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A proposal for a UK Dementia Eye Care Pathway

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1 CET point for UK optometrists

Dementia is a major public health problem in the developed world, and has become the focus for UK government and NHS initiatives in recent years. There are many different types of dementia, with Alzheimer's disease being the most common and best known, but other main types include dementia with Lewy bodies and vascular dementia. The risk of developing dementia is also raised in a number of other conditions, including Parkinson's disease, multiple sclerosis and motor neuron disease (Alzheimer's Society 2015). In the UK approximately two-thirds of people with dementia live in private households and one-third in some form of institutional care setting (Matthews et al. 2013).

The extent of dementia as a public health problem emerges from the most recent estimates of the number of people in the UK who have some form of dementia, which range from 670 000 (Matthews et al. 2013) to 835 000 (Alzheimer's Society 2014). Dementia prevalence increases with age, rising dramatically from 1.7% of people aged between 65 and 69 years to affect over 40% of people over the age of 95 years (Alzheimer's Society 2014). Improvements in life expectancy in the developed world are a tribute to the quality of modern healthcare but the increased prevalence of dementia in older people means that by 2021 it is estimated that over one million people in the UK will have dementia, a figure expected to rise to over two million by 2051 (Alzheimer's Society 2014). The 2011 census report *Population and Household Estimates for England and Wales* (Office for National Statistics 2011) highlights the increased longevity in the UK population with some startling data. For example, the percentage of the population aged 65 years and over was 16.4%, the highest recorded in any census. There has been a notable increase in the frequency of the oldest old, with 430 000 residents aged 90 and over in 2011 compared with 340 000 in 2001 and 13 000 in 1911 (Office for National Statistics 2011). It should be remembered, however, that dementia is not exclusively a disease of older people, and there are approximately 40 000 people in the UK aged under 65 years who have this debilitating condition (Alzheimer's Society 2014).

UK optometrists continue to provide eye care to their patients who develop dementia. As the majority of optometric patients are mature adults, the growth of the older population will inevitably mean that optometrists will encounter increasing numbers of people with dementia. It is in the interests of this patient group and the interests of the profession that eye care provision is designed to meet the needs of people with dementia and those who care for them. Evidence of the extent of the optometric profession's involvement in eye care for those with dementia comes from the College of Optometrists' recently completed Clinical Practice Survey (College of Optometrists, unpublished data) which revealed that 40% of respondents regularly, and 58% occasionally, examine patients with dementia.

The College of Optometrists has recently updated its guidance for the profession in the *Guidance for Professional Practice*, which has a section 'Examining patients with dementia or other acquired cognitive impairment', which contains much valuable advice for practitioners (College of Optometrists 2014). In addition to following this guidance, optometrists and others working in their practices can take simple steps to improve the eye examination experience of those with dementia and their carers by making their practice dementia-friendly. The Dementia Friends initiative (www.dementiafriends.org.uk), which in England is run by the Alzheimer's Society and Public Health England, was created to address the widespread stigma and lack of understanding of dementia in our communities. By February 2015, only 2 years after the launch of the scheme, there were over one million Dementia Friends. Becoming a friend is simple, involving attending a face-to-face information session and viewing videos online, with the objective of increasing people's knowledge of dementia and the steps they can take to 'make a difference' to the lives of people with dementia and their carers.

The continued growth of Dementia Friends – there is an ambitious target of achieving four million Dementia Friends by 2020 – is dependent on the recruitment of

Dementia Friends champions, volunteers who run the Dementia Friends information sessions. The overall objective of Dementia Friends is to build a dementia-friendly society, and optometry has a role to play here by creating more dementia-friendly practices which are sympathetic to the needs of people with dementia and their carers. Dementia Friends is a UK-wide initiative, with Dementia Friends in Wales supported by the Welsh government, the Dementia Friends Scotland initiative supported by Alzheimer Scotland, and the Dementia Friends in Northern Ireland scheme. Furthermore, optometrists are often able to direct people with dementia and/or their carers to valuable sources of information regarding the condition. The Alzheimer's Society website contains excellent resources on dementia in general, its symptoms and diagnosis, living with dementia and advice for carers (<http://alzheimers.org.uk/site/index.php>). The Alzheimer Scotland website is another useful resource (<http://www.alzscot.org/>).

