Productivity Commission Inquiry into Caring for Older Australians

Macular Degeneration Foundation

Submission

August 2010

Contact: Julie Heraghty
Chief Executive
Macular Degeneration Foundation
Suite 302, 447 Kent Street, Sydney
Toll Free: 1800 111 709
Fax: (02) 9261 8912
Email: ceo@mdfoundation.com.au

Contact: Jayne Gan
Client Project Officer
Macular Degeneration Foundation
Suite 302, 447 Kent Street, Sydney
Toll Free: 1800 111 709
Fax: (02) 9261 8912

1. Introduction

i. The Macular Degeneration Foundation

The Macular Degeneration Foundation is the peak body in Australia offering information and support for people with Macular Degeneration (MD), also referred to as Age-related Macular Degeneration (AMD).

It has a client base of over 32,000 people and support from Government, eye health professionals, industry and the wider community. The major linkages are with the health, ageing and disability areas.

The Macular Degeneration Foundation is committed to working on behalf of the entire Macular Degeneration community, specifically those with the disease, their families and carers.

The Foundation's vision is to reduce the incidence and impact of MD through education, awareness, research, support services and representation.

The Foundation promotes early intervention and prevention of MD through its information, education, and awareness programs. Furthermore, the Foundation encourages independence and quality of life for people with MD through its support services.

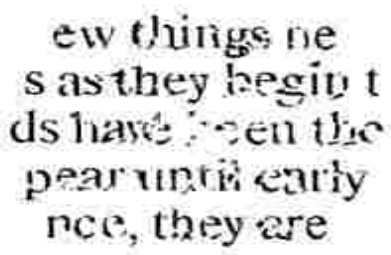
The Foundation's key message is that; early detection is vital to saving sight and to ensure eye health measures related to diet, nutrition and lifestyle are practiced to reduce the risk or slow the progression of the disease. In addition, ensuring those with vision loss have information on low vision services and access to low vision aids and technologies is a primary objective of the Foundation.

ii. Macular Degeneration

The macula is the central part of the retina, the light sensitive tissue at the back of the eye and processes all images. Macular Degeneration is the name given to a group of degenerative retinal diseases that cause progressive loss of central vision. There are two types of Macular Degeneration – Dry MD and Wet MD. Dry MD results in a gradual loss of central vision while Wet MD is characterised by an aggressive and sudden loss of vision.

Key symptoms of AMD include distortion (when straight lines appear wavy or bent), dark patches or empty spaces in the centre of vision. Impairment of central vision results in a loss of detailed vision which includes the ability to read, recognise faces, drive a car, see colours clearly and any other activity that requires fine vision[1].

Distortion



Empty Spaces

Dark Patches

AMD is the leading cause of blindness and severe vision loss in Australia[2], affecting one in seven people over the age of fifty[3]. It is hereditary with a fifty per cent chance of developing AMD if a family history is present[4]. AMD is caused by genetic and environmental factors. Risk factors include age, family history, smoking[5].

The disease is often called AMD or Age-related Macular Degeneration (defined as developed after the age of 50 years) and can result in physical disability. It primarily affects people within the aged community who will live in a range of accommodation and care situations - at home, in retirement villages and in residential care.

AMD and associated vision impairment can restrict activity and affect independence and quality of life. Many people with AMD require assistance from family, friends and/or carers, service providers, and a range of government services.

Facts about Macular Degeneration:

(a) Macular Degeneration is the leading cause of blindness and severe vision loss in Australia.[6]

(b) One in seven people over the age of 50 are affected by the disease and the incidence increases with age and it is commonly referred to as Age Related Macular Degeneration or 'AMD'[7].

(c) The disease is primarily a disease of the ageing and has a direct relationship with the older Australians and subsequently the care of older Australians.

(d) AMD is responsible for 50 per cent of blindness among Australians over the age of 40 years[8].

(e) The total economic cost of vision loss in Australia is estimated to be $16.6 billion in 2009 (with a total health system cost of $2.98 billion) [9].

(f) The direct and indirect costs of vision impairment for people with AMD ($2.6 billion in a year, this will grow to $6.5 billion in 2025)[10].

(g) Early detection can save sight and early intervention can help slow the progression of AMD[11].

