

Lobbying for the UK Vision Strategy

in the run-up to the General Election

The lobbying campaign in England



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The lobbying campaign in England

Background

The UK Vision Strategy has brought together blind and partially sighted people, users of eye care services, eye health and social care professionals and statutory and voluntary organisations. This ground-breaking coalition has produced a unified framework for action on all issues relating to vision

In line with that successful process of joining together at national level, this campaign is designed to involve the eye health and sight loss sectors in each locality using the messages of the vision manifesto expressing its aims and aspirations.

The aim

The aim is to lobby each Member of Parliament and the Parliamentary candidates of the other two political parties in each constituency in the run-up to the UK General Election. It is intended that this work should be carried out from spring 2009.

It is conceivable that the election will be held as early as June this year. Although that does not seem very likely at this stage, we need to complete this work to promote the UK Vision Strategy agenda.

The Lobbying opportunity

Because the outcome is likely to be close, the next General Election will provide us with a more favourable lobbying environment than we have known for some time. The run-up to the Election, and the Election itself, offer a powerful opportunity to spread understanding about our issues. The campaign is non-party political, and there is every reason to

believe that all three parties can be persuaded to adopt policies that will improve the delivery of eyecare in the community and services for blind and partially sighted people. There will, of course, be competing health and social issues, but we have to do all we can to ensure some prominence for our agenda.

This is an opportunity we have to grasp to push our issues up the political agenda within the scope of the UK Vision Strategy.

The Manifesto

The campaign will seek to advance the UK Vision Strategy. The National Manifesto (attached) is based on the Strategy.

Top Line Messages

- Eye care services and support for blind and partially sighted people should have a much higher priority in the next Parliament. The UK Vision Strategy sets out what needs to be done.
- Sight loss has a devastating impact on people's lives.
- Sight loss costs the nation over £5.5bn a year.
- Half of all sight loss is preventable.

Supporting points

- There needs to be improved and easily accessible community eye care provision (as exists in Scotland and Wales). This means more people having a regular eye test; more eye disease detected at an earlier stage; and more people's sight is saved.
- We need to ensure high quality specialist services are available in secondary care, and that people referred through from primary care get the treatments they need to save their sight.
- We need rapid access to services at time of sight loss including rehabilitation and emotional support.
- We need a society that promotes the independence of blind and partially sighted people. Our specific asks are for an

accessible environment without shared space and the continuation and enhancement of Attendance Allowance.

Timing

As indicated above, this is timed from spring 2009 as a focussed programme of lobbying.

Whilst this is primarily aimed at England, there is relevance to the other countries of the UK, notably for UK determined issues. The details of the lobbying campaign in Northern Ireland, Scotland and Wales will need to be planned by the local Vision Strategy groups to suit their differing needs.

Approached in the right way, politicians of all parties will be interested in what we have to say. We can win friends and make important and influential allies.

The Campaign

The proposal is that a consortium representing all health and social care providers and groups representing blind and partially sighted people, will invite the local Member of Parliament and, separately, the candidates of the other two parties to visit an appropriate location such as an optometric practice or a resource centre in their constituency.

It is essential that all parts of the wider sector are represented at each event, including blind and partially sighted people.

These should be individual visits (i.e. one candidate at a time) on a specific invitation, perhaps to a practice where the optometrist or owner is sympathetic to that party – or at least able to converse in a friendly way! According to the strength of the bodies locally, one will have to take the lead. Candidates are likely to welcome such an invitation, particularly if you arrange for someone to take photographs for the local paper. You could also supply a photo for the candidate to use in literature and on their website.

Organising the visit

Agree among the organisations who will take the lead, and who will make the approach. This could be the owner of the practice hosting the visit, the manager of the local society or someone from secondary care. The scope of services available at the resource centre, if you have a good one locally, should be highlighted to the MP/Candidate alongside the services available at optometric practices.

Write to the MP or candidate (see sample letter) asking them to visit and meet a team from the organisations taking part. Say that you want to highlight gaps in the community eye care services locally, explain the impact that improved services would have on preventing blindness, and discuss the availability of appropriate support for blind and partially sighted people.

Follow this up with a telephone call to their office to try to fix up the visit, and be armed with a variety of dates and times to offer. Explain that it need not be a lengthy meeting, but you want to outline how the UK Vision Strategy relates to their constituency, what gaps there are in services locally, and how they can be improved.

