

H.8.2 Informational needs of people with suspected or confirmed AMD and their family members/carers

RQ3a: What information do people with suspected AMD and their family members or carers find useful, and in what format and when?

RQ3b: What information do people with confirmed AMD and their family members or carers find useful, and in what format and when?

Review finding	Contributing studies	Confidence in the evidence	Explanation of confidence in the evidence assessment
Theme 1: Information required and when			
Timing: Before diagnosis			
Information about types of AMD and risk factors/causes			
<ul style="list-style-type: none"> Patients and carers want increased public awareness of the causes and symptoms of AMD (Burton, Vukicevic). This could provide a context for diagnosis, could help people seek advice earlier (Burton). This could help improve public interaction with people with AMD (more understanding of the challenges facing the visually impaired) (Vukicevic). 	Burton (2013) Vukicevic (2016)	Moderate confidence	This review finding is rated as moderate, because there were two studies with minor methodological limitations. The studies were internally and externally coherent. There were no serious problems with relevance and fairly adequate data from UK and Australia.
At the opticians- detection of possible AMD			
<ul style="list-style-type: none"> Patients reported very different experiences at the opticians when they were told that they may have a severe eye condition. The way a person was told and what they were told appeared to have a big effect on the anxiety and fear they feel prior to formal diagnosis. 	Burton (2013)	Moderate confidence	This review finding is rated as moderate, because was one study with minor methodological limitations. The study was internally coherent. There were no serious problems with relevance and fairly adequate data from UK.
Timing: At or following diagnosis			
<ul style="list-style-type: none"> The information at diagnosis needs to be matched to the person's disease stage: early AMD patients needed information about monitoring their condition and spotting changes; wet AMD patients needed to know about available treatments and outcomes; patients with advanced disease needed to hear about support services and equipment 	Burton (2013)	Moderate confidence	This review finding is rated as moderate, because was one study with minor methodological limitations. The study was internally coherent. There were no serious problems with relevance and fairly adequate data from UK.
Information about types of AMD and frequency of diagnosis			

Review finding	Contributing studies	Confidence in the evidence	Explanation of confidence in the evidence assessment
<ul style="list-style-type: none"> Patients were confused about the different names and types of AMD (Dahlin Ivanoff) Patients were unaware that AMD was so common (Burton, Dahlin Ivanoff). 	Burton (2013) Dahlin Ivanoff (1996)	High confidence	This review finding is rated as high because there were two studies with minor methodological limitations. The studies were internally and externally coherent. There were no serious problems with relevance and adequate data from UK and Sweden.
Information about potential causes and risk factors			
<ul style="list-style-type: none"> Patients often lacked a clear understanding of the potential causes and risk factors associated with AMD (Burton, Crossland, Dahlin Ivanoff). Most patients were not aware of the potential effects of smoking on disease development and progression, while those patients that mentioned smoking as a cause did not necessarily believe it (Crossland). Patients often linked AMD to wear and tear and ageing (Crossland, McCloud). The role of genetic susceptibility in developing AMD was not widely understood (Crossland). 	Burton (2013) Crossland (2007) Dahlin Ivanoff (1996) McCloud (2015)	High confidence	This review finding is rated as high, because there were 4 studies with minor methodological limitations. The studies were internally and externally coherent. There were no serious problems with relevance and adequate data from UK, Sweden and Australia.
Information about disease progression			
<ul style="list-style-type: none"> Patients were suffering unnecessarily due to inaccurate/insufficient information about disease progression, leaving them to worry about going completely blind (Burton, McCloud, Dahlin Ivanoff). Patients discussed a need for accurate information to help them plan for the future and avoid unrealistic expectations (Burton, Dahlin Ivanoff, Patients reported giving up favourite pastimes to help preserve their vision (Burton). 	Burton (2013) Dahlin Ivanoff (1996) McCloud (2015)	High confidence	This review finding is rated as high, because there were 3 studies with minor methodological limitations. The studies were internally and externally coherent. There were no serious problems with relevance and adequate data from UK, Sweden and Australia.
Information about treatment regimens			
<ul style="list-style-type: none"> Patients often had unrealistic expectations of treatment outcomes and this was not helped by inaccurate information 	Burton (2013)	Moderate confidence	This review finding is rated as moderate because there were three studies with minor methodological