(h) Early detection is critical to saving sight and for the best possible treatment outcomes for people with Wet MD[12].

iii. The Impact of Vision Impairment

(a) Vision impairment prevents healthy and independent ageing and is associated with the following:

- Risk of falls increased two times
- Risk of depression increased three times
- Risk of hip fractures increased four to eight times
- Admission to nursing homes three years early

- Social dependence increased two times
- Social independence decreased two times[13]

(b) The socio-economic impacts of vision impairment include:

- Lower employment rates
- Higher use of services (including two times as likely to use health services)
- Social isolation
- Emotional distress[14]

(c) Access to rehabilitation services can lessen the daily impacts or burden of disease and improve quality of life for people with low vision[15]

iv. Creating an Effective Aged Care Framework (ACF)

The Macular Degeneration Foundation supports an Aged Care Framework (ACF) which:

(a) Addresses the immediate and long term needs of people with AMD and their carers in any aged care setting (community and residential care)

(b) Promotes independence and quality of life

(c) Incorporates key criteria of prevention, early intervention, equity of access and a continuum of short and long term care based on individual needs

(d) Incorporates the medical and rehabilitation needs of those with vision loss due to AMD

(e) Provides access to low vision services and aids and technologies

(f) Includes consideration of the role of the family and the carer

(g) Acknowledges education of aged care workers and service providers is essential to providing appropriate and quality care for people with AMD and their carers

(h) Addresses the education and training of aged care workers on AMD and low vision within various aged care settings such as retirement villages, Aged Care Assessment Teams (ACATs), Home and Community Care (HACC) agencies, Veterans' Affairs, and residential care.

v. Principles Underpinning a Strong Aged Care Framework

The following principles are required to underpin the development of a strong Aged Care Framework in relation to the AMD community:

(a) Recognition and acknowledgement that those in our communities with AMD can be affected by vision impairment resulting in disability;

(b) Recognition and acknowledgement of those with AMD require support and care from a range of services, providers and professionals;
(c) The importance of access to early intervention strategies, rehabilitation services and treatment to meet individual needs;

(d) The importance of self determination, choice, and flexibility with service provision;

(e) The Macular Degeneration Foundation be a part of any consultative body in the review, consultation and implementation of any framework covering aged, disabled and vision impaired;

(f) The Macular Degeneration Foundation be included in the education of aged care workers and service providers regarding AMD and low vision;

(g) Ongoing participatory consultation and effective representation by the AMD community;

(h) Efficient and effective participatory monitoring and evaluation of any framework, and a process for continuous improvement be implemented;

(i) Empowerment and capacity building be promoted to support and enhance social inclusion principles throughout the new framework;

(j) The provision of services to cover medical, social and emotional requirements of those with AMD be a key consideration;

(k) The development of a transparent and accountable system through guidelines, minimum service standards, or an accreditation process for rehabilitation services be implemented to guarantee the delivery of quality services;

(l) The development of a strong policy addressing AMD and low vision with a mandatory professional development requirement to effectively educate aged care service providers on AMD and low vision;

(m) A 'level playing field' be created for the fair allocation of resources across the aged care system and disability services, including the recognition of the impact and burden of disease for people with AMD;

(n) The inclusion of key component of equity and access to:
    a. Low vision aids and technology
    b. Transport
    c. Carer Services
    d. Respite Services

(o) A national framework be developed which is economically sustainable, comprehensive, seamless, accessible, efficient and fair;

(p) The *Convention on the Rights of Persons with a Disability* be acknowledged and included;

(q) The United Nations *Principles on the Rights of Older Persons*, including independence, participation, care, self-fulfilment and dignity be acknowledged and included.

2. The Need for Care and Support

(i) AMD Requires Care and Support

The stages of disease for AMD are defined in Table 1 below and will be referred to within this report.

The level of vision impairment defines the level of physical disability experienced by a person with AMD and therefore the level of care and support required.

People with a physical disability due to AMD should have access to appropriate care and support. Care and support includes medical services, rehabilitation and support services; and education and health promotion services.

Table 1: Mapping Aged Care and Support Requirements to Classifications of AMD and Vision Impairment

Aged Care and Support Requirements	Stage of Disease	Stage of Vision Impairment	Clinical Description	VA	Burden of Disease
None	No AMD	Early Diagnostic Stage	No sign of AMD	VA >6/12	0%
Low	Early AMD	Mild Severity	Intermediate Drusen	6/18<VA≤6/12	6%
Intermediate	Intermediate AMD	Moderate Severity	Geographic Atrophy or Neovascular MD	6/60≤VA≤6/18	36%
High	Advanced AMD	Blindness (Severe)	Geographic Atrophy or Neovascular MD	VA<6/60	58%

(ii) AMD and Burden of Disease

The burden of disease for vision impairment for an individual with AMD can be measured to determine the quality of life impacted by low vision.

The burden of disease is measured in Disability Adjusted Life Years (DALYs) being healthy Years of Life lost due to Disability (YLD). For example, a disability weight of 0.02 for mild sight loss is interpreted as losing 2% of a person's quality of life relative to perfect health outcomes[16].

The DALY burden for YLD for vision impairment due to AMD in Australia is:

- 35.7% or moderate vision impairment (6/60 ≤ VA ≤ 6/18)
- 62.1% for blindness (VA < 6/60)

The burden of disease for AMD in Australia is calculated at approximately $62,000 per individual in 2010[17].