Most MPs will need to do this on a Friday or Saturday, but the team greeting the MP will need to be flexible to fit in with the very busy diary of your MP and candidates. It may be necessary to arrange the visit during the evening. Most MPs and candidates are likely to agree to a visit and this is by far the most effective way to influence them. But if this proves to be impossible then, as an alternative, you could arrange to meet them either at the MP's advice surgery, or at a venue and time to suit them.

When you have agreed a time and place for each visit, please let us know about it. See contact details on page 8.

How to handle the visit

Before the visit you must make sure that the team are up to date with:

- The local epidemiology www.eyehealthmodel.org.uk.
- Local extended eye care services schemes.
- The quality and accessibility of local support services such as rehabilitation and emotional support.
- Any particular local access issues e.g. shared space.

During the visit, you should explain who the organisations are and why you have come together. If held in an optometric practice, the practice owner (or manager) should briefly outline why the optometric practice is central to a number of these issues, what services are provided, and what could additionally be provided for patients, and the impact that would have on detecting eye disease and preventing blindness. If held in a local society resource centre, the manager or Chief Executive and people who use the service should demonstrate the equipment and services available.

The team greeting the MP or candidate should reflect the organisations taking part, but not be so large as to swamp the occasion, and those taking part should be capable of sticking to the brief. After all, it is all about informing and influencing the MP, not an occasion for every participant to reel off their shopping list of ideas and problems. Having said that, it is vital that someone who is blind or partially sighted is present at every visit.

At the end, give the MP/Candidate a copy of the Manifesto.

Two things to do after the visit

Write a note of thanks. (See sample) Include the points made during the visit and in particular the key points from the brief.

Let us know about the responses you receive. They are potentially valuable allies, and knowing how each visit went will enable us to keep in touch with them if this is appropriate,

and initially to thank them for their support. Please send brief details to: Heather Marshall (Eye Health Alliance) or Chris Hedges/Moira Fraser (NALSVI/RNIB) (see below for contact details).

If possible please send or email the appended form.

Further information

Heather Marshall or Sarah Lapham

Eye Health Alliance

email: electioncampaign@aop.org.uk

website: www.eyehealthalliance.co.uk

Or

Chris Hedges **NALSVI** or Moira Fraser **RNIB**

email: chris.hedges@opensight.org.uk

website: www.opensight.org.uk

email: moira.fraser@rnib.org.uk

website: www.rnib.org.uk

Other organisations:

Guide Dogs

email: susan.sharp@guidedogs.org.uk

website: www.guidedogs.org.uk

Royal College of Ophthalmologists

email: kathy.evans@rcophth.ac.uk

website: www.rcophth.ac.uk

Vision 2020UK

email: m.brace@vision2020.org.uk

website: www.vision2020uk.org.uk

Who is your MP and who are the candidates?

For information about your local MP or candidates and local press please contact:

Heather Marshall or Sarah Lapham

Eye Health Alliance

email: electioncampaign@aop.org.uk

website: www.eyehealthalliance.co.uk

Or

Chris Hedges **NALSVI** or Moira Fraser **RNIB**

email: chris.hedges@opensight.org.uk

website: www.opensight.org.uk

email: moira.fraser@rnib.org.uk

website: www.rnib.org.uk

To find out who your local MP is and which constituency they represent type in your postcode:

<http://findyourmp.parliament.uk/commons/l/>

For further information about the UK Vision Strategy and to download the full strategy document go to:

<http://www.vision2020uk.org.uk/news.asp?newsID=1140§ion=000100050006>

To find out the latest prevalence data on people with AMD, Glaucoma, Cataract and Low Vision in your area go to:

www.eyehealthmodel.org.uk

Background briefing

The UK Vision Strategy is a ground-breaking UK-wide initiative which has brought together, for the first time, people with sight loss, users of eye care services, eye health and social care professionals and statutory and voluntary organisations to produce a unified framework for action on all issues relating to vision.

The UK Vision Strategy has been developed in response to the World Health Assembly VISION2020 resolution to reduce avoidable blindness by the year 2020 and improve support and services for blind and partially sighted people. The UK Vision Strategy responds to shortfalls in the UK's eye health and sight loss services and addresses the exclusion of blind and partially sighted people and widespread ignorance and apathy about eye health.

Three strategic outcome areas

1. Improving the eye health of the people of the UK

Five-year aim: To raise awareness and understanding of eye health among the public, including those people most at risk of eye disease, to allow every individual to develop personal responsibility for eye health and to achieve maximum eye health for all. To raise awareness of eye health among health and social care practitioners, and to ensure the early detection of sight loss and prevention where possible.

