



Experiences of Health and Social Care Services for People with Sight Loss (2021-2)

Summary

Background:

There is a great deal of variation in the extent of sight loss between individuals who may or may not be registered as blind, and the conditions people have can vary over time too. Little thought is given to the causes of sight loss and to how those diseases or conditions affect sight in different ways as we found when we talked to people about eye health in 2017 (read more here).

In 2021-2 we started making links with community groups to better understand their experiences of health and social care services and any issues that are important. We found that there was a need to better understand support services available in Wandsworth and that we needed to launch a survey to collect views from people about their experiences.

What we did:

We surveyed 24 people with different sight loss conditions via an online survey, during telephone interviews and in face-to-face conversations. We also held a workshop of interested people.



What we were told and recommendations:

The people we talked to had various conditions that had led to different types of sight loss at different stages in their life. Slight loss is not the only medical issue for the people we spoke to and many people told us about different support that they get and other health and social care needs they have that need to be addressed in appropriate ways, taking into account the sight loss.

More can be done about the following to increase access to support to meet people's needs in the following ways:

- Information provision and general 'paperwork' needs to be provided in accessible formats and/or support needs to be provided.
- Explore opportunities to reduce loneliness and isolation and improve independence and access to support and contact with people in the community. Barriers to accessing technology and digital support may need to be understood further as well as potential digital solutions.
- People with sight loss should be listened to about their needs as experts on what will work for them and how. Sight loss is a very personal experience. Clinicians and others should not make assumptions. We heard about a varied experience in accessing services and the attitudes and knowledge of staff in how they support people.

**Thank you to everyone who shared their experience with us to help us write this report.
Thank you also to all staff and volunteers involved in this research and writing this report.**

Background

To people without sight loss, varying degrees of sight loss or 'blindness' is often thought of as one condition. Little thought is given to the causes of sight loss and to how those diseases or conditions affect sight in different ways, as we found when we talked to people about eye health in 2017 (read more [here](#)). Nevertheless, there is a lot of variation in the extent of sight loss between individuals who may or may not be registered as blind, and the conditions people have can vary over time too.

In 2021-2 we started making links with community groups to better understand their experiences of health and social care services and any issues that are important. Through attending meetings with members of a Macular Society support group, we came to find that there was a need to better understand support services available in Wandsworth and that we needed to launch a survey to collect views from people about their experiences.

What we did

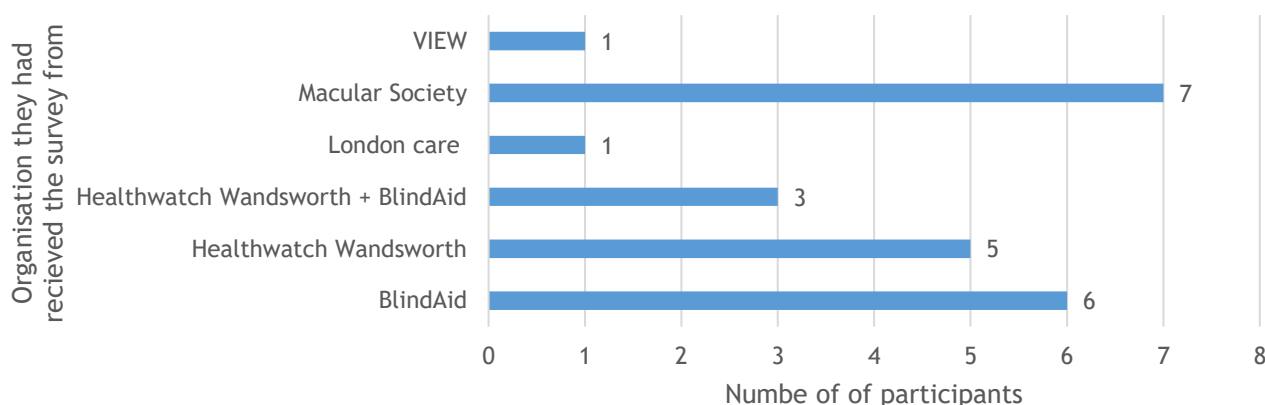
We developed an anonymous survey to ask people affected by sight loss about their experiences of using health and care services. The survey was hosted online and was promoted to local community groups as well as via our newsletter and website. We took the survey to a few local organisations as follows:

- We visited Macular Society group meetings and completed the survey with people face-to-face.
- A support worker at BlindAid, who visits people in their own homes spoke to the people they saw to ask them if they would consent to our telephoning them to complete the survey.
- We hosted a workshop in conjunction with Visual Impaired Experience in Wandsworth (VIEW) to showcase organisations that support people with sight loss in Wandsworth and to advertise our survey.

Findings

Who was involved and what services they use

In total 24 people shared their views in our survey. 23 respondents told us they received the survey through the following organisations:



How our participants described their condition:

Three respondents referred to themselves as blind, one as nearly blind and another as partially sighted. 11 people had some form of age-related macular degeneration,¹ making this the most common condition

¹ See NHS website for more information on age related macular degeneration: <https://www.nhs.uk/conditions/age-related-macular-degeneration-amd/>

in our sample. Three had retinitis pigmentosa and three had glaucoma.^{2 3} Other people reported their sight being affected by: Charles Bonnet syndrome, keratoconus, optic atrophy and Stargardt disease.

Name of condition	Total
Partially sighted	1
Nearly blind	1
Blind	3
Charles Bonnet syndrome	1
Kerataconus	1
Retinitis pigmentosa	3
Stargardt	1
Bilateral optic atrophy + Nystagmus	1
Glaucoma	1
Glaucoma + Age-related macular degeneration	2
Age-related macular degeneration	3
Wet age-related macular degeneration	4
Dry age-related macular degeneration	2
Grand Total	24

The experiences of these people in terms of when their sight loss started and how their sight is affected were very different. The onset and progression of sight loss conditions at different stages of life shapes people's ability to cope, as will become clearer below when we discuss the impact of sight loss on everyday life.

Accessing services

Where our respondents received treatment

Most respondents (16 people) received treatment at one of the Moorfields treatment centres, with 12 people having attended a Moorfields Eye Hospital, St George's Hospital, Chelsea and Westminster, the Royal Eye Unit at Kingston Hospital, and the opticians. Five respondents said they were receiving no treatment.

Treatment centre	Total
Moorfields Eye Hospital, City Road	3
Moorfields Eye Hospital, St. George's	11
Moorfields Eye Hospital, St. George's + Moorfields Eye Hospital, City Road	1
The Royal Eye Unit, Kingston Hospital + Moorfields Eye Unit, Queen Mary's Hospital	1
Chelsea and Westminster Hospital	1
Chelsea and Westminster Hospital + Opticians	1
Opticians	1
No treatment available	5
Grand Total	24

² See NEI for more information on retinitis pigmentosa: [https://www.nei.nih.gov/learn-about-eye-health/eye-conditions-and-diseases/retinitis-pigmentosa#:~:text=Retinitis%20pigmentosa%20\(RP\)%20is%20a,that%20people%20are%20born%20with.](https://www.nei.nih.gov/learn-about-eye-health/eye-conditions-and-diseases/retinitis-pigmentosa#:~:text=Retinitis%20pigmentosa%20(RP)%20is%20a,that%20people%20are%20born%20with.)

³ See NHS for more information on glaucoma:

<https://www.nhs.uk/conditions/glaucoma/#:~:text=Glaucoma%20is%20a%20common%20eye,not%20diagnosed%20and%20treated%20early.>

When our respondent's received services

Most respondents (18) had had some treatment in the last year or two, with only four reporting that their experience was longer ago.

Experiences of services

Nine respondents described their experience as positive. Seven of those referred or alluded to Moorfields hospital staff or NHS staff more generally, and one person praised the Macular Society in particular.