The global DALY burden for YLD for vision impairment is:

- 36% for moderate vision impairment (6/60 ≤ VA ≤ 6/18)
- 58% for blindness (VA < 6/60) [18]

DALY weights are fairly consistent across countries; however the Australian DALY is calculated as slightly higher than the global DALY.

The global cost of VI due to AMD is US$343 billion including US$255 billion direct health care costs. The Global Burden of Disease (GBD) for people with vision impairment will be deprived of the equivalent of 118 million years of healthy life (DALYs) due to disability and premature death in 2010, with AMD the cause of 6 million of these DALYs. If current trends continue this health burden will rise to 150 million DALYs in 2020[19].

(iii) AMD is a Physical Disability

The World Health Organisation defines vision impairment as broadly covering a limitation in one or more functions of the eye, which includes impairment of visual acuity (sharpness or clarity of vision) experienced by people with AMD.

Moderate vision impairment is defined in terms of Visual Acuity (VA) as 6/60 ≤ VA ≤ 6/18 and (legal) blindness VA < 6/60[20].

AMD is responsible for 50% of severe vision loss in Australia[21], with over 98,070 Australians having moderate to severe vision impairment due to AMD in 2010 (40,394 Geographic Atrophy and 57, 676 Neovascular) [22].

All people who have moderate to severe vision impairment are identified as having a physical disability and should have access to appropriate vision care and support services.

Moderate to severe vision impairment has a significant impact on a person's quality of life due to their disability[23]. In any framework it is important that the relative level of disability should be judged on an individual basis using both measures of VA and burden of disease (DALYs).

Given that the definition of a disability is the "limitation, restriction or impairment that is likely to last for at least six months and restricts everyday activities", the following evidence supports that AMD can be classified as a physical disability and should be recognised as such in this inquiry.

Vision impairment prevents healthy and independent ageing. It is associated with an increased risk of depression, loss of independence, increased social dependence, inability to participate in valued and daily activities and early admission into nursing homes[24].

Research has identified that a consequence of visual impairment for people with AMD is that quality of life is significantly worse than the general population. The quality of life of people with AMD has been found to be comparable to other chronic illnesses such as cancer and heart disease[25].

Central vision loss due to AMD also greatly affects a person's ability to perform valued daily activities such as reading, leisure activities, watching TV, driving and recognising faces[26]. A multi-country cross sectional study in Canada, France, Germany, Spain and the UK found that people with AMD have a third of the ability to perform everyday activities[27].

A person's inability to maintain participation in activities due to vision loss has been associated with an increased risk of depression[28], loss of independence[29] and a lower level of life satisfaction[30]. The short and long term effect of these outcomes is that people with vision impairment are at a greater risk of social isolation, social dependence and the need of earlier nursing home care[31].

It is evident that people with moderate vision impairment and blindness due to AMD can experience a physical disability. Disability due to AMD should be judged on an individual basis as the burden of disease can affect people differently having a direct impact on independence and quality of life[32].

The following times are identified as the highest need for people diagnosed with AMD are:

a) When first diagnosed with AMD;

b) When experiencing sudden or severe vision loss;

c) When vision loss affects independence and quality of life as measured by the burden of disease;

d) When the person with AMD faces unpredictable circumstance related to emotional, social and economic impacts, such as loss of a job, the loss of a partner or social isolation;

e) When the effect of vision loss is compounded due to co-morbidity; and

f) Other incidents that affect a person's vision or healthcare.

The burden of vision impairment highlighted in "The Global Economic Cost of Visual Impairment" report can be reduced through early implementation of national Aged Care Framework which addresses effective prevention, treatment and low vision rehabilitation strategies[33].

3. Appropriate Care and Support Services

Access to appropriate care and support services directly correlates to the ability of people with AMD to retain independence and continue to live within their own home. It is crucial that any Aged Care Framework provide the treatment and rehabilitation services to the meet individual needs of a person with AMD, thereby supporting independence and quality of life.

(i) Education and Training for Aged Care Service Providers and Workers

Early intervention for AMD can help to save sight. Aged care workers are at the forefront of delivering care and support services for people with AMD. It is vital that there is a comprehensive education and training program about AMD and low vision which is developed, implemented and supported for aged care workers within any Aged Care Framework.

A holistic education and training program would address the following for people with AMD:

1. Ensure aged care service providers and staff facilitate regular eye health checks (especially for people within residential care);

2. Ensure that medical treatment and rehabilitation services are accessed as required;

3. Require aged care facilities and services to consider the unique needs of people with low vision with regard to equity and access;

4. Certify that standards and protocols for aged care services are developed specific to people with AMD;

5. Facilitate the delivery of services to meet the physical, social, economic and emotional needs of a person with AMD; and

6. Provide education and training on working effectively with people who have low vision.

There is a need for adequate and effective education and training (or professional development) of aged care workers and service providers to help promote vision health, independence and quality of life for people with AMD.

