



Living with Macular Degeneration in Wokingham. Impact in relation to mental, physical & social wellbeing.

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EXECUTIVE SUMMARY

Healthwatch Wokingham Borough commissioned the local Macular Degeneration (MD) support group to capture stories of those living in Wokingham Borough with the condition, to find out about the ease of accessing information and services locally.

Fifteen people were interviewed, living with varying stages of the condition, from recent diagnosis to significant sight-loss. Nine were registered as partially sighted. Common experiences and trends were identified.

The study has shown that the experience of MD is one of losses, with many of these losses leading to increased social isolation. All those interviewed had made many adaptations to their daily-living activities and sought to find a way round difficulties in order to maintain as much independence and pleasure in life as possible.

INTRODUCTION

Macular Degeneration (MD) is a condition affecting central vision which, over time, leads to impaired sight. It generally presents later in life and its impact is far reaching. As yet there is no cure; treatments aim to stabilise and slow deterioration of sight but even these are not suitable for all types of MD. As visual changes progress, greater challenges to activities of daily-living and social interaction occur. Adaptions have to be made to lifestyle and increased support sought.

This study has aimed to cast light on the effects brought about by MD in relation to mental, physical, and social wellbeing, in particular highlighting how living with this problem can lead to isolation and prevent full participation within a community. In addition, it has enquired into whether MD inhibits successful access to healthcare services.

Fifteen people were interviewed, living with varying stages of the condition, from recent diagnosis to significant sight-loss. Nine were registered as partially sighted. Common experiences and trends were identified and have, for clarity, been categorised into the three overlapping domains of mental, physical and social well-being.

However, in the 'lived-experience' of MD there is no such separation and various effects can be felt across the three domains. The respondents own remarks have been presented in italics throughout this report.

Identified effects of MD on:

MENTAL WELL-BEING: Loss of independence
 Loss of confidence
 Shock
 Depression
 Anxiety
 Fear

PHYSICAL: Impaired sight
 Restricted mobility
 Safety issues
 Loss of practical skills

SOCIAL: Decreasing involvement in social activities
 Restricted opportunities for socializing
 Anxiety over personal grooming
 Embarrassment when eating out
 Increased dependency and concern over
 'becoming a burden'

MENTAL WELLBEING: DEALING WITH DIAGNOSIS

Reaction to diagnosis was varied. Some respondents accepted the situation with calm resignation; for others, diagnosis was a shock leading to acute anxiety relating to the impact of their condition, their ability to cope in the future and deep depression regarding impending sight loss.

.....'I was shocked when I was given my diagnosis at the hospital. I'd been referred because I had a cataract problem. Instead the consultant told me he wouldn't be treating my cataracts because it wasn't worthwhile as I had MD. There was no 'bedside manner', no sympathy or caring and no information given to me. I left the hospital frightened and not knowing anything. I thought I might be totally blind before too long. It was just by chance that I saw a poster a couple of days later advertising the Wokingham MD group. It is through them that I learnt about MD'.



Losing independence was of great significance on mood, particularly the thought of having to give up driving. Newly diagnosed respondents projected ahead and tried to imagine what the future would hold and feared becoming a burden on their family. Learning more about MD and its degenerative nature also led to depression in some.

.....'I feel more pessimistic about life because I know things are only going to get worse.'

Another source of anxiety was fear of being misunderstood. Loss of central vision results in an inability to see faces clearly. Chance encounters in the street could go unnoticed, reducing opportunities for socialising, and respondents were concerned that they would be considered unfriendly.

.....'You don't look different when you have poor sight and people don't think that there may be a problem. I don't want people to think that I'm stand-offish.'

.....I don't want to be thought of as unfriendly or snobbish'

.....'people aren't patient enough'

Initially emotional reaction was that of grieving for all the losses, both current and anticipated. In time, it would appear that an acceptance of 'having to get on with it' was reached and the charged emotional state settled into steady coping.

PHYSICAL WELL-BEING

Physical well-being was controlled by the degree of impaired sight experienced.