“Staff are stable and professional and are very focused on each particular case.”

“Even though the room wasn't set up for me and my wheelchair they did everything they could to assist me.”

[Moorfields Eye Hospital, St George's Hospital]

“I was picked up by NHS transport as recently had an eye operation, picked me up and took me to the hospital staff are friendly and knowledgeable about eye condition and got taken home.”

[Moorfields Eye Hospital, City Road]

Two people said they'd had a negative experience.

“Pension credit advisor arranged for a carer to visit but interviewee turned carer away. No warning had been given that carer would arrive, it was late in the day and interviewee felt her visual impairment made her too vulnerable to let a stranger into her flat.”

[Moorfields Eye Hospital, City Road]

“Social services have no social workers available to see me. they told me 5 years ago I would get a social worker but I haven't seen anyone. I have a support worker I see him about every 3 months. The blind send me magazines but no, I good as can't read them.”

However, most peoples' experiences were more complicated: four people said they had a mixed experience, five were unsure and four 'neutral'.

“They sent me an appointment and I went to the hospital appointment and I went to the hospital to be told it was a telephone appointment. This has been going on for some time as hospital appointment as keep getting cancelled, my neighbour chased and they asked me to go on a Saturday and they do an assessment and they send an appointment, then doctor was ill so got cancelled.”

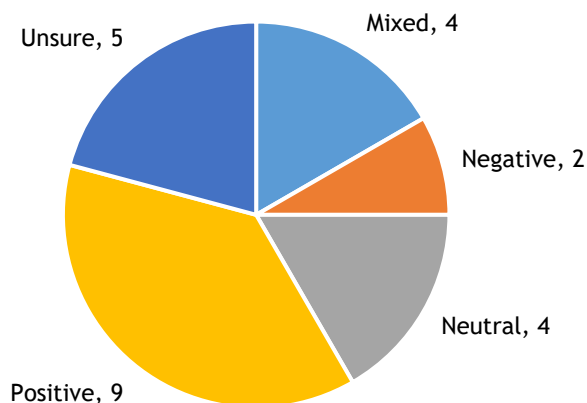
“Good experiences when treated by staff who take me seriously when I self-report problems. This is not always the case, particularly with more junior medical staff.”

[Moorfields Eye Hospital, St George's Hospital]

Interviewees comments were largely negative, reflecting the fact that there has been no treatment and check-ups are now infrequent. On her last visit to Moorfields at St George's in last month she had to wait over 4 hours as "the system was down."

The interviewee was also critical of the impact of Covid on GP services - the interviewee never gets to see a doctor and telephone consultations can be rushed and inconvenient.

How was your experience?



There were no obvious correlations between the type of condition or the location/type of service accessed and people's evaluation of their treatment.

It is worth noting that 'services' was interpreted in different ways by respondents: one mentioned occupational therapist and social worker, and another mentioned shopping and one help with correspondence and finances. Three people mentioned support from charities (a combination of BlindAid, Macular Society and London Vision) and one mentioned a friend.

“Just finished with someone from BlindAid that had been coming to me regularly but signed off as so many clients, then they had to stop due to Covid. Now she comes once a fortnight, now has so many clients so now once a month. She is a gem and she helps with correspondents and finances. She is very helpful and a lovely lady.”

Although most people were referred to services associated with their sight loss, one mentioned difficulty getting a hospital referral for a knee problem and one 'other conditions'. These differing interpretations were reflected in the fact that people reported on different aspects of their care, as we will see below.

The following are themes we identified as important to our respondents.

Attitudes and knowledge of staff was important:

Five respondents specifically praised staff at various organisations but four people thought the staff or the department were too busy (one of these was referring to social services). One person referred to a bad experience with a carer (rather than hospital staff). Two people had mixed experiences with staff.

“Staff are stable and professional and are very focused on each particular case.”