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<p>from neighbours/family members (Burton).</p> <ul style="list-style-type: none"> • Patients did not necessarily understand the importance of the use of vitamins and food to promote eye health and when they could be useful during disease progression (Burton, Dahlin Ivanoff). • Patients did not understand why glasses were not able to correct their vision problems (Dahlin Ivanoff). • Patients were often unaware of the purpose of hospital visits and medical procedures (Burton). • An understanding of the processes involved in treatment and the short -term side effects allowed patients to plan their post-treatment activities to cope with these problems (McCloud). • Information about abnormal outcomes and when to seek help would also be useful (McCloud). • Good communication regarding changes in treatment regimens was linked to better patient experience (McCloud). 	<p>Dahlin Ivanoff (1996) McCloud (2015)</p>		<p>limitations. The studies were internally coherent, but with limited overlap. There were no serious problems with relevance and adequate data from UK, Sweden and Australia.</p>
Other non-NHS support services/ financial help			
<ul style="list-style-type: none"> • Patients were unaware of support groups or unlikely to attend them for fear of associating with depressed people. • Patients were not necessarily aware of sources of financial help (e.g. attendance allowance) or the advantages associated with being registered as partially sighted. 	<p>Burton (2013)</p>	<p>Moderate confidence</p>	<p>This review finding is rated as moderate, because there was one study with minor methodological limitations. The study was internally coherent. There were no serious problems with relevance and fairly adequate data from UK.</p>
Monitoring of symptoms- when to seek help?			
<ul style="list-style-type: none"> • Patients who were not being regularly monitored were expected to identify advancing vision loss and seek appropriate support as and when it was necessary. However, they did not understand what constituted a serious change and were worried about wasting doctor's valuable time and NHS resources. They were also relatively unlikely to attend accident and emergency if their vision changed as they did not associate A and E with this type of care. 	<p>Burton (2013)</p>	<p>Moderate confidence</p>	<p>This review finding is rated as moderate, because there was one study with minor methodological limitations. The study was internally coherent. There were no serious problems with relevance and fairly adequate data from UK.</p>

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Theme 2: Format of information			
<ul style="list-style-type: none"> • Verbal communication of information was problematic for many patients as they struggled to understand and retain the information given to them in hospital consultations. They also reported problems with hearing and understanding the doctors' accents. • The use of written sources of information was potentially problematic as patients could be confused by the volume of information and find it hard to read the documents. • Patients reported finding the language use by medical staff to be confusing and inaccessible. 	Burton (2013)	Moderate confidence	This review finding is rated as moderate, because there was one study with minor methodological limitations. The study was internally coherent. There were no serious problems with relevance and fairly adequate data from UK.
Theme 3: Additional sources of information			
<ul style="list-style-type: none"> • These were varied and not always accurate. In particular, information from neighbours and friends could be very misleading and discourage people from seeking help in a timely manner or lead them to have unrealistic expectations from treatment. • Support groups could be useful sources of information, but patients were not necessarily aware of them. • Public presentations were raised as a useful source of information, but required pro-active patients. 	Burton (2013)	Moderate confidence	This review finding is rated as moderate, because there was one study with minor methodological limitations. The study was internally coherent. There were no serious problems with relevance and fairly adequate data from UK.
Theme 4: Caregiver perspectives and needs			
<ul style="list-style-type: none"> • Carers need sufficient information to allow them to understand the condition and the physical/emotional effects on the person's wellbeing. • Caregivers raised the point that since AMD has a genetic component it is important that all family members of AMD sufferers are aware of their increased risk and have regular eye tests. • They lack information about support services and respite care 	Vukicevic (2016)	High confidence	This review finding is rated as high, because there was one study with minor methodological limitations. The study was internally coherent. High relevance with adequate sample size from an Australian study.

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options.			
Additional points			
<ul style="list-style-type: none"> • Patients were unaware that medical research was being carried out (Dahlin Ivanoff). • Patient experiences were more positive if they received reassurance, support and caring communication from medical staff (McCloud). 	Dahlin Ivanoff (1996) McCloud (2015)	Moderate confidence	This review finding is rated as moderate because there were two studies with minor methodological limitations. The studies were internally coherent, but with limited overlap. There were no serious problems with relevance and fairly adequate data from UK and Australia.