – go to:

<http://bit.ly/buspasscampaign>

Alternatively, call RNIB campaigns on 020 7391 2323, and we will send you information.



## Legal action against shared surfaces

As councils around England continue to propose shared surface designs for redeveloping town centres, RNIB continues to support Guide Dog's "Say no to shared streets" campaign.

Plans for Exhibition Road in London, home to the Science Museum and the Natural History Museum, have been declared unsafe and unlawful by the campaign. Guide Dogs have issued a Judicial Review against the Royal Borough of Kensington and Chelsea council who plan to start work on the scheme this January. Also, Lord Low, former chairman of RNIB, has secured a short debate in the House of Lords on this issue which is likely to take place in January.

The council's plans to redesign Exhibition Road come at an estimated cost of £25 million and include replacing the raised kerbs with an untested tactile corduroy strip to separate cars and pedestrians. As Tom Pey, Guide Dogs' Director of External Affairs says "Blind and partially sighted people need consistency in the design of streets. If they can't tell where the road begins and the pavement ends, how can they feel safe?"

Exhibition Road represents a potentially dangerous trend that is happening across the country. The creation of a single surface for cars, cyclists and pedestrians to share can be disorientating and dangerous to blind and partially sighted users.

### Take Action!

If you have heard that your local council is planning a shared space scheme in your area now is the time to act. Guide Dogs have produced a "campaign in a box" which contains all the tools campaigners need to start a campaign in your local area and can be downloaded from [guidedogs.org.uk/sharedstreets](http://guidedogs.org.uk/sharedstreets)

For more information about the judicial review or to join the "Say no to shared streets" campaign contact Guide Dogs on 0118 983 5555 or email [guidedogs@guidedogs.org.uk](mailto:guidedogs@guidedogs.org.uk)



## The future of Attendance Allowance?

In the summer of last year, the Government published a Green Paper on the future of social care called “Shaping the future of care together” to address the challenge of growing demands on England’s social care system.

This paper contained the proposal that Attendance Allowance should be abolished and the money used to plug the gap in the funding of social care. Disability Living Allowance (DLA) for people aged 65+ is also under threat. We responded to all the proposals, but it was this issue that we felt needed urgent action.

The Green Paper does say that existing claimants will be protected, but this misses the point. This whole debate is about the future.

Over the course of a four month public consultation many of you joined the fight

to save this important benefit. As a campaign network, individually as RNIB and with other charities we wanted to make sure the government understood the importance of Attendance Allowance and DLA. A “Number 10” online petition to ensure that the benefits are not removed as part of any future reform of the social care system in England collected 23,694 signatures, showing just how great the support is.

The Government is currently looking at this paper to decide what parts of it they want to take further. If the threat to Attendance Allowance and similar benefits continues, so will the campaign.

For more information, or to discuss the Social Care Green Paper further, please contact us on 020 7391 2123 or email [campaigns@rnib.org.uk](mailto:campaigns@rnib.org.uk)



## Ofcom consultation – audio description (AD)

Just under 500 individuals, organisations (including RNIB and local societies), broadcasters and other interested groups replied to Ofcom's consultation on the future of AD. The vast majority of those were from blind and partially sighted people who told Ofcom they supported Option 2 – increasing AD targets to 20 per cent on all TV channels. Thank you to everyone who took the time to reply to Ofcom and to those who wrote to their MP.

We expect a recommendation from Ofcom in late January or February. The Secretary of State must then decide whether to accept their recommendation. If Ofcom

recommend increasing audio description targets we will urge the Government to act quickly. Because it's likely that a general election will be called in late March there isn't much time to make this change in law. If that doesn't happen before the election we will need to work with whichever party forms the new Government to make this change.

We may need your help to put pressure on Government. We'll be in touch by email as soon as we hear from Ofcom. However, please do call us on 020 7391 2123 if you would like to be involved.



A still from Coronation Street appeared in an advertising campaign to raise awareness of AD

## Future Vision begins tour of colleges

RNIB's "Future Vision" tour was officially launched at Hull College by the Home Secretary, Alan Johnson on 4 December. The event was a great success attended by students, local PCT staff and Dr Elaine McMahon, Principal of Hull College.

The Future Vision tour is an exciting and innovative RNIB project aimed at 16-25 year old students studying at vocational colleges. The project uses a virtual ageing booth to increase awareness of the relationship of lifestyle choices to the risk of developing eye disease as we age. The project also highlights the importance of regular eye tests in adult life.

After a week at Hull College the tour will move to Southall College, West London in January, followed by a visit to Oldham College, Manchester and Matthew Boulton College, Birmingham in February before going to seven other sites across England, Scotland and Wales in 2010-11.



Jonjo Minns and Kim Walker, students at Hull College, outside the Future Vision booth

## Election fever!

Election fever is nearly upon us! Although at the time of publication we can't be sure when, we believe that Gordon Brown will call a general election in spring 2010.