Reading was often cited first when respondents were asked about which were the most significant challenges to their daily-living activities. All involved in the study were familiar with the difficulties of struggling with text and those registered with impaired sight were no longer able to read standard text at all. Large black print on a strongly contrasting background has been found to be of most benefit (yellow has been identified as very useful in MD) but is rarely, if ever, used. Other than the Macular Society, hospital eye departments were the only exceptions. However, even within the same hospital, this did not extend to other departments suggesting that as yet there is no flagging of this need on a patient's notes once it has been identified. One respondent described his enormous difficulty, without any real success, of getting his GP surgery to communicate with him in appropriate font size, despite repeated requests. Some respondents had opted to receive bank statements and tax returns in large print but generally none of the sample was proactive in this area. Those with a spouse or 'significant other' relied on them to deal with household bills etc. Modern technology in the form of Kindles, tablets and illuminated magnifiers were a useful way of mitigating problems.

Reading labels on food packaging, often in small print and on a poor background made shopping a frustrating experience.

.....'I used to enjoy shopping, now I hate it. I can't see the labels and can't compare prices. Getting someone else to come round with you is not the same.'

.....There's not much pleasure in shopping when you can't see and have to rely on someone else describing an item. Christmas shopping is not so much pleasure now that I can't browse or wrap the presents myself.'

.....When I'm looking for things on a supermarket shelf, being directed 'over there in that corner' is very frustrating'.

Handling change and distinguishing coins was another difficulty identified. Ways had been found to help overcome this. Two respondents actively kept purchases below £30 in order to use contactless cards and others would offer a note to avoid the embarrassment of not being able to find the correct change. Another would offer a handful of change for the shop assistant to select from.

Mobility was a big issue and the study looked at this in particular. Once driving was no longer possible, walking or using public transport became the alternative unless friends and family offered lifts. A loss of confidence was consistently quoted by respondents.



Negotiating public spaces could be frightening.

. 'Wokingham is pedestrian unfriendly'.

..... Wokingham's pavements are terrible. I walk round looking at my feet all the time'.

..... Car parks are terrifying. I like it when there is a kerb to feel with my stick. Then I can walk with a little more confidence'.

Shared pedestrian/cycling/car areas are terrifying, especially so if there are no markings or kerbs'

Poorly maintained traffic lights were another hazard. One set in particular, (Rectory Road/Glebelands/Palmer School crossroads) was quoted by several respondents. These did not always bleep thus causing confusion as to when to start crossing and anxiety about getting across in time.

..... The green man comes on but it doesn't always make a noise. I go when someone else goes whenever possible'.

Steps were yet another problem, especially if the edges were not highlighted in white or yellow strips. Handrails which ran for a length, stopped for a short distance and then restarted were also considered hazardous.

‘Using stairs, particularly those going down, are difficult. Some people ask why I don’t just use the lift, but I can’t see to operate it’.



Travel by bus, a means of maintaining independence, could be a challenge. Identifying the bus number involved asking others in the queue. Failed ‘next stop’ announcement systems on buses generated acute anxiety as the sense of location was lost. Buses which started before a seat was found, causing a loss of balance, were frightening and dangerous. Indicator boards in bus, railway and airport termini were cited as too small to be read, including the newly opened Terminal 5 at Heathrow airport. Having to cope with these difficulties eroded independence, increased loss of confidence and reduced the desire to go out and about alone.



.....’I go out when I’m less likely to be jostled – particularly when going to a supermarket’

For those trying to maintain independence or who were forced to travel alone to hospital appointments a ‘hidden expense’ was incurred. Public transport could be used for the journey going there but not for going home. The effect of dilation of the eye for examination is that of complete loss of focus and a taxi home was required. This was anything between £25-£35 each trip.

SOCIAL WELL BEING

As sight deteriorated a corresponding reduction in independent travel became inevitable. A common experience cited was that of having to give up interests and skilled hobbies resulting in curtailed social interaction

and further loss. Going out after dark was stopped. Activities requiring concentrated focus such as sewing, knitting, card playing and bowls were no longer possible.

.....'I rely on the internet now for socialising'

For the most severely affected, cooking became a safety issue and had to be stopped leading to increased reliance on spouses or more simple methods of preparing food.

.....'I buy ready-meals now. The (meals on wheels) firm that used to deliver went out of business.....Sometimes they didn't arrive till 2pm, or they might turn up at 11.30am and this upset my digestion which is fragile and needs regular meals'.

Eating out also became less pleasurable for those with advanced sight-loss and was given up by some.

