

# Lost and Found

## Improving support for people when they discover they are losing their sight: A step-by-step campaign guide

### Lost and Found campaigners' resource pack

Being told that you are losing your sight can be emotionally traumatic. People often liken the experience to bereavement, with shock, disbelief and anger being common emotions. Yet emotional and practical support to help people adjust to this enormous change when they first receive the news that they are losing their sight is severely limited.

RNIB's "Lost and Found" campaign is calling for improved support when patients are diagnosed in the eye clinic. There are systemic failings in our health service which mean too many people are diagnosed with sight loss but are then effectively left to "rattle along on their own" with no idea where they can find help.

We hope this pack gives you the information and tools to be able to support our campaign by taking action in your local area to improve the information, advice and support that are so vital to someone who has just been told that they are losing their sight.

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### What needs to change?

#### The facts

"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, Lost and Found campaign report.

- Fewer than one in ten (only 8 per cent) of blind and partially sighted people are offered formal counselling by their eye clinic when they are diagnosed.
- Nearly a quarter (or 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.
- One fifth of people say they do not recall receiving any visit from social services in the year after they were registered as blind or partially sighted
- The number of people with sight loss is set to double to nearly 4 million by 2050.

## The campaign aim

The "Lost and Found" campaign aims to ensure that high-quality information, advice and emotional support are routinely available to individuals who are told that they are losing their sight.

## What is high-quality support?

"High-quality support" describes the patient's whole experience of health care services when they are first informed their sight loss is permanent. It consists of information, advice and emotional support commissioned or provided direct by the NHS which enable eye clinic patients to feel:

- **K**nowledgeable about next steps, including referral to low vision and community care services
- **I**nformed about their eye condition and sources of local and national help
- **E**ncouraged by the fact that their needs have been properly assessed by a trained professional
- **R**eassured that practical and emotional support is available and comforted that there are people they can speak to about the implications of their diagnosis.

We use the acronym "**KINDER**" to describe this approach.

## The crucial role of patient support officers

Having a dedicated patient support officer in the eye clinic ensures provision of crucial information, advice and support to individuals at time of sight loss which promotes independence and well-being.

The role of a patient support officer, known as an "ECLO" (Eye Clinic Liaison Officer) is central to the welfare of patients in an eye clinic as they act as a bridge between medical staff and other sources of support, including Community Support Services (for example social services), counsellors and local societies of and for visually impaired people.

Perhaps most importantly, ECLOs ensure that patient care continues beyond the consultation room doors. For one individual this might mean help with keeping a job, referral to a helpline service and support with financial problems. For another person, it might mean giving information on their eye condition, referral to peer support groups and benefits advice.

## **The three key campaign messages**

1. High-quality information, advice and support for individuals who are told they are losing their sight should not be left to chance.
2. At present, patient support services in eye clinics are extremely patchy, with some areas of the country delivering a number of high-quality services to people who lose their sight and some barely any at all. In fact, fewer than 50 Primary Care Organisations across the UK currently have an ECLO service. This is significantly less than half the total number of ECLO services required.
3. Primary Care Trusts have a duty to consider the future health needs of their local population. ECLO services will become more important as sight loss is set to increase. By 2050 the numbers of people with partial sight and blindness in the UK will double, to nearly 4 million people.

Despite their effectiveness in supporting independence and adjustment to sight loss, thereby preventing long-term dependence on health and social care service, local NHS and local authorities have funded few ECLO posts to date.

## **Section 1: Lost and Found – three steps to taking action**

We need as many people as possible to take all three steps outlined in this section. By taking these steps you can support the campaign nationally and within your local area. We have supplied the tools in the form of letter templates and a survey that will be used to raise awareness and gather vital information and support.

Regardless of where you live in England, you can take three simple actions now to support the Lost and Found campaign and help to secure high-quality information, advice and support so that no one has to struggle alone when they first find out they are losing their sight.

### **Step One: Write to your Primary Care Trust**

Your Primary Care Trust (or PCT) is responsible for buying and securing health services (referred to as "commissioning") on behalf of the population in an area of the country or for a group of patients. There are 152 PCTs in England, each one covering a separate local area. Your PCT has a duty to work together with local councils to identify the priorities for local health and wellbeing in something called a "Joint Strategic Needs Assessment" (JSNA).

We have created a template letter which you can send to the Director of Commissioning at your local PCT to ask them what their plans are for delivering high-quality support to people who are losing their sight. The template includes a response form which the letter asks the PCT to complete and send back to you.