2. Eliminating avoidable sight loss and delivering excellent support for people with sight loss

Five-year aim: To improve the coordination, integration, reach and effectiveness of eye health services, and services and support for those people with permanent sight loss.

3. Inclusion, participation and independence for people with sight loss

Five-year aim: To improve the attitudes, awareness and actions of service providers, employers and the public towards

people with sight loss and to remove significant barriers to inclusion, so that people with sight loss can exercise independence, control and choice. To achieve improved compliance with disability discrimination legislation.

The UK Vision Strategy seeks a major transformation in the UK's eye health, eye care and sight loss services. A determined and united cross-sector approach will make that change a reality.

The policy purpose is to focus on four main areas:

- Raising awareness of the importance of regular sight testing in preventing vision problems and avoidable blindness.
- The value of eye care being provided in the community as it is in Scotland and Wales supported by high quality specialist services.
- The need for early support to be made available to those with vision loss.
- The need to remove the barriers to inclusion, so that people with sight loss can exercise independence, control and choice.

The team meeting the MP will need to use local examples and statistics to illustrate these points. For instance, the prevalence of AMD, Glaucoma and Cataract, and Low Vision is available for each PCT area in the recent National Eye Health Epidemiological Model, available at www.eyehhealthmodel.org.uk.

Eye care in the community

In relation to eye care, we need to expose those areas where PCTs are ignoring eye care issues and not making provision for acute referral services, stable glaucoma monitoring, and adequate diabetic retinopathy screening services. These initiatives require the provision of adequate hospital based specialist services. We will particularly concentrate on the

borders with Wales and Scotland, and areas adjoining PCTs who have funded high quality community provision. In relation to services for visually impaired people, we will need to highlight areas where PCTs and local authorities are not providing appropriate levels of service.

With an ageing population the number of people who will have an eye condition or visual impairment is set to increase, placing a greater demand not only on eye care services but rehabilitative social services and secondary health services. Early detection through regular eye tests and early treatment will therefore be crucial to reduce the number of people with avoidable sight loss and to reduce the burdens on the NHS.

Early support at time of sight loss

In relation to support at time of sight loss, we need to focus on those areas where PCTs are not supporting an Eye Clinic Liaison Officer/ Patient Support Officer Service, and where emotional support services for those newly diagnosed are poor. Also, in some areas, newly registered people are having to wait many months before having their needs assessed by the local authority social services department. This needs to be challenged as do instances of poor provision of rehabilitation services. The local society for the blind as well as service users (RNIB members or Guide Dog users) will be aware of the service quality in the area.

An inclusive society

In any area there are likely to be some “hot issues” regarding blind and partially sighted people’s ability to access services, or to move around safely and independently in the external environment and obtain paid employment. For example, the local authority may be planning to introduce a shared space scheme and this could be discussed with the candidate.

Sample invite: MP/PCC letter

[Address of host]

House of Commons,
London,
SW1A 0AA

OR

[Address of the Prospective Parliamentary Candidate(PCC)]

[Date]

Dear (insert name),

On behalf of (names of organisations) I am writing to invite you to meet with us to discuss issues in relation to eyecare provision and support for the visually impaired people in your constituency.

We are concerned that much of the provision here does not match up to what is available in some parts of the country and we would like to explore with you how services can be improved in (name of town).

If possible, we would like to meet with you at (name and address of optometric practice or resource centre). We know that your diary will be busy, and we are very happy to fit in with your schedule.

The (Insert names of local participating organisations) have come together as part of the UK Vision Strategy which was launched last year to try to ensure that we eliminate preventable blindness and to improve the availability of services to those with visual impairment. It is estimated that two million people are at risk of losing their sight in the UK.

I will telephone your office to discuss a convenient date and time.

With best wishes

Yours sincerely,

[Name]

Sample invite: MP/PCC letter (illustration)

Mrs Sally Handy
Chairman
Anywhere Local Optical Committee
14, The Avenue
Anywhere
AW3 8QT

John Blunt MP,
House of Commons,
London,
SW1A 0AA

26th January 2009

Dear Mr Blunt,

On behalf of Anywhere Society of Blind People and Anywhere Local Optical Committee, I am writing to invite you to meet with us to discuss issues in relation to eyecare provision and support for the visually impaired people in your constituency.