Interviewee finds nursing and technical staff friendly and welcoming. But he finds the consultants, whom he now rarely sees, distant, curt and uninformative.

“Staff were too busy, rushing around.”

The appointment process - long waits or cancellations:

This was mentioned by six respondents: one mentioned **waiting too long**, one that the 'system was down', and another had experienced **cancellations**.

When asked about the timeliness of their treatment, four people reported trouble getting appointments, three mentioned issues with referrals (two saying the referral process was slow), and one mentioned waiting times at Moorfields at St George's A&E.

“The letter from doctor takes a long time and need this before you get a referral to Moorfields. If you have not visited Moorfields in a 6 month period you have to start the whole process again which is frustrating.”

“Have to go through to GP and get referral and can take time. Makes anxious if need an urgent appointment, as have to wait a few weeks and go through whole referral system again.”

“sometimes I find I am still awaiting to be allocated a social worker. If I need any help I need to call up duty and ask to get a OT. OT then put you on a waiting list can be very frustrated and you feel isolated because of age range. As I am 55 I can't go to over 60 groups and nothing for younger than me. So I am isolated at home with no where for me to go to socialise. Nothing to help at all.”

“I have a knee condition and doctor referred to hospital and that was 6 months ago and I am still waiting.”

Only two people reported getting timely access to services.

“Yes I've been able to access hospital services when I've had a severe problem. I've been waiting for some time to receive an updated Certificate of Visual Impairment from the hospital, as advised by my local optician.”

Five people had very low expectations reporting that they received no services or that services do nothing to change their situation.

“I don't expect anything when I go.”

One person (who said their treatment had been at Moorfields at St Georges Hospital) reported **accessibility issues** as a wheelchair user, although staff did address the problem.

“Even though the room wasn't set up for me and my wheelchair they did everything they could to assist me.”

The GP was mentioned by five respondents both positively and negatively:

“Not sure - [the need for timely treatment] hasn't happened so far. My GP is very good.”

“GP occasionally phones to see how you are. I think there should be annual check-up.”

Respect for personal preferences such as lifestyle, culture and beliefs:

17 people felt that their personal preferences had been respected.

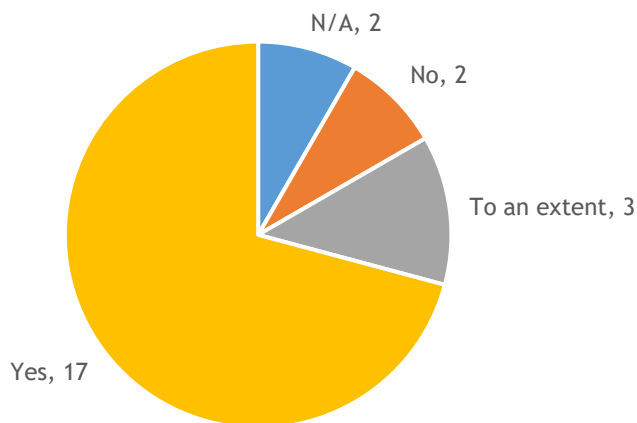
Five people mentioned that they do not feel that they are always listened to and/or that staff have no understanding of their condition.

“I had to complain then they listened to me.”

“A new GP at the surgery has given time to listen, apart from GP above, interviewee feels no one has time to listen and no understanding of her situation.”

“He feels the consultants look down on him and pay no attention to his questions.”

Were your personal preferences respected?



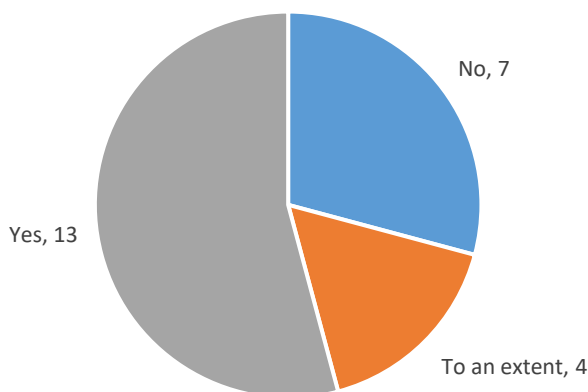
One respondent suggested:

“Ensure that all staff have the necessary education and training to deal with patients and to accept that patients with a long-term condition become expert in relation to their own condition.”