.....'When you can't see, it's easy to spill food without realising'

.....'there is no such thing as a large-print menu and menus printed on boards are impossible'

Inability to read menus, missed cues to passing plates, seeing what food was on a plate and fear of spillages all reduced the pleasure of eating in company. In addition, using toilet facilities in restaurants could be awkward because of poor signage on toilet doors, particularly those situated down a few poorly-lit steps. Gradually, eating socially became a 'family only' activity.

There was a general anxiety about personal grooming. Worry about clothing being correctly colour coordinated, having toothpaste residue on faces or food on clothes resulted in loss of confidence in dealing with social encounters.



SUMMARY

The study has shown that the experience of MD is one of losses, with many of these losses leading to increased social isolation. All those interviewed had made many adaptations to their daily-living activities and sought to find a way round difficulties in order to maintain as much independence and pleasure in life as possible (see Frank's story in the appendix). Modern technology has come to the aid of many. Kindles, computers, especially tablets, enable reading to continue long after it would have been lost to previous generations. Household gadgets which 'talk' such as clocks, watches, scales and telephones were also found to be extremely useful.

RECOMMENDATIONS

Increased life expectancy has led to more people being affected by MD as it is mainly an age-related disease. Despite increased prevalence the general population is still not familiar with what it is or of its ramifications. Even those in the study said that they had little or no knowledge of it prior to diagnosis.

The study has also thrown light on where greater improvements could be made:

The Macular Society produces plenty of **informative and helpful literature** which should, at the very least, **be available in key places such as GP surgeries and hospital eye departments**.

The MD Society, RNIB, Berkshire Vision, ECLOs (Eye Clinic Liaison Officers) and the local MD group in particular are invaluable in disseminating knowledge of what is available to improve day to day living.

Communicating to sufferers of MD in a suitable format is still far from the norm. If hospital and GP systems were 'flagged' once those with MD are identified, they could receive notifications in either large print or email, whichever is the more suitable, whenever they use the service, across all departments.

Local MD groups can help combat isolation and disseminate practical knowledge on how to adapt to the challenges of the condition. Other care services (eg Chiropodists, who are in high demand from those with impaired sight) and voluntary organisations (eg The Link, a befriending organisation in Wokingham) could be made aware of MD and the help available so that those working for them can give advice when opportunities arise.

In public spaces **attention to traffic-light maintenance, quality of pavements, marking of stairways and steps needs to be improved.**

When designing new public areas introduction of kerbs, separation of traffic from pedestrians, continuous handrails where applicable and clear signage in large, bold contrasting text should receive high priority.

It is hoped that by raising the profile of MD, further outreach can take place and more done to improve life for the growing population who experience it.

APPENDIX 1: STORIES AND ANECDOTES

Frank, aged 80, lives with his wife in central Wokingham and contracted AMD 12 years ago with the first symptoms being a loss of night vision. AMD was then identified by a high street optician and confirmed by the RBH eye clinic.

Frank knew how AMD could progress as he had supported his father who “had big black spots in front of his eyes”. This was before the Macular Society had publicised AMD and there was no known treatment or means of warding off the deterioration. He was eventually registered blind.

Being computer literate Frank was able to research AMD and soon found and joined the Macular Society where he became one of their volunteer speakers and daily living champions. More importantly he learned the value of kale and oily fish in the diet and with his wife’s support he adjusted his diet accordingly.

Frank also found how helpful it is to be open about his AMD and to share experiences with other sufferers. Since he can no longer read normal-sized print one welcome discovery was the excellent talking-book services of RNIB and Calibre plus the associated book groups.

Frank had to give up driving shortly after his diagnosis, he also found it useful to move from a house with large garden to his present apartment.

Frank was a very active member of the University of the Third Age (U3A) before his diagnosis and has had to adjust his range of interests since many of the activities depend on access to a car. None the less he continues to maintain interests in military history and industrial heritage being a speaker for both groups. He has also started and leads an audio book group – another good place for exchanges of information.

I used to go out for lunch two or three times a week (this was an alternative to delivered meals) but I haven't done so for weeks now.

When you can't see, it is easy to drop or spill food without realising, or if you do know you have then you can't see to wipe stains off

quickly so it's difficult to keep clean. I don't want to be seen out like that. At home I wear some protection.

I buy 'ready meals' now. The local firm that used to deliver meals to me went out of business and if they have to come from further away then of course they will cost more. Besides, sometimes they didn't arrive till 2pm, or they might come at 11.30am and this upset my digestion which is fragile and needs regular meals.