We need to make sure that eye health and support for people who are blind or partially sighted is on the agenda, and that people with sight loss have the chance to have their say. A group of organisations – charities and professional bodies – got together last year to write the "UK Vision Strategy Manifesto", laying out the main things which we want a new Government to achieve.

Between now and the election, RNIB, along with local blind and partially sighted people and societies, Action for Blind People, Guide Dogs and other supporters, is co-ordinating meetings in marginal seats with candidates for each of the main three parties. We've already had meetings in Bristol, Stoke, Loughborough and Aylesbury, with lots more planned.

### Take Action!

MPs and candidates need to know about the issues and how they affect blind and partially sighted people. Get a copy of the "UK Vision Strategy Manifesto" by calling the campaigns hotline on 020 7391 2123, and contact your MP and candidates and tell them how these affect you and what you want them to do – we can help you find out who they are.

## In your area

**Our regional campaigns officers have been working with campaigners across the country. If you would like to contact your regional campaigns officer about these or other issues, you can find their details at the end of the update.**

### Action for Independent Living – Northumberland (Low Vision) Action Group

The Director of Adult Care at Northumberland Care Trust has responded to evidence collected by Northumberland Action Group (NAG) regarding standards of care experienced by blind and partially sighted people.

25 service users contributed to a positive and lively debate which followed the submission of evidence that NAG collected against each of the benchmarks of good practice contained in RNIB's "Good Practice in Sight" guide.

At a subsequent meeting with the manager of the Sensory Services Team of Northumberland Care Trust and the Northumberland County Blind Association, delays in issuing the Certificate of Visual Impairment (CVI) was identified as a major problem. The CVI is the trigger for support services to commence and any delay can adversely affect services individuals receive.

### Safe access denied at Sheffield Railway Station?

A planning application to install automatic barriers and touch screen ticket machines at Sheffield railway station has brought together RNIB, Sheffield Royal Society of the Blind and local residents who are concerned that access would be severely compromised.

Having access to the town centre and station platforms from the Supertram is of great assistance to people who are blind or partially sighted. Preventing free access from the Sheffield Supertram to the town centre and university would also mean the loss of a safe route for people who are blind or partially sighted. Roy Ruddick, RNIB Regional Campaigns Officer has submitted an objection to the planning application.

### Touch-screen ticket machines in Manchester – your views needed!

New touch-screen ticket machines are being introduced across much of the Manchester Metrolink tram service. This tram network extends from central Manchester out to places such as Salford, Eccles, Altrincham and Bury. Touch-screens can be problematic for blind and partially sighted people as it can be difficult to navigate round the screen if there is no audio output.

If you or anyone you know regularly uses the Metrolink service or if you are travelling into Manchester from elsewhere, we need your feedback. Let us know how easy you find these machines to use or if you encounter any problems purchasing a ticket.

## Manchester opens new eye hospital

The Manchester Royal Eye Hospital opened its doors to a new development in August this year. It is the second largest eye hospital in the UK and one of the largest eye-teaching hospitals in Europe. Despite this, we do have concerns over some access issues with the new development, such as a lack of tactile signage or flooring, inconsistency in lighting levels, access to lifts and the training of volunteers who are there to escort patients. We are looking to work with the Hospital Trust on these issues but if you have any feedback about your experiences of using the new hospital, we would very much like to hear from you.

## Birmingham New Street Station announcements back on

Network Rail has responded to pressure from campaigners concerned that the train announcements on the concourse at New Street Station had been stopped, putting blind and partially sighted travellers at a disadvantage.

As a result of a number of meetings and media coverage, Network Rail agreed to switch over half of the announcements (one per train) back on for a trial period of time to find out if this worked for both staff and users of the station.

Blind and partially-sighted campaigners took part in an organised 'walk through' of Birmingham New Street station to investigate the impact of the compromise. The feedback given has been submitted to Network Rail and we are currently awaiting a response.

## Nottingham city walk about

The refurbishment of Nottingham city centre has left blind and partially sighted people finding it harder to get about. Members of the Nottingham branch of the National Federation of the Blind, supported by RNIB and the Nottinghamshire Royal Society for the Blind, wanted action.

An invite to Nottingham City Council resulted in an opportunity to show the Council Leader, Chief Executive and key council officers the problems of no colour contrast on tactile paving or bollards; tactiles that didn't extend to the building line; badly placed crossings which lead people into the middle of busy roads; and tram stops next to crossings where you have to be careful not to end up toppling off the platform instead of crossing the road.

Showing council representatives the day-to-day impact of these hazards resulted in a meeting where issues were acknowledged and agreements made to investigate changes. The next phase of refurbishment starts in January 2010.



Interactive demonstration of pavement obstacles organised by Guide Dogs for "Sight Matters" Day in Nottingham

## Cars off pavements launched in Essex

The Lord Lieutenant of Essex, Douglas Carswell MP and a host of local dignitaries and representatives gathered to share a “Cars Off Pavements” cake at the launch of the Tendring parking campaign.