Information and advice

Over half the respondents (13 people) felt they had had sufficient information while seven felt they did not. Four people indicated they had some information but could use more.

Sufficient information?



Charities were a major source of information and advice with five people mentioning different charities (including Macular Society and BlindAid). Medical professionals were also important: three people mentioned the hospital, one their GP and one a private doctor. One person mentioned friends and family. Two people mentioned the need for information in appropriate formats - e.g. not being able to read the information provided.

“They assume that you have sight available and can find out about things”

Most respondents did not mention the specific information they received (or would like to have received). However, one mentioned technology such as mobile phone apps, talking books and a talking microwave. One person wanted to know about research and alternative treatments but felt the doctors have been unwilling to discuss his condition with him. Three mentioned that information was ‘ongoing’ e.g. via charity publications.

The impact of sight loss on everyday life and the support people need

How people reported the impact sight loss has on their lives reflected the type of their condition. Many of the respondents to this survey have macular degeneration which is a condition often related to age. One respondent described how they had learned to cope with their condition over time. But for many respondents, sight loss is a relatively new experience.

“Born with the condition, so able to make gradual adjustments over the years.”

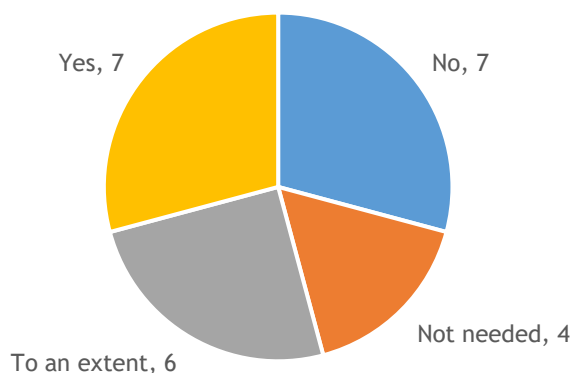
“I am blind, I can't read, I have to rely on other people to read for me. It has changed my life completely.”

“The diagnosis in 2013 was devastating, as I was still young”

Seven people mentioned not being able to read as a major impact.

When asked specifically about the support they receive, nine people reported that they have support, but seven people said they have not got the support they need. Four people felt they did not need any support.

Are you able to access the support you need?



“There is no support and I don't know where to go if my condition deteriorates.”

“Only support out there is about me getting up and doing it. When I have asked for support there is support available, emotional. I do have problems asking for support.”

10 respondents mentioned various charities (including BlindAid and Age UK) as being their main source of support. 4 mentioned friends and family, two people mentioned private care, and one mentioned supermarket delivery.

“I have had a negative experience with services as there is nothing they can do. I receive most of my support from family and friends.”

Respondents mentioned different types of support: emotional, phone calls, personal care, cleaning, shopping, paperwork. Three people mentioned help with benefits or finance, three specific help with cleaning or shopping and three general advice (from charities). Some people shared other positive things that they do that they find helps:

“I go for a walk every day but needs to be close to home. Limiting, I cope, Farm foods come once a week and pop in microwave so have a main meal every good. I go dancing once a week and go to a choir, I try and keep in touch.”

“Born with the condition, so able to make gradual adjustments over the years. Have managed to cope well psychologically, but there are always ups and downs. What I had is gone so I concentrate on what I have. Travel the main restriction now, miss it.”

Social isolation affects support available and mental health wellbeing

Shopping was also mentioned by 4 people. Two people said they couldn't go out, one mentioned losing their independence, not being able to drive and difficulties with travel.