We are concerned that much of the provision here does not match up to what is available in some parts of the country and we would like to explore with you how services can be improved in Anywhere.

If possible, we would like to meet with you at my optometric practice which is at 69, The High Road in Anywhere. We know that your diary will be busy, and we are very happy to fit in with your schedule.

The Society of Blind People and the Local Optical Committee have come together as part of the UK Vision Strategy which was launched last year to try to ensure that we eliminate preventable blindness and to improve the availability of services to those with visual impairment. It is estimated that two million people are at risk of losing their sight in the UK.

I will telephone your office to discuss a convenient date and time.

With best wishes

Yours sincerely,

Sally Handy

Sample thank you note

[Address of host]

House of Commons,
London,
SW1A 0AA
OR

[Address of the Prospective Parliamentary Candidate.]

[Date]

Dear Mr./ Mrs./ Ms./ Dr. [NAME],

Thank you very much for meeting with us.

We greatly enjoyed the occasion, and we are grateful for the opportunity to meet you and to explain the range of services that are available and to explain how they could be improved.

As we explained, we do think that a major transformation is needed in eyecare provision and sight loss services in (name of Town). We think that this needs a national approach, and we hope that, in the next parliament, you will support:

- better community eye care provision (as exists in Scotland and Wales).
- regular sight testing in order to detect eye disease at an earlier stage.
- rapid access to services at the time of sight loss including rehabilitation and emotional support.
- independence for blind and partially sighted people
- proactive government-supported campaigns targeted at saving people's sight.

If you have any further questions or if we can assist you in any way, please do not hesitate to get in touch.

Thank you once again for meeting with us and for listening to our concerns.

Yours sincerely

(Name)

UK Vision Strategy

General Election Campaign 2009

Please return this form via email, fax or post to the
Public Affairs team at the AOP

Sarah Lapham, Public Affairs Officer

Email: sarahlapham@aop.org.uk

Fax: 020 7261 0228

Post to: Sarah Lapham, c/o AOP, 6th Floor, 61 Southwark St
London SE1 0HL

Your Information

Name

Organisation

Job title

Telephone number

Fax number

Email address

About your event

Date of meeting

Location

MP / Candidate

Name:

Party:

Sum up briefly how the event went, i.e. was there a positive response from
the candidate/ were they supportive of the issues raised?

Was a press release issued?

If yes, who issued it?

Appendix 1: The UK Vision Strategy

A Manifesto for England

Sight loss

... has a devastating impact on people's lives

... costs the nation over £5.5bn a year

But half of sight loss is preventable

So we are asking for

... a higher priority for eye care services

... improved support for people who have lost their sight

... a society that includes visually impaired people

What is the UK Vision Strategy?

The UK Vision Strategy has been developed in response to the World Health Organisation's initiative to eliminate avoidable blindness by the year 2020 and improve support and services for blind and partially sighted people.

In the UK all the leading organisations concerned with eye health and sight loss played a direct role in developing the Strategy. Also many people who use eye health and sight loss support services were involved in its formulation. This powerful combination gives the UK Vision Strategy a credibility that cannot be ignored.

The UK Vision Strategy seeks a major transformation in the UK's eye health, eye care and sight loss services. We need your support to make this happen.

1) We need:

- **better community eye care provision, as exists in Scotland and Wales**
- **more people having a regular sight test**
- **eye disease detected at an earlier stage – which will save the sight of more people.**

Half of all sight loss is preventable. However, far too many people are not having a regular eye test that can identify eye disease at an early stage. Even though sight loss is more feared than cancer, AIDS, stroke, and heart disease (1) many people are simply not caring for their eyes. With a disease

(1) American Foundation for the Blind, 2007.

such as glaucoma robbing up to 40% of a person's sight before they are aware of it, a regular sight test is vital. Many eye diseases, such as glaucoma, one of the main causes of blindness, are treatable if detected early enough.

Sight Tests: There is an urgent need to increase the proportion of the population having a regular sight test. There is also a need to provide uniform high standards of community eye care across the UK, with England following the example of Scotland and Wales.

2) We need to ensure high quality specialist care is available in secondary care. People referred through from primary care get the treatments they need to save their sight.

In the UK, age-related macular degeneration (AMD), glaucoma and diabetic retinopathy are the three main causes of certification as blind or partially sighted. Their age specific incidence has increased over the last 15 years, with diabetic retinopathy figures more than doubling in the over 65s. All three conditions are treatable and it is therefore vital that high quality specialist services are readily available.