[<Click here to download a pdf of the PCT letter and response form>](#)

[<Click here to download an accessible word version of the PCT letter and response form>](#)

## Your letter will:

- Highlight RNIB's Lost and Found campaign within the PCT
- Draw attention to the new "World Class Commissioning" guide, 'Improving eye health services' and most importantly,
- Ask how the PCT plans to cooperate with the local council to identify the future eye health needs of the local population, providing world class services for people with visual impairments.

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### How to send your letter

1. Download the template letter and response form in PDF format or accessible word (see links above).

2. Find out which PCT covers your local area by contacting your GP surgery or local hospital, your RNIB Regional Campaigns Officer or by searching via the following link: <http://www.nhs.uk/ServiceDirectories/Pages/ServiceSearchAdditional.aspx?SearchType=PCT&ServiceType=Trust>

3. Add your address details and the name of your PCT to the top of the letter, and again to the top of the Primary Care Trust response form. This is section that you would like your PCT to return to you.

4. If you can, ask a couple of your friends or neighbours if they will also send a copy of this letter to the PCT.

5. Please do send a copy of any responses you receive from your Primary Care Trust to "Lost and Found", RNIB campaigns, 105 Judd Street, London, WC1H 9NE or email [campaign@rnib.org.uk](mailto:campaign@rnib.org.uk).

Please ensure you indicate your name and the name of your PCT at the top of the Primary Care Trust response form before you send your letter to your PCT. This will help us to track responses.

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### Step Two: Ask five people to complete the "Expectations Survey"

Throughout the campaign we want to raise awareness of the unacceptable gap between the services people think they would get if they were to lose their sight and the reality of the situation as revealed in the "Lost and Found" campaign report (see Section 3 for details). We have included a campaign tool in your pack that will help you to raise awareness of the need for high quality support at the time of sight loss amongst people who do not have personal experience of sight loss.

This tool is the "Expectations Survey" (Appendix 1). The survey asks people three questions about the kind of support that they believe would be available to them if they were to lose their sight.

## How to use the Expectations Survey

1. Hard copies of the survey are available from the campaign team, or you can download them in pdf format, print off from the campaign website (see link above) and post back to us. Alternatively you can complete the accessible Word version and email to the campaigns team (click on link above).
2. If you can, ask five to ten people who do not have personal experience of sight loss to complete the survey. This could involve asking your friends, family, neighbours or colleagues, setting up a campaign stall on your high street, or asking a community group that may not have any connection with sight loss issues to complete the survey. Undertaking the survey this way will help raise awareness of the issues amongst the general public.
3. The survey is designed to be quick and easy to complete. Once it is completed, ask the individual to compare their responses to the statistics revealed in the "Lost and Found" campaign report. If you are doing face-to-face surveys it might be useful to memorise the three statistics on the reverse of the survey so you can talk them through with people, explain the impact the lack of support can have and why the current situation isn't acceptable.
4. Ask the individual if they would like to help ensure no one is left to struggle alone when they first lose their sight by finding out more about the campaign and how they can get involved themselves. If the answer is yes, ask them to provide their contact details on the survey. Of course there are plenty of other ways to register your interest in the campaign if you are not taking part in the "Expectations Survey" – read Step Three or find contact details in Section 3 of this pack.
5. Please email completed surveys to us at [campaign@rnib.org.uk](mailto:campaign@rnib.org.uk) or post to "Lost and Found", RNIB campaigns, 105 Judd Street, London, WC1H 9NE and we will send them their own "Lost and Found" campaign pack and ensure that they are kept up to date on the progress of the campaign.

If you are interested in getting more involved at a local level (see Section 2), you can use your expectations survey to support your local campaign work. Ask your Regional Campaigns Officer for more information on how to do this.

## Step Three: Become an RNIB campaign supporter

Joining the free campaign supporters' network is the best way to keep up to date with the progress of the "Lost and Found" campaign.

Securing an ECLO in every eye hospital will not be a quick or easy task, particularly in today's economic climate with decision-makers seeking to cut services and reduce budgets wherever possible. However, with the number of people with sight loss set to double to nearly 4 million by 2050, it is more important than ever that we work together to ensure no one has to struggle alone without information, advice and practical support when they find out that they are losing their sight.

Our Regional Campaigns Officers are working with Action for Blind People (part of the RNIB group), volunteers, campaign supporters and local organisations to secure

improved support in targeted areas across England. We can keep you updated when there are developments in your region, and will invite you to take further action in support of the campaign as it develops.

