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1 **Response to Comment on: ‘You’ve got dry macular degeneration, end of story’: a qualitative study**
2 **into the experience of living with non-neovascular age-related macular degeneration.**

3 Deanna J. Taylor¹

4 Lee Jones¹

5 Alison M. Binns¹

6 David P. Crabb (corresponding author)¹

7 1. Division of Optometry and Visual Science, School of Health Sciences, City, University of
8 London, Northampton Square, London, EC1V 0HB, UK

9 Email address of corresponding author: david.crabb.1@city.ac.uk

10 Conflicts of Interest: None

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1 **To the editor,**

2 We thank Mr Gandhi for his letter, which supports some of the key messages from our recent
3 publication in Eye (1). Namely, that dry AMD can have a devastating emotional impact on the
4 patient, and that whilst eye clinics are overburdened and currently under immense pressures, more
5 must be done to support people living with this lifelong condition, in terms of both practical and
6 emotional support.

7 Mr Gandhi makes several excellent observations in his letter and we simply elaborate on the
8 evidence base supporting some of the pertinent points. First, the point that ‘many specialists convey
9 information with lucidity, but their words can nonetheless be difficult to retain at the door’
10 highlights a key problem – that many individuals can feel overloaded with information at the point of
11 diagnosis. Therefore, we are thrilled to hear about the design of a patient information booklet
12 tailored for the specific purpose of directing patients to both local and national support. We hope
13 other institutions follow this example. Another excellent resource to signpost individuals to for
14 information and support is the Macular Society (www.macularsociety.org).

15 We agree the ‘home situation’ of patients is of paramount importance. Interesting work is being
16 carried out elsewhere on optimising risk assessment in the home for people with vision impairment
17 (2, 3), although to our knowledge this tool has not as yet been applied to an AMD cohort. Another
18 element to an individual’s home situation that can be key to patient support is that of the informal
19 caregiver. Informal caregivers in wet AMD report a substantial psychological burden (4, 5) and we
20 speculate that this is likely the case for caregivers of individuals with dry AMD, and that these
21 individuals (described as ‘the hidden patients’) also require support. We also agree that referral to
22 low vision services should not just be for those with severe visual disability; our previous work (6-8)
23 has shown that performance of tasks relating to everyday visual function may be affected in some
24 patients with intermediate AMD whilst visual acuity remains relatively preserved. Moreover, the
25 subtle visual symptoms of AMD are often misunderstood (9).

We believe that the following quote from a participant with AMD in our study echoes Mr Gandhi's very pertinent comment about patients desperately seeking personal autonomy:

"It does take away your individuality of being you... You've got to rely on somebody else to do the things that you've always done."

We hope that people working within the field of dry AMD care consider these comments and the very relevant observations made by Mr. Gandhi.

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