More than thirty of the local great and good joined RNIB volunteer campaign coordinator, Diane Stedman, Jill Allen King from the National Federation of the Blind and Ruth Stockdale, Regional Campaigns Officer from RNIB at the launch. Everyone was encouraged to spread the word about the campaign and get involved by telling Police Community Support Officers (PCSOs) when cars block pavements.

In the first month of the campaign, PCSOs handed out 39 warning leaflets to urge car drivers to park elsewhere or face a fine. So far none of those drivers have been caught parking on the pavement again. Many car drivers have been positive too saying they appreciate the campaign and will take more care about where they park in the future.



Volunteer campaign co-ordinator, Diane Stedman (fourth from right) at the launch of the “Cars off Pavements” campaign.

## Noises off in South West London

We were contacted by an optician in South West London who alerted us to a traffic light controlled crossing which had been ‘updated’ by Transport for London. The ‘update’ was to remove the audible signal, leaving the crossing with just a tactile indicator – a rotating cone – of when it was safe to cross.

Questions to the Mayor of London, Boris Johnson, though have revealed that crossings should have both tactile and audible signals unless this would cause a noise nuisance to local residents. The audible signal on this crossing is being reinstated, but it could be a worrying future trend.

Be aware of any ‘updates’ to crossings in your area of London, we need to ensure they have both audible and tactile signals so that the mobility of blind and partially sighted people is not reduced.

## Bristol Cycle City

An RNIB volunteer campaign coordinator and RNIB are working with Bristol City Council over the design of new cycle paths.

Bristol City Council has been awarded money to turn Bristol into the country’s first Cycle City, hoping to double its number of cyclists. Whilst we applaud encouraging healthy living and reducing CO2 emissions from cars, a number of blind and partially sighted people have started to raise concerns about the number of cyclists using pavements as cycle paths.

We are asking Bristol City Council to raise awareness of pedestrians and to encourage safe cycling on cycle paths and the road.

## Losing Patients in Batley

The Society for the Blind of Dewsbury, Batley and District hosted a successful “Losing Patients” event on Friday 20 November. Among the sixty people attending were key people from the local NHS, including the Chief Nurse and Director of Patient Experience from Mid Yorkshire NHS, the Head of Public Involvement at Kirklees NHS and a senior Orthoptist at Calderdale and Huddersfield NHS.

The gathering heard from individuals who had not been able to independently access their health information, from appointment letters to test results and medicine instructions. People at the event took away their own campaign action pack. There will be ongoing engagement with NHS professionals to keep up the pressure to end the practice of giving blind and partially sighted people health information in print that they cannot read.

Contact your regional campaigns officer if you would like your own copy of the “Losing Patients” campaign resource pack or visit [rnib.org.uk/losingpatients](http://rnib.org.uk/losingpatients)



## Losing Patients in Lincolnshire

RNIB volunteer campaign coordinator, Cyril Wakefield, contacted his GP surgery in response to the “Losing Patients” campaign. Cyril is registered blind and for years tried to get audio health information but always failed. This looked likely again when the standard print response from his GP said alternative formats weren’t possible, but they did pass his query on to NHS Lincolnshire.

Rachel Taylor, Diversity Manager at the United Lincolnshire Hospitals NHS Trust, emailed immediately asking for Cyril’s feedback on a new interpretation and translation policy including information about accessible information. A positive meeting was held on 30 November. Cyril and colleagues from the South Lincolnshire Blind Society are now helping Rachel work out how the new policy will be implemented to provide accessible health information for blind and partially sighted people across Lincolnshire.

## Losing Patients in North London

The “Losing Patients” campaign got off to a very successful start in London with an event in Enfield.

The audience heard from two MPs, local health trusts and most importantly two people who were speaking about their own experiences with failing to access health information. The success of the event was to a large extent the result of the relationship between Enfield Vision, the local society, campaign supporters and RNIB. Thank you to the impressive numbers who came out to support us on a dreary wet day.

## Shape the way RNIB is run

As a valued campaign supporter, we know you like to add your voice and lend support to causes that matter to you. Becoming an RNIB Member gives you an opportunity to do this, connecting with other members in your area, proactively shaping the work of RNIB.

We want blind and partially sighted people to be at the heart of everything we do, so we've recently introduced a new way of working, which gives our members a greater influence at the highest level of RNIB, through a network of 12 regional Member Forums.

Forum discussions are driven by what members tell us the key issues are. Travel,

shopping and banking were the hot topics talked about during the autumn events. Attendees also had the opportunity to put themselves forward to represent their region nationally at the UK Member Forum.

Member Forums are just one of the great things about being an RNIB Member. There are a range of benefits including an award winning bi-monthly magazine, *Vision*. Membership costs £15 a year by direct debit or £17 for other payment methods.

To find out more call our Membership Team on 0303 1234 555 or email [membership@rnib.org.uk](mailto:membership@rnib.org.uk)



RNIB Members attend the South East Members Forum in Brighton

## Are you online?

Help us save resources and improve our campaign communications: let us know if you're online and if you are able to receive your campaign update by email. Please contact the campaigns team 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) or visit [rnib.org.uk/campaigns](http://rnib.org.uk/campaigns)

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