Don’t Lose Sight of Sight Loss

An estimated 188,000 people have significant sight loss in Scotland. By 2030 this is set to double.

Manifesto for the 2011-2015 Scottish Parliament

RNIB Scotland supporting blind and partially sighted people
Introduction

The fourth term of the Scottish Parliament will take place against a backdrop of reducing public expenditure. It is therefore essential that Scotland’s resources are used as efficiently and cost-effectively as possible.

RNIB Scotland seeks to move forward on three areas that blind and partially sighted people tell us matter most to them: stopping people losing their sight unnecessarily; supporting independent living; and creating an inclusive society. Within these broad aims, we have identified a number of specific issues that we will campaign on. A key theme will be the need to maintain investment in eye-health services in order to minimise future preventable sight loss.

At present, around 36,000 people are formally registered as blind or partially sighted in Scotland, with up to 188,000 living with significant sight loss. However, the number of Scots with sight loss could double to almost 400,000 between now and 2030 due to our ageing population and the persistently poor health that continues to disadvantage many of our communities.

The annual cost of sight loss per person is around £17,600 - roughly equivalent to ten hospital admissions. We estimate the total cost to Scotland’s public sector to already be £194m a year. But this will increase significantly because the elderly population is set to rise by 62 per cent over the next two decades. Already up to one in six out-patient appointments at some Scottish hospitals are for eye-care.

We urge all political parties to ensure that Scotland remains a world leader in eye-health provision, and to support initiatives for those already living with sight loss that enable independent living and which remove barriers to inclusion.

John Legg
Director - RNIB Scotland
Accessible healthcare information

Being able to easily access information on eye healthcare, as well as on other health conditions, is vitally important to people who are blind or partially sighted.

Despite existing legislation, all too often, people receive such information in formats they can’t understand, even when healthcare providers are aware they have a sight loss condition.

In a recent RNIB Scotland report, 96 per cent of blind and partially sighted respondents reported they had a preferred reading format (e.g., braille, audio, large print), but on average only 10 per cent of communications from health services were received in this format.

Health care information in inaccessible formats may have serious consequences, both practically and emotionally. Some reported experiencing difficulty in identifying and using medication, and some had to rely on others to help identify and administer it. Others reported feeling a loss of autonomy and privacy.

We are also calling for the X-PIL pharmaceutical information service to be more widely promoted. X-PIL allows patients to call a helpline to request information in accessible formats explaining how to administer individual medications. Alternatively, the leaflets can be read to the patient over the phone.

91 per cent of blind and partially sighted respondents thought they had a right to receive health information in a format they could read. RNIB Scotland believes they do as well.

Policy Asks:

1. That the Scottish Government requires Health Boards to ensure that all patients with sight loss receive all healthcare information in an accessible format.

2. That the Scottish Government and Health Boards more widely promote the availability of the X-PIL service for blind and partially sighted people.
Emotional Support for newly diagnosed patients

Every day in Scotland ten people are told that they have irreversible sight loss. This can be devastating news that forces people into serious life changes.

It can cause trauma, affect people’s mental health and wellbeing and impact hugely on their lifestyle. It often leads to unemployment, isolation and depression.

In Scotland at the moment, once someone is diagnosed with irreversible sight loss there is very little provision for emotional support. There are some excellent examples in some areas but no universal provision.

RNIB Scotland is working to establish a network of Vision Support Services (VSS) in Scotland’s eye clinics. This will offer newly diagnosed people dedicated and sympathetic support, and act as a signpost to the other services available to help them, both emotionally and practically, in adjusting to their new circumstances.

Policy Asks:

1. That the Scottish Government supports and facilitates the development of local Vision Support Services across Scotland with health boards, local authorities and the third sector.
Learning Disability and Visual Impairment

More than three quarters of people with a learning disability are estimated to have sight difficulties. As a consequence of communication difficulties and the often hidden nature of sight loss, tens of thousands go undiagnosed and may be excluded from mainstream eye-care.