AMD: Rapid access to NICE approved treatment for wet AMD should be in place across the whole of England. All patients should be seen by a retinal specialist within two weeks of referral from an optometrist.

Glaucoma: Patients with glaucoma should be seen regularly and no one should lose their sight because of cancelled or delayed follow-up appointments. We need properly resourced and managed shared care schemes involving a range of health care providers.

Diabetic Retinopathy: A high quality diabetic retinopathy screening service with uniformly high take-up should be in place, as recommended in the Diabetes National Service Framework. Full diagnosis and treatment should be quickly available following a positive result.

3) We need rapid access to services at time of sight loss including rehabilitation and emotional support.

Rapid access to support and services at time of sight loss is essential if people are to maintain their confidence and independence. However, the reality across the UK all too often falls a long way short of this. Many eye

clinics do not provide any form of support service. One in five people recently diagnosed as blind or partially sighted have not been visited by a social or rehabilitation worker to have their needs assessed and services provided.

Eye Clinic Liaison Officers are critical to delivering support. Working in the hospital Eye Department, they provide a rapid assessment of the needs of the individual, immediate advice and onward referral to appropriate health and social care services. This service should be uniformly available across England.

Emotional support including counselling is almost non-existent, despite the trauma of sight loss. A lack of support means that people regain their confidence much more slowly and struggle to learn new skills. Depression is at least twice as high in visually impaired older adults than in older people with good vision (2). Sight loss is also associated with a higher risk of suicide (3). It is therefore essential that appropriate mental health and counselling services are available to address what can be severe emotional support needs.

Rehabilitation services are needed to provide practical coping strategies and new mobility skills for the home and the external environment. This should include a range of specialist equipment and training, such as a CCTV to assist with reading and a computer with speech software.

4) We need a society that promotes the independence of blind and partially sighted people.

People with sight loss face huge challenges in undertaking everyday tasks that sighted people take for granted. Access to public services, leisure and employment opportunities can be seriously limited by inaccessible public transport and the lack of recognition in the benefits system of blind people's real transport costs. A visit to the local shops can be made hazardous by busy roads, street clutter and poor highway design.

Accessible environments: Local authorities that implement shared space schemes by removing the boundaries between the road and the pavement

(2) Evans J R et al, "Depression and anxiety in visually impaired older people", *Ophthalmology* 2007.

(3) Waern M et al, "Burden of illness and suicide in elderly people", *British Medical Journal*, 2002.

are undermining the confidence and independent mobility of blind and partially sighted people. Even with the use of a long cane or guide dog they are unable to move around in these spaces independently and safely. A moratorium on these schemes must be implemented.

Greater financial support for people with sight loss: The decision to give people under 65 with severe visual impairment access the higher rate mobility component of Disability Living Allowance from 2011 is warmly welcomed. Attention now needs to shift to visually impaired people over 65 in receipt of Attendance Allowance. This extra cost benefit makes a vital contribution to their quality of life. Not only should it be maintained but a mobility element must be added in recognition of the significant transport costs that older people face.

Saving sight and supporting those with sight loss

This is the challenge. Sight is precious but we do not do enough to take care of it, either as individuals or society.

We need to invest more to identify eye disease in the community at an earlier stage and provide high quality treatment in both primary and secondary care. This will be money well spent. The total cost of sight loss in the UK has been estimated at £5.5 billion a year (4). Failure to invest in early detection and treatment of eye conditions means increased spending on health, social care, education and training to support people in the later stages of eye disease.

There is a clear economic case for early and effective intervention: an Australian study has found that for each dollar spent on eye care and the prevention of sight loss, there could be a five-dollar return to the community.

We also need to do much more to support those living with sight loss. Around 2 million people in the UK are affected - on average 3,000 in every parliamentary constituency.

The UK Vision Strategy seeks a major transformation in our eye health, eye care and sight loss services. Please work with us to make this happen.

**The UK Vision Strategy sets out what needs to be done.
Please support its implementation**

(4) Winyard S, The Costs of Sight loss in the UK, RNIB, 2004.

UK Vision Strategy – Strategic Advisory Group



The Royal College
of Ophthalmologists



Guide Dogs



EYE HEALTH ALLIANCE



Action for blind people



supporting blind and
partially sighted people



THE **NHS** CONFEDERATION



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