For those people who have both dementia and sight loss, Thomas Pocklington Trust (TPT) is a charity which provides housing and other support (<http://www.pocklington-trust.org.uk/>). TPT has taken a particular interest in visual impairment and dementia and has funded research and published a number of excellent reports in this area. Of particular interest to optometrists, people with dementia and their carers is a recent publication funded by TPT from the University of Stirling, entitled *Good Practice in the Design of Homes and Living Spaces for People with Dementia and Sight Loss* (Greasley-Adams et al. 2015), which is full of good advice presented in an easily accessible format. The Royal National Institute of Blind People (RNIB) has been a major contributor to the most informative sight loss section in the 'Dementia and sensory loss' component of The Social Care Institute for Excellence's Dementia Gateway (<http://www.scie.org.uk/publications/dementia/living-with-dementia/sensory-loss/files/sight-loss.pdf>). The sensory loss section of the Gateway covers hearing loss, deafness and dual sensory loss, in addition to sight loss. There is a wealth of good advice here for professionals, carers and people suffering from dementia, focusing on the ways in which communication can be improved for people with sight loss and/or hearing loss and dementia. The guide also covers how to adapt the environment to assist people with sight loss and/or hearing loss.

The RNIB estimates that almost two million people in the UK live with sight loss that has a significant impact on their daily lives, and predicts that this will rise to almost four million by 2050 (Access Economics 2009). One in four people aged 75 years and over are living with sight loss, and in the population aged over 85 years this rises to one in three. The prevalence of dementia and the prevalence of eye conditions with the potential to cause visual impairment both increase with age. Visual impairment and dementia may coexist but there is a dearth of UK prevalence data on visual impairment among people with dementia. This was the basis of a recently completed large-scale England-wide study into the prevalence of visual impairment in people with dementia. The PrOVIDe study (Prevalence of Visual Impairment in Dementia) was undertaken by a multidisciplinary team led

by the College of Optometrists and funded by the National Institute for Health Research (NIHR).

The study was carried out in two stages. In stage 1 a total of 708 people with dementia, aged 60–89 years, underwent a domiciliary sight test complying with General Ophthalmic Services (GOS) requirements and professional guidelines. The sample included people living in their own homes (389) and in care homes (319). Stage 2 of the study collected qualitative data from 119 participants using interviews with people with dementia, and interviews and focus groups with family carers, professional care workers and optometrists. It is hoped that the study findings will be published in full by the NIHR later in 2015.

The potential effects of dementia and visual impairment comorbidity are considerable. The ability of someone with dementia to cope with visual impairment is reduced when compared to someone with an otherwise similar health profile, but without dementia. This can impact significantly on activities of daily living and cognitive performance (McKeefry and Bartlett 2010). In a study of over 9000 participants, those with a cognitive impairment were significantly more likely to have falls (odds ratio for falls of 2.3) when compared with those with no cognitive impairment (Yamashita et al. 2012). Dementia alone has a significant impact on quality of life, and visual impairment in older people can lead to functional impairment which may adversely affect quality of life (Binns et al. 2012). The effects of having both sight loss and dementia concurrently are much more severe than those resulting from either dementia or sight loss alone (Trigg and Jones 2007).

Creation of a Dementia Eye Care Pathway

Research findings like these, together with data emerging from the PrOVIDe study, lead to a conclusion that there is a pressing need to develop a Dementia Eye Care Pathway (DECP) to reduce the risks and prevalence of visual impairment among people with dementia, to facilitate appropriate treatment and care and to signpost services to people with dementia, carers and healthcare professionals. It is our recommendation that a dementia diagnosis should automatically trigger a range of measures. The DECP would promote the prevention and treatment of visual impairment by providing timely information for people with dementia and their carers and additional subsidies for spectacle provision, and improving access to optometric and ophthalmic services. The proposed elements of the DECP are described below within the context of emerging findings from the PrOVIDe study.

The need for information

The participants in stage 1 of the PrOVIDe study ranged from people with early-stage dementia and little cognitive impairment to people who had advanced dementia and considerable cognitive impairment. Cognitive impairment was assessed using a commonly used test, the standardised Mini Mental State Examination (sMMSE) (Folstein et al. 1975). A total of 54 participants (7.6% of the total sample) could not be assessed using the sMMSE, mainly because no coherent responses could be obtained when attempting the test, plus a small number were unavailable, asleep or

uncooperative. A further 138 participants (19.5%) had an sMMSE score of 9 or less, which represents severe cognitive impairment.

Despite the limitations of cognitive impairment, only eight participants were unable to undergo at least some part of the eye examination, and most key tests, including retinoscopy and direct ophthalmoscopy, were possible in over 80% of the overall sample. The main elements of the eye examination which caused difficulty for some participants were assessment of visual fields and carrying out a dilated fundus examination. Many of the family carers and care workers who took part in the qualitative stage 2 of the study said that they did not know if it was possible to conduct a full eye examination on people with dementia due to their cognitive impairment. This demonstrates the need to provide information to people with dementia, and carers, to encourage them to have regular sight tests. It cannot be assumed that everyone appreciates the need for regular sight tests or that eye care will not be overlooked when carers are faced with meeting more pressing healthcare needs which may take priority.