Several conditions, including Down’s Syndrome and Cerebral Palsy, are particularly likely to cause sight problems. Carers and professionals can sometimes assume someone has diminished capabilities or challenging behaviours - but it could be that their sight difficulty is doing more to hold them back.

The prevalence of sight problems increases dramatically with the severity of the learning disability and with age. One report found this client-group generally experiences eye problems ten years earlier than the general population.

Increased detection of sight loss amongst people with a learning disability will result in improved and more efficient intervention strategies to help the individual.

Eye tests can also detect the first signs of Alzheimer’s disease, which people with Down’s Syndrome are more likely to develop before the age of 30. Confirming the condition is present early on can have a major impact on the success of treatment.

Policy Ask:

1. That a formal vision assessment is undertaken as part of all community care assessments of people with a learning disability in Scotland.

2. That the Scottish Government ensures that young people with learning disabilities leaving school have a formal vision assessment to ensure that undetected sight loss does not adversely impact on their transition.
Employment

There are an estimated 8,500 registered blind and partially sighted people of working age in Scotland.

While the employment rate of other disadvantaged groups, and disabled people in general, continues to increase, the position of blind and partially sighted people has remained almost static (29 percent of blind and partially sighted people in employment compared to 76 percent in the general population).

People with sight loss face too many barriers in gaining and retaining employment. The most significant of these are low confidence and expectations; transport difficulties; lack of access to skills training; limited access to assistive technology (either because it is too costly or not available).

There are around 100 blind and partially sighted people working in Scotland’s supported business sector (enterprises which employ at least 50 per cent people with disabilities). RNIB Scotland believes that vibrant and innovative supported businesses can play an important role in generating employment and development opportunities for blind and partially sighted workers.

We believe the Scottish Government should promote the use of Article 19 - an EU Directive which allows for public bodies to exclusively reserve procurement contracts for supported businesses - across Scotland’s public sector. This would improve the income stream into supported businesses, allowing innovation to improve opportunities for blind and partially sighted people.

Policy Ask:

1. That the Scottish Government actively promotes the use of Article 19 across Scotland’s public sector, by ensuring that each public body meets the Government’s policy of having at the very minimum one contract reserved through Article 19.
Education

RNIB Scotland believes that blind and partially sighted people in education should have the same level and range of opportunities as their sighted peers. Her Majesty’s Inspector of Education states that there are 1,400 blind and partially sighted children in Scotland’s schools.

The participation of children with disabilities in mainstream education is now well established. Evidence indicates however that the quality of provision can be patchy and that learning materials are not consistently made available in accessible formats (such as braille, audio or large print).

It is essential that blind and partially sighted children and young people leave education with equivalent qualifications to their sighted peers, enabling them to maximise their chances of employment and achieve the quality of life they desire. Unfortunately at present, 24 per cent of blind and partially sighted people under 60 have no qualifications as compared with 15 per cent of the general population.

RNIB Scotland welcomes the development of the GLOW system as a national library for transcribed text books and other educational materials. However, like many systems, the quality of the information provided is absolutely crucial. We believe there is a need for a strong partnership involving the Scottish Government, RNIB Scotland and others to ensure that the materials placed onto GLOW are quality assured.

Once GLOW is fully accessible it has great potential benefits. In the meantime it is imperative that work is undertaken to ensure that blind and partially sighted children do not miss out in the interim because of a lack of support or access to alternative format educational materials.

Policy Asks:

1. That the Scottish Government work with RNIB Scotland and other experts in the sector to ensure the GLOW system is made fully accessible to the needs of blind and partially sighted school pupils, and that alternative format materials archived with GLOW have been quality checked to a consistently high standard.

2. That, until GLOW is fully operational, the Scottish Government works to ensure that current provision of educational materials for blind and partially sighted school pupils is accessible.
Haggeye - Stop and Stare

As a forum supporting blind and partially sighted young people, one of Haggeye’s key messages is inclusion. We believe that all young people should have the opportunity to learn about inclusion and the barriers faced by those with disabilities.

