

what
would you do?

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NHS Long Term Plan

Barnsley Macular Society - Support Group

10th March 2019

1 Introduction

1.1 Description of the focus group/engagement activity

Barnsley Macular Society Support Group

The group is organised and run by volunteers, most of whom have macular disease, or know someone who has a macular condition. The group offers support and help in understanding macular disease and coming to terms with sight loss. They share information about obtaining treatment, accessing other services and staying independent.

1.2 Acknowledgements

The Macular Society Regional Officer

2 What was the purpose of the activity/session?

2.1 Purpose

The group meet on a weekly basis socially, with a more formal meeting once per month, when they invite various organisations to speak to the group about the work they do, and how they can support people in various stages of Macular Degeneration. They are a good form of support for each other. They are very welcoming of new members who have often received information about the group from their consultant at the hospital and don't know what they need to do next.

They are a very supportive group, meeting informally to give each other support advice and information. They have small fundraising events such as raffles etc. to ensure the group is self-supporting. They have formed close friendships and are very helpful, caring and considerate to new members attending the group.

The information they can give to new members is invaluable and really helpful when trying to understand Macular Disease.

2.2 What did you do?

We met with the group at one of their meetings with the Regional Manager and the local support worker. There were 12 people at the meeting (one new member). We discussed Healthwatch Barnsley and the work we do briefly, then went on to give a short presentation about the NHS Long Term Plan.

The group were used to asking questions of organisations and we encouraged them to do this throughout the presentation. We placed the main points of the presentation on the wall in large print, after a discussion with the regional manager about the best way to present the information to the group.

The group were also supported by the regional manager and the session support worker.

2.3 Results of the activity/session(s)

The group told us that 200 people a day in the UK are diagnosed with macular disease and it is important that services are in place to meet this demand. They felt that the Ophthalmology Department at Barnsley Hospital is one of the busiest areas in the hospital and this was what the group suggested would be helpful through the NHS Long Term Plan.

- Assistance to get to appointments safely, especially for people who do not have anyone to provide transport. There is an awareness within the group, that public transport is not adequate to meet the needs of this group, especially as there is a necessity for patients to also attend the specialist centre at Sheffield NHS Trust which is approximately 15 miles away. Public transport is diminishing in some areas, especially rural ones, and this can also be a barrier as parts of Barnsley are in more rural areas.
- Flexible appointments with specialists and local clinics within their own communities, would make a vast difference in the support they need to manage their condition.
- There needs to be more support for people with visual problems, from first diagnosis onwards, as newly diagnosed patients are very susceptible to depression and anxiety. The group also discussed the situation around a patient getting their diagnosis. The feeling was that they are then almost left to their own devices. In this situation the person has been diagnosed with a life changing condition, doesn't know what the future holds and where to go next?

- If an Eye Clinic Liaison Officer was based within the eye clinic, and a macular specialist nurse in every eye clinic, as well as a trained counsellor, this would help with support and care of patients.
- Eye clinics locally (in GP surgeries) could help a lot. There is no provision for some eye conditions at Barnsley Hospital, therefore some patients need to attend appointments at the Sheffield NHS trust. If specialists were available locally this would benefit the group.
- The group then linked their medical condition to Ageing Well and leisure activities. They felt that activities, e.g. swimming groups would be helpful in combatting mental health symptoms, and were aware that staff needed training to support people with visual impairments. This has funding implications but would help people manage their health better. They also felt that an increase in befriending organisations to help people get out and about would make a vast difference too.
- The group talked about care for people with Macular Degeneration who are housebound. They felt that this group of patients were particularly vulnerable to a deterioration in their condition and that isolation made them susceptible to depression and anxiety.
- Looking at improvements in technology may make access to care better, but it is more difficult for people with degenerative eye conditions coupled with ageing to get to grips with new technology and this should be taken into account. They also said Zoom Text is helpful for some sites on the internet, but it struggles to cope with new apps and software.
- The group wanted awareness raising sessions about Macular Degeneration in all areas and departments. They wanted Disability Awareness training to be provided more regularly, as sometimes staff do not understand that people with significant sight loss, may need extra support to do everyday things that a sighted person takes for granted. For example, emergency cords at bedsides and in the toilets need to be pointed out for some patients.
- The group felt that at their local hospital there is an issue with the proximity of the eye clinic to the entrance of the hospital; it is up an escalator, when in actual fact the group felt that it should be more easily accessible from the entrance
- Last but not least the group pointed out that the booking system at Barnsley Hospital is not suitable for people with visual problems.

Feedback from people who took part

The group were really pleased to have been able to voice their opinions on order to help make changes for the better to the NHS in the long term.

Feedback from staff/volunteers who took part

The support staff said they had learnt a lot from the session and would add their information through the website survey.

2.4 Conclusion

Key messages

- ❖ Work with the Department of Transport to improve bus routes to the local hospital and the specialist hospitals, especially for people who live in rural areas.
- ❖ Offer flexible appointments as it is difficult to get to appointments on time when you need support to get to the clinics.
- ❖ Look at providing eye clinics locally (in GP surgeries)
- ❖ Look at the support mechanisms, especially for newly diagnosed patients
- ❖ Increase support for people who are at risk of depression & anxiety.
- ❖ Have an Eye Clinic Liaison Officer and a Macular Specialist nurse in every eye clinic. Also a trained councillor.
- ❖ Provision and advice of suitable leisure activities for patients, to avoid loneliness and depression
- ❖ Provide awareness raising training for staff.
- ❖ Make improvements in technology, relevant to this community

- ❖ The CCG to look at their local hospital and speak, with local groups to improve the clinic and the booking systems.

2.5 Data and information summary

Please complete the table below with all the info gathered from your focus group/engagement session

Date of Focus Group/Engagement Session	10 th March 2019
Group name	Barnsley Macular Support Group
Description of the group or session	Support Group
Life stage – (Starting Well, Living Well, Ageing Well)	Living Well & Ageing well
No. of attendees	12
Theme area (Mental Wellbeing, Choice and Control and Independence, Care near where you live)	Mental Wellbeing, Independence, and Care near where you live
Was it a condition specific session – if so please identify the specific condition	Macular Degeneration
What were the key outcomes	<p>Transport an issue</p> <p>Access to appointments</p> <p>Local Community based Eye Clinics with specialist staff</p> <p>Support for newly diagnosed including mental health and wellbeing</p> <p>Information and Advice about leisure services</p> <p>Awareness Raising Training</p> <p>Improvements in technology for this community</p> <p>Booking Systems an issue</p>