Under the proposed DECP, when an individual is diagnosed with dementia, either by the GP or by an old-age psychiatrist, the person should receive written information about the role of regular eye examinations by community optometrists in preventing visual impairment and the potential problems caused by visual impairment. The individual should be advised regarding the most appropriate frequency of GOS sight tests, and reassured that dementia is not a barrier to having an eye examination by an optometrist. In addition to the information being provided by the responsible medical practitioner, organisations involved in promoting dementia care, eg Alzheimer's Society, and eye care, eg the College of Optometrists, RNIB and TPT, will make the information available through their websites and other patient information resources.

Domiciliary eye care

Another finding from the study was that most of the study participants living at home, and their carers, were unaware that domiciliary sight tests were available to people unable to attend an optometric practice unaccompanied. Part of the core information provided through the DECP, and referred to above, should be information about how to access a domiciliary service if required. The College of Optometrists' 2014 Clinical Practice Survey asked how frequently optometrists would carry out a domiciliary eye examination on patients in their own homes. Only a minority of respondents reported carrying out domiciliary examinations regularly (10%) or occasionally (14%) in people's own homes, with even fewer carrying out examinations regularly in care homes (6%) and 15% occasionally (College of Optometrists, unpublished data). The College of Optometrists' *Guidance for Professional Practice* (College of Optometrists 2014) states that 'If you do not offer a domiciliary service you, or your practice, should make information available about where patients can access these services'. It behoves all practitioners to ensure that they provide this information

to ensure that individuals who have difficulty attending a practice do not miss out on regular eye care.

As previously stated, the ProVIDe study showed that most key elements of a sight test were possible with over 80% of the study participants. While many of the care home residents involved in the study were able to participate in a full eye examination, a minority of those living in care homes were unable to complete several elements due to severe cognitive impairment. Many care homes arrange for residents to have annual sight tests carried out by a domiciliary provider. Their diligence in seeking to provide regular sight tests for those living in their care homes is commendable, but our findings suggest that further research should be carried out to assess whether a two-stage approach to domiciliary sight testing would be more effective for people living in care homes who also have dementia. This two-stage approach would provide a basic fee for conducting an eye examination to assess the health of the eye and to check for the presence of sight-threatening conditions such as cataract, glaucoma, diabetic retinopathy and age-related macular degeneration, while a higher fee would be payable for a full sight test, including refraction. This would require changes to GOS regulations. However, given the perception by some carers that full eye examinations are not possible, and the reality that this may be true in a minority of situations, introducing the more basic health check might increase public confidence and encourage wider uptake of some level of eye examination.

Arrangements for sight testing/eye examinations

Optometrists who took part in the ProVIDe study suggested a range of strategies to improve the experience of the eye examination for people with dementia. These included scheduling longer than usual appointments or, to reduce stress on the individual, spreading the eye examination across two separate appointments. Overall the feedback was that there was a benefit to being able to approach the examination in a much more flexible way, to account for the individual preferences and capacity of a person with dementia to cope with either a longer appointment or several shorter sessions with the optometrist.

This type of flexibility in appointment arrangements is another recommendation of the proposed DECP. The funding structure for NHS eye examinations currently militates against such flexibility, so realising the DECP would require a GOS revision. In the interim, practitioners are encouraged to adopt flexible processes wherever possible in the interests of the patient.

Early referral for cataract surgery

A small number of studies have suggested that cataract removal has a positive outcome on cognitive impairment in people with dementia (Ishii et al. 2008; Lerner et al. 2014; Owsley et al. 2007; Tamura et al. 2004). In stage 2 of the ProVIDe project, people with dementia were interviewed about their experiences and attitudes towards eye care. When asked if they would consider cataract removal if

advised of the need for such surgery, all but one said they would have the operation. Family carers appreciated the possible benefits but had concerns regarding the physical and emotional demands on their relatives and were less likely to support intervention for cataracts.

There is clearly an issue about capacity to consent if individuals who still have mental capacity to consent say they would want surgery yet relatives would be reluctant to proceed, even though their reticence is based on wanting the best for their loved one. Our recommendation is that under the DECP an individual who is subsequently found to have dementia and cataract – irrespective of whether the dementia or the cataract is diagnosed first – is referred to ophthalmic services immediately so that a discussion about surgery can take place while the individual still has capacity to consent. This does not necessarily mean that everyone who has dementia and cataract will have early surgery. As with all surgery, assessment of the risks and benefits for the individual should be carried out and further research into the adjusted risk/benefit analysis for earlier cataract removal for people with dementia would be helpful.

