

Sight loss follows you home

The Royal National Institute of Blind People (RNIB) defines low vision as vision which is causing difficulties with your day to day activities, despite having the best spectacles or contact lens correction. As part of our work on access to primary care we wanted to speak to Surrey residents with low vision about their experiences of specialist eye care services, as well as the information and support they receive between appointments and following discharge.

What did we do?

We spoke to **30** Surrey residents at 3 Macular Society meetings and a VisionZone event.

What did people talk about?

Hospital appointments and clinical support

- Most people we spoke to were attending hospital eye clinics annually or biannually. They reported varying degrees of support, with some saying they felt very well supported and others saying they felt “dismissed”.



“I go every six months now just for a check up. I don’t have injections anymore. I was told that if I’m concerned about anything I should go to A&E. I have had to do this and have got to see the right person. I feel well supported.”

Reigate & Banstead resident, female aged 80 years



- We heard from some that there was a lack of “personal touch”, with appointments changing and little consistency in who people saw. The experience was described as like “being on a conveyor belt” with short, routine appointments lasting only a few minutes, despite long waits to be seen.
- Some reported being shocked by the insensitive way bad news was delivered and others talked about professionals going above and beyond to help and support them.



“When I asked the first consultant I saw, who diagnosed me with macular degeneration, what the prognosis was he said, “Well, you are going blind”. It was a shock. I am lucky I had someone with me.”

Runnymede resident, male aged 74 years





"When my other eye went, my consultant went the extra mile. He took me to get the eye injections I needed in his afternoon off so that I didn't have to wait too long."

Reigate & Banstead resident, female aged 80 years



Information and advice

- We heard concern about gaps in the information being provided following consultations. For example, one person told us that they were not informed to stop driving and not warned about items in their vision which may disappear and then reappear when closer (sometimes referred to as the 'polo effect') which they felt was dangerous for driving.
- Some reported a reticence or reluctance from their consultant to tell them if their condition was stable or declining and to confirm that they had exhausted all treatments options.
- Others felt they were not given any information about their condition or how to manage it at all and had to rely on their own research.



"There is no information about the condition or how to manage it. I had nothing from my GP. I go straight to Sight for Surrey for information and help when I need it. You have to be proactive to get the information."

Fetcham resident, female aged 75 years



"They (health care professionals) are caring but they don't tell me what they are looking at. If you're a child you are given lots of help and support and are taught how to cope. If you are an old person, you get nothing. I'm lost, swimming around in nothing. The only people who have helped me are people who come here (community centre). The help I've had has been by chance."

Bookham resident, female aged 85 years



"The hospital doctors are just focussed on the medical condition, there is no time for wider discussions. They don't give practical day to day information. The hospital is medical and the charities pick up the social and holistic side, but, really, you just have to immerse yourself in the subject and search it out for yourself."

Fetcham resident, male aged 80+ years



Disconnect between services

- Some people talked about not being given access to the eye care services they needed and finding themselves shuttling between their GP, optometrists and hospital eye care services.



“When I went with my glaucoma, I asked about macular degeneration and was told that she couldn’t test for both and that I should go back to Specsavers. I mentioned it the next time I went and they said it shouldn’t have happened.”

Runnymede resident, male aged 74 years



Non clinical support: friends, family and Voluntary, Community and Social Enterprises (VCSE)

- Some people depended on friends and relatives to help them access eye care and other health care services and to help them manage their day to day lives. They shared their concern about the extra stress and inconvenience this causes their carers.
- People found [Sight for Surrey](#) really helpful, providing them with information about their eye condition and what to expect over time, as well as equipment and technology to help them manage their daily lives.
- However, they were not routinely signposted to Sight for Surrey by hospital eye care services, instead finding them through friends and neighbours or by coming upon posters by chance.



“Sight for Surrey have given me lots information and equipment, plus technical support too and their support is ongoing. I found the symbol cane they gave me very useful.”

Runnymede resident, male aged 74 years



- Many people we spoke to were at local Macular Society groups and found them helpful. However, we heard from others that they don’t attend for various reasons, including travel issues which can be problematic with low vision.



“The hospital put me in touch with the Macular Society but there isn’t a local group in Guildford.”

Runnymede resident, female aged 74 years



- Some people told us that the Eye Clinic Liaison Officers (ECLOs) who visit Macular Society meetings as part of their guest rotation, were useful for “translating what the doctor says”, but weren’t always aware of the support groups available.

We asked people how their low vision had impacted their daily lives:

“I can’t read bus numbers and I need help catching the train. I use passenger assistance but this is something I found out about myself. I can’t read the washing machine dials either. I used to be an embroiderer but I can’t see the needle now. I’ve just cancelled my TV license as I can’t see the screen but I’m not bad enough to qualify for the 50% discount you get. I think you have to be blind for that.”

Fetcham resident, female aged 75 years

“I used to sing and I used to practice German but I can’t read music any more or read German text so I’ve given up. I have had to overcome so many things. We are self taught. You have to use a bit of ingenuity.”

Bookham resident, female aged 85 years

We asked people what would help them cope with their low vision better:

Regular, clearly promoted support groups that are easy to get to and focus on practical solutions to the everyday problems of living with low vision.

We would like to thank the groups who welcomed us and everyone who gave their time to speak to us. People told us that they valued being listened to and that it was the first time anyone had asked them about their experiences.