I just buy microwaveable ready meals now. Writing on the packages is difficult to see. They often put the use-by date in smaller and less bold type and I have bought oven-bake meals by mistake.

I travel into Windsor for my eye appointments. I have to take a bus to Bracknell then another to Windsor.

After my treatment I can't see so I have a taxi home. This costs £35. I go in monthly.

Car parks are terrifying. I like it when there is a kerb to feel with my stick. Then I can walk with a little more confidence knowing that I'm on the footpath. If there are no kerbs I soon don't know where I am. Traffic comes from all directions and only a few cars have a beep sound when they are reversing.

I was shocked when I was given the diagnosis at the hospital. I'd been referred because I had a cataract problem. Instead the consultant told me he wouldn't be treating my cataracts because it wasn't worthwhile as I had MD. There was no 'bedside manner', no sympathy or caring and no information given to me. I left the hospital frightened and not knowing anything. I thought I might be totally blind before long. It was just by chance that I saw a poster a couple of days later advertising the Wokingham MD group. It is through them that I learnt about MD.

When out, say in a restaurant, the toilets are often in a dark corner or down a few steps. I have difficulty going down steps. Some people say that I should use a lift but I can't see well enough to operate a lift.

Public toilets are difficult. It is sometimes hard to identify the ladies from the gents. You have to wait a while to see who comes

out from where. Inside it is difficult to manage taps and automated machines. Which tap is hot or cold? Which buttons should be pressed and when?

APPENDIX 2 – INTERVIEW RESULTS

How long since diagnosis?	Registered impaired sight	Challenges to daily living	How do you feel?	Mobility	Does anyone communicate in ideal format?	How is your eyesight?
4 years	Yes	Reading, shopping, giving up activities	Shocked at beginning, frustrated, more isolated.	Steps difficult, pavements terrible, traffic lights don't beep.	Macular society, hospital eye dept, bank	Worse
9 years	Yes	Reading, stairs, Charles Bonet syndrome	Isolated, lost confidence	Uses keep mobile, volunteer drivers	hospital eye dept	Worse
4 years	Yes	Getting meals, shopping, glare and poor light	Depressed, frustrated, anxious	Uses keep mobile, volunteer drivers, taxis	Hospital eye dept, son	Worse
27 years	Yes	Getting meals, glare and poor light, loss of independence	Loss of confidence, worry re personal appearance	Uses public transport, taxis, difficulty with steps	Macular Society, hospital eye clinic	Worse
5 years	Yes	Reading, shopping, finding things and recognising people	Loss of confidence, frustrated	Walks. Pavements are poor.	Macular Society	Worse
10 years	Yes	Finding things, not recognising people, occupying time	Frustrated	Walks with stick. Lost confidence, kerbs helpful, car parks terrifying	Macular society, audio telephone reminder re appts	Worse
12 years	Yes	Reading, shopping, not recognising people	Depressed, frustrated,	Walks. Pavements are atrocious.	Macular society, hospital eye dept	Worse
7 years	Yes	Reading, eating, getting dressed.	Loss of confidence, isolated	Doesn't get out now	Grandson organises audio books	Worse
8 years	No	Reading, walking into doors, glare and poor light	Loss of confidence, isolated, worries re personal appearance	Slower and more cautious, steps difficult	Macular society, Bank	Same
5 years	No	Reading	Frustrated	Lost confidence	Macular society, hospital eye dept	Same
2 years ago	No	Reading, not recognising people, shopping	Worries re the future	OK	Macular society, bank	Same
2 years ago	No	Reading	Lost confidence	OK	No	Same
3 years ago	No	Reading, glare and poor light	Depression, worries about future	OK	Macular society, hospital eye dept, tax office	Worse
9 months	No	Reading	Depression, worries about future	OK	Macular society, hospital eye dept	Same
10 years	Yes	Moving around, travel to hospital, can't socialise	Lonely, life feels very restricted	Doesn't go out at busy times or in the evening. Uses public transport	Hospital eye dept	Worse

APPENDIX 3 – WOKINGHAM MACULAR SUPPORT GROUP

The Wokingham Macular Support Group is run by Jane Figg. It meets on the third Monday of each month at Chestnut Grange, Glebelands Road, Wokingham.

All those who suffer from Macular Degeneration, who support someone who suffers or who would just like to know more are welcome to attend.

Further details can be obtained from Jane Figg via email janefigg@icloud.com by phone on 01344 485477.



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With thanks to 