Financial subsidies for spectacles

The ProVIDe study revealed problems associated with spectacle wearing among people with dementia. This included people being reluctant to wear spectacles, but other problems, particularly in residential care, were spectacles going missing and broken spectacles. Although people on low incomes are often eligible for a voucher towards the cost of spectacles, which may cover the full cost of the spectacles, this does not apply to everyone with dementia. Under the proposed DECP, anyone with dementia should be entitled to financial assistance with spectacles to ensure that missing or broken spectacles can be replaced. Subsidies to allow the provision of more resilient frames made from flexible materials or from materials less likely to break, where appropriate, should also be considered.

Conclusion

These emerging findings of the ProVIDe study are based on eye examination data and qualitative data on the attitudes and experiences of people with dementia, carers and optometrists. Collectively they provide insights into why some people do not receive the eye care they need and identify ways of preventing or managing visual impairment. The study was undertaken by a multidisciplinary team representing organisations and professions concerned with vision and dementia. It is our assertion that a DECP, by formally acknowledging the individual's right to information and appropriate eye care services, could reduce the prevalence of visual impairment in people with dementia and the considerable impact of visual impairment on an individual's quality of life. This article is intended to introduce this proposal and outline the areas that should be covered within a pathway. We hope that members of the optometric profession will comment on the proposal to enable further development and refinement before it is presented formally to policy makers and healthcare commissioners.

Any comments should be sent by email to the College of Optometrists' Research Team at researchteam@college-optometrists.org.

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● Summary

Dementia is a major public health problem in the developed world; approximately 750 000 people in the UK have some form of dementia. A recent survey found that around 40% of optometrists regularly, and 58% occasionally, examine patients with dementia. The profession has a role to play in creating more dementia-friendly practices and some of the resources available to optometrists on dementia and its management are discussed in this article. The ProVIDe study (Prevalence of Visual Impairment in Dementia), led by the College of Optometrists, used a multidisciplinary approach to investigate the prevalence of visual impairment using eye examination data and qualitative data on the attitudes and experiences of people with dementia, carers and optometrists. One conclusion from ProVIDe is that a Dementia Eye Care Pathway, by formally acknowledging the individual's right to information and appropriate eye care services, could reduce the prevalence of visual impairment in people with dementia and the considerable impact of visual impairment on an individual's quality of life. This article introduces this proposal and outlines the areas that should be covered within a pathway.

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1. By 2021, how many people are expected to be affected by dementia?
 - (a) 430 000
 - (b) 835 000
 - (c) 1 000 000
 - (d) 2 000 000
 2. How many people under 65 years old are currently affected by dementia?
 - (a) 13 000
 - (b) 40 000
 - (c) 340 000
 - (d) 430 000
 3. Which section in the College of Optometrists' *Guidance for Professional Practice* gives advice to improve eye examination for those affected by dementia?
 - (a) Examining patients with dementia
 - (b) Examining patients with acquired cognitive impairment
 - (c) The routine eye examination
 - (d) Examining patients with dementia or other acquired cognitive impairment
 4. The ProVIDe study showed that key elements of a sight test were possible with how many of the study participants?
 - (a) 10%
 - (b) 14%
 - (c) 19.5%
 - (d) 80%
 5. What did family carers and care workers who took part in the qualitative stage 2 part of the ProVIDe study report?
 - (a) They did not know if it was possible to conduct a full eye examination on people with dementia due to their cognitive impairment
 - (b) They always knew it was possible to conduct a full eye examination on people with dementia, regardless of their cognitive impairment
 - (c) They reported eye examinations were a priority for those affected by dementia
 - (d) They reported that eye examinations were a low priority for those affected by dementia

CET multiple choice questions

This article has been approved for one non-interactive point under the GOC's Enhanced CET Scheme. The reference and relevant competencies are stated at the head of the article. To gain your point visit the College's website www.college-optometrists.org/oip and complete the multiple choice questions online. The deadline for completion is 31 July 2016.

6. What would be one of the outcomes of the proposed Dementia Eye Care Pathway?
- (a) Reduce the prevalence of visual impairment in people with dementia
 - (b) Ensure those with dementia have an eye examination every year
 - (c) Change the law of consent to ensure access to cataract surgery
 - (d) Recommend not completing a visual field test on those affected by dementia

● CPD Exercise

After reading this article can you identify areas in which your knowledge of a proposal for a UK Dementia Eye Care Pathway has been enhanced?

How do you feel you can use this knowledge to offer better patient advice?

Are there any areas you still feel you need to study and how might you do this?

Which areas outlined in this article would you benefit from reading in more depth, and why?

● Reflection

1. What impact has your learning had, or might it have, on:
- your patients or other service users (eg those who refer patients to you, members of staff whom you supervise)?

- yourself (improved knowledge, performance, confidence)?

- your colleagues?

2. How might you assess/measure this impact?

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