(ii) The Role of Aged Care Service Providers and Workers

A primary role of the aged care service provider or worker is to ensure that regular eye health checks are conducted for people within the aged care system and to facilitate access to medical treatment and vision rehabilitation services. Immediately reporting any changes in vision are essential for early detection and intervention to save sight.

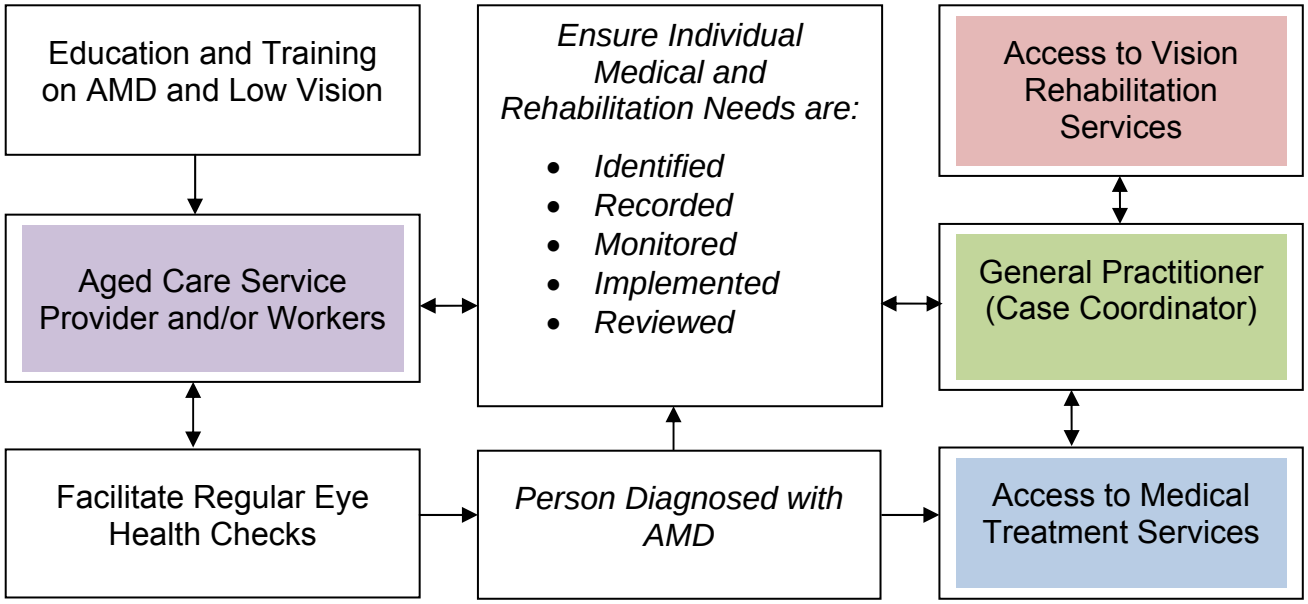
The GP can act as the key health professional or gatekeeper to ensure complete care for those with AMD to ensure the provision of relevant medical and rehabilitation services. As a part of this role the GP can conduct a simple needs assessment to create referrals onto relevant medical and rehabilitation services.

As part of ensuring that an individual's health and aged care needs are being met; the aged care provider or worker must be adequately educated on AMD and low vision as a necessary requirement for service provision, and a mandatory component of professional development.

The MD Foundation can play a major role in the area of professional development for aged care providers. Comprehensive education and training should be covered and financially supported within the Aged care Framework.

When a person is diagnosed as having AMD, the role of the aged care worker is to facilitate access to an assessment and subsequently identified appropriate health care services. An assessment should be conducted by an appropriate health care professional to determine the individual needs of the patient for medical and rehabilitation services. The involvement of the GP as case coordinator is essential for ongoing continuum of care and as a central record keeper of the health of the patient.

Flow Chart 1: Mapping the Role of Aged Care Providers and Workers



(iii) Needs-based Assessment Tool

Emotional, social and economic impacts of AMD can be assessed using well established and internationally used assessment tools to identify the individual needs of a person with AMD.

The assessment tool should be comprehensive, structured, consistent and easy to use. Effective models of GP-based assessment processes are currently seen with the Australian GP Mental Health Plan Assessment Tool[34] or the Type 2 Diabetes Risk Assessment Tool[35]. The assessment will provide information which will enable early intervention and management of patients, as well as clearly defined referral pathways to health and allied service providers for medical treatment and vision rehabilitation.

4. The Role of the General Practitioner

As with the management of