People's social lives are also affected: one person said they had difficulty recognising people and another mentioned not being able to socialise. At home, leisure activities also become more complicated: one mentioned struggling to watch TV as the condition progressed and another having to give up a much-loved hobby of model-building.

Leading on from this, four respondents specifically mentioned loneliness and isolation and one mentioned feeling sad.

“No treatment available, you are registered blind, no one checks up on you to see how you are doing, you fall off the radar. All you receive is a yearly check from the council. If you are not proactive you are left in isolation. I can see how people get depressed.”

Eight respondents mentioned the help they get from friends and family - with three of these highlighting the additional stress they feel is put on those supporting them.

“I feel that I've lost my independence and that it's difficult for my wife to cope.”

“I have lost my independence, if I want to go to the shops I need to ask my son.”

“When I go out I get panicked, in shops I need to go down isles a few times. Not being able to see this properly even if in front of me. It gets me down as I feel like I have become a burden on family members, I need to have someone with me at all times.

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Four people mentioned the difficulties involved in asking for help.

“I live in sheltered accommodation Hill Lodge, no one has shown me how to use the washing machine or cooker ... I have a microwave in my room and do my food there. I have asked for someone to show me how to use but no one wants to help in any way.”

“In general people not understanding my condition ... With sight loss people are treated as second class citizens as [its] not visible like a wheelchair.”

“Daily life is challenging ... trying to get shopping and can't read product, trying to find a staff member to ask for assistance”

“Sometimes when asking for assistance I don't always get and makes me feel uncomfortable. Makes you feel more isolated and it doesn't make you want to go back to shop.”

Technology

But technology was also highlighted by three people, with two people finding it a problem:

“I am no good at technology and everything is online and find this a barrier.”

Other people mentioned housing, minor repairs, support with shopping and others the need for more check-ups and support from clinicians.

Five people didn't think there needed to be any changes or didn't receive services.

Suggestions for improved support

When people were asked what improvements to services they would like, there were a wide variety of suggestions.

Five people wanted help with paperwork. People value support but also needed appropriate formats.

“Sight loss gives me problems with correspondence and documentation usually sending with wrong fonts”

“Being able to have access to a support group and also being able to educate people about being more disabled friendly and how my condition can help others by speaking out. Wandsworth Council to provide stickers for shops so you know they have passed the disabled-friendly. As there are so many people with no visible disabilities.”

Healthwatch England have researched accessibility of information in the health service and have published recommendations for change. You can read more [here](#).

Adaptations and equipment were also mentioned by two people:

“Keep up to date with technology that organisations provide for sight loss.”

Conclusions and recommendations

The people we talked to had various conditions that had led to different types of sight loss: some people had lost their sight early in life, whilst others had age-related sight loss. Moreover, talking to people, we were not just looking at the slight loss as a medical issue. People have other health and social care needs and many told us about different support that they get, especially from charities, but also from social services and the NHS. These might be related to sight loss or independent of the sight loss (two people specifically mentioned arthritis or joint pain). These need to be addressed in appropriate ways taking into account the sight loss.

We can conclude that more can be done to improve access to support and provide support to meet peoples needs in the following ways:

- Information provision and general ‘paperwork’ needs to be provided in accessible formats and/or support provided.
- Losing your sight can result in loss of social and other activities which might lead to loneliness or have a negative impact on mental health wellbeing. Difficulty reading was a particular barrier mentioned by some. Opportunities to reduce isolation, improve independence and to improve access to support and contact with people in the community could be explored further. There could be opportunities for digital solutions as well as a need to make sure people are not digitally excluded. Check-ins/check-ups were suggested by our participants.
- People with sight loss should be listened to about their needs as experts on what will work for them and how. Sight loss is a very personal journey and clinicians and other should not make assumptions. We heard about a varied experience in accessing services and the attitudes and knowledge of staff in how they support people.