There are several ways you can contact us to join the campaign network and keep up to date on "Lost and Found" campaign developments:

- Telephone the campaign team in London on 020 7391 2123 or email [campaign@rnib.org.uk](mailto:campaign@rnib.org.uk)
- Write to "Lost and Found", RNIB Campaigns, 105 Judd Street, London, WC1H 9NE
- Contact your Regional Campaigns Officer – details are contained in Section 3 of this pack.

## **Section 2: Getting more involved at a local level**

This section gives an overview of how you can raise awareness of the need for and benefits of patient support officers in eye clinics who can provide vital information, advice and support to people when they first find out they are losing their sight.

### **Finding out what's going on**

Before you begin campaigning, it is really important to find out what support is already provided locally and whether there are any groups who are already working to try to improve the information, advice and support available to people who find out they are losing their sight.

A good way to do this is to make contact with groups and individuals locally. Local societies of or for blind people, service users, UK Vision Strategy Groups and local low vision services committees will all be invaluable sources of information. You may find that there are groups in your area who are already trying to secure a patient support officer in your local eye clinic.

Your Regional Campaigns Officer may be able to tell you what is going on in your area, or provide you with contacts to get you started.

### **Influencing decision makers**

Your Primary Care Trust (or PCT) is responsible for buying and securing health services in your local area and therefore has the power to commission patient support services in the eye clinic. They are a key public body to influence locally.

You will need to provide the evidence and the arguments that will persuade your PCT of the importance and benefits of providing a dedicated patient support officer in your local eye clinic.

Joining your Local Involvement Network (referred to as LINKs) could be a really important way to influence those who make decisions about new or existing services for blind and partially sighted people. LINKs are open to everyone and aim to provide their local

communities and individuals with the chance to have their say about how local services are planned and run.

To find your local LINK, contact your local council or telephone the NHS Centre for Involvement on 024 7615 0266 or visit the website, [nhs.uk](https://www.nhs.uk) and search for "LINKs".

## **Influencing local strategy**

Your local council and PCT have a duty to work together in undertaking a Joint Strategic Needs Assessment (or JSNA).

The JSNA is an important strategic document that should identify the current and future health and wellbeing needs of the local population, together in one place. This information is then used to inform future service provision and commissioning strategies to meet those needs, so it is important to try to influence the content of the JSNA, ensuring it contains information related to eye health and sight loss. RNIB's campaign report "Cost Oversight" is a useful source of evidence to help you do this (see Campaigners' Directory in Section 3).

Try to find out who is taking a lead on producing the JSNA for your local area by searching the council's website, or telephoning your council's Democratic Services Officer. Three essential questions to ask are: 1) Have you consulted with blind and partially sighted people when putting together your JSNA?; 2) Have you included information about the prevalence of sight loss in your JSNA?; and 3) Did you know that the number of people with sight loss is set to double to nearly 4 million by 2050?

Often JSNA consultation events will be promoted through LINKs. Signing up to LINK newsletters will keep you updated with this.

## **Increasing the pressure**

As your campaign progresses, you may decide that it would be useful to bring the issues to the attention of your local council's Health Overview and Scrutiny Committee. These committees have a role in reviewing performance by external organisations in the local area, such as local NHS organisations. They can recommend that NHS bodies should consider taking certain steps to improve policy, and because councils and the NHS work in closer partnership than ever, Health Overview and Scrutiny Committees have greater powers to review how services are being provided.

Your Regional Campaigns Officer can give you more information about how and when to ask your local Health Overview and Scrutiny Committee to review how local health and social services are working together to support people when they lose their sight.

In April 2009, Government placed a statutory duty on local councils to respond to local petitions that achieve a certain number of signatures, including electronic petitions. A new "Councillor Call for Action" also came into effect around this time making it easier to bring certain issues to the attention of, and to be debated by, a local authority's Overview and Scrutiny Committee. What this means is that if you bring concerns about the lack of support available to local people when they lose their sight to the attention of councillors, they now have the ability to call for debate and discussion at a Committee meeting so neighbourhood concerns are properly raised.



Organising a local petition, inviting your local MP to champion your campaign and getting your local media interested in the issues are all good ways to increase the pressure, raise awareness and get others involved in your campaign. Your Regional Campaigns Officer can give you advice on any of these campaign techniques.

## **Advice and information to help you campaign**

RNIB's Regional Campaigns Officers are working with colleagues in targeted areas to improve information, advice and support for people when they first lose their sight. To find out more about the information contained in Section 2 of this pack, contact your Regional Campaigns Officer (contact details can be found in Section 3) and ask for your step-by-step guide to "Campaigning for better support in your local eye hospital". This guide covers:

- the evidence that you will need to gather to support your campaign
- how you can effectively engage the public and raise awareness
- what your routes of influence are and
- who you may need to lobby to achieve your campaign aim.