Article 28 of the United Nations Convention on the Rights of the Child states: “every child has the right to an education in which they feel included”. However the experience of Haggeye members is that people are usually misinformed or have a genuine lack of understanding about disability.

Haggeye has developed an educational toolkit - Stop and Stare - to explain the issues that blind and partially sighted young people experience.

The motivation behind Stop and Stare derives from the increased confidence felt by young people from their involvement with Haggeye. One Haggeye member recalls how raising awareness ended the verbal bullying she was experiencing at school.

“The bullying had been going on for a while and the reason was simply that my peers didn’t understand what living with sight loss was like. They also did not understand my sight loss condition. But by taking the time to explain this, the bullying stopped.”

Policy Ask:

1. That the Scottish Government and local education authorities embed inclusion at the heart of school governance, to give all pupils a better understanding of the nature of disability.
Prevention

Alarmingly, the number of Scots with sight loss could double to almost 400,000 between now and 2030. Already up to one in six out-patient appointments at some Scottish hospitals are for eye-care.

The annual cost of sight loss per person is around £17,600 - roughly equivalent to ten hospital admissions. When you add in the indirect costs of sight loss it totals £434m. But this will increase significantly because the elderly population is set to rise by 62 per cent over the next two decades.

RNIB Scotland is calling for the Scottish Parliament to prioritise prevention, maintain our investment in free eye examinations, and continue to support the implementation of the Scottish Vision Strategy.

A preventative approach must target those most at risk. While Scotland is a world-leader in eye-healthcare, it also has one of the poorest health records in Western Europe. Diabetic retinopathy is now the leading cause of blindness among the working-age population, and people from some ethnic minority backgrounds are more vulnerable (those of South Asian origin, for instance, are six times more likely to develop Type 2 diabetes). Scotland must improve its record in tackling those health inequalities.

Policy Asks:

1. Embrace prevention as a cornerstone within future investment strategies for Scotland’s Eyecare services.

2. That eye tests continue to be free to everyone in Scotland to ensure that sight-threatening conditions are identified earlier, when treatment can arrest or reverse damage.

3. That “healthy lifestyle” and “self management” campaigns are developed aimed at improving eye health.

4. Commission a five-year forward plan for the provision of services concerning macular-related diseases such as Age-Related Macular Degeneration (the leading cause of sight loss among older people).
Summary
RNIB Scotland has the following asks for the next Scottish Parliament, and will be campaigning to achieve them over the course of the next 4 years.

Accessible healthcare information
1. That the Scottish Government requires Health Boards to ensure that all patients with sight loss receive all healthcare information in an accessible format.
2. That the Scottish Government and Health Boards more widely promote the availability of the X-PIL service for blind and partially sighted people.

Emotional Support for newly diagnosed patients
1. That the Scottish Government supports and facilitates the development of local Vision Support Services across Scotland with health boards, local authorities and the third sector.

Learning Disability and Visual Impairment
1. That a formal vision assessment is undertaken as part of all community care assessments of people with a learning disability in Scotland.
2. That the Scottish Government ensures that young people with learning disabilities leaving school have a formal vision assessment to ensure that undetected sight loss does not adversely impact on their transition.

Employment
1. That the Scottish Government actively promotes the use of Article 19 across Scotland’s public sector, by ensuring that each public body meets the Government’s policy of having at the very minimum one contract reserved through Article 19.

Education
1. That the Scottish Government work with RNIB Scotland and other experts in the sector to ensure the GLOW system is made fully accessible to the needs of blind and partially sighted school pupils, and that alternative format materials archived with GLOW have been quality checked to a consistently high standard.
2. That, until GLOW is fully operational, the Scottish Government works to ensure that current provision of educational materials for blind and partially sighted school pupils is accessible.

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