## **Section 3: Campaigners' Directory**

### **Your central Campaign contacts**

For general queries, campaign updates and to register your interest in "Lost and Found".

Address: "Lost and Found", RNIB Campaigns, 105 Judd Street, London, WC1H 9NE

Telephone: 020 7391 2123;

Email: [campaign@rnib.org.uk](mailto:campaign@rnib.org.uk)

Website: [rnib.org.uk/campaign](http://rnib.org.uk/campaign)

### **Your Regional Campaigns Officers**

Contact your Regional Campaigns Officer for an update of what is going on in your region, for hard copies of campaign reports and briefings and for general advice and information on campaigning.

- For the Yorkshire, Humber and North East regions contact Roy Ruddick on Telephone: 0113 386 2808; or email [roy.ruddick@rnib.org.uk](mailto:roy.ruddick@rnib.org.uk)
- For the South West region contact Tara Melton on Telephone: 0117 934 1707; or email [tara.melton@rnib.org.uk](mailto:tara.melton@rnib.org.uk)
- For the North West region contact Lindsay Armstrong on Telephone: 0151 298 3233; or email [lindsay.armstrong@rnib.org.uk](mailto:lindsay.armstrong@rnib.org.uk)
- For the London and South East regions contact Richard Holmes on Telephone: 020 7391 2112; or email [richard.holmes@rnib.org.uk](mailto:richard.holmes@rnib.org.uk)
- For the East Midlands and Eastern regions contact Ruth Stockdale on Telephone: 01509 632 403; or email [ruth.stockdale@rnib.org.uk](mailto:ruth.stockdale@rnib.org.uk)



## **RNIB Briefings and research**

The reports and briefings listed here are useful background reading and include evidence that can be used to support your local campaign.

- "Lost and Found" campaign report – hear directly from individuals who struggled to find information, advice and support when they first lost their sight and access nationwide statistics which can support your calls for improved support. Download the report at [rnib.org.uk/campaign](http://rnib.org.uk/campaign)
- "Cost Oversight" campaign report. Information on the costs associated with sight loss which can provide you with essential arguments and evidence to support your campaign – download at [rnib.org.uk/campaign](http://rnib.org.uk/campaign)
- RNIB campaign briefing on high-quality information, advice and support. What are the key elements that enable people to feel knowledgeable about their next steps, informed about their eye condition, encouraged by the fact that their needs have been properly assessed by a trained professional and reassured that there is practical and emotional support available when they are first diagnosed with sight loss? This briefing outlines the practical and emotional support that should be available for everyone diagnosed with sight loss.
- RNIB campaign briefing on patient support officer roles in eye clinics. This briefing looks at the essential role that a patient support officer (or ECLO) plays and outlines the benefits both to patients and the NHS and social services.
- RNIB campaign briefing on influencing your Overview and Scrutiny Committee.
- "Levers for Change" campaign report – due for publication in Spring 2010. Contact the campaigns team for more information.

## **Campaign resources, guides and further reading**

The NHS centre for information guide to Local Involvement Networks (LINKs) can be found at website: [nhscentreforinvolvement.nhs.uk/linksguides](http://nhscentreforinvolvement.nhs.uk/linksguides)

The Centre for Public Scrutiny's guides and publications on Scrutiny can be found at website: [cfps.org.uk/what-we-do/health/guides-and-publications](http://cfps.org.uk/what-we-do/health/guides-and-publications)

The Centre for Public Scrutiny's guide "10 questions to ask if you are scrutinising local eye health provision" can be found at website: [cfps.org.uk/what-we-do/publications/cfps-health/?id=102](http://cfps.org.uk/what-we-do/publications/cfps-health/?id=102)

The world class commissioning guide "Primary Care and Community Services: Improving eye health services" can be found at website at [dh.gov.uk](http://dh.gov.uk) then type the words "eye health" into the search field.

The Centre for Public Scrutiny and IDEA's guide – designed for councillors – sets out how councillors might seek to get a local issue debated by a council meeting. It can be found at website [idea.gov.uk/idk/core/page.do?pagelid=10393727](http://idea.gov.uk/idk/core/page.do?pagelid=10393727)

## **Campaign supporters' network**

Join our campaign supporters' network and you'll receive a campaign update which currently goes out to all RNIB campaign supporters three times a year and will include stories on how the campaign is progressing at a national and local level. Contact the

campaign hotline on telephone 020 7391 2123 or email [campaign@rnib.org.uk](mailto:campaign@rnib.org.uk) and tell us that you are interested in following the progress of the "Lost and Found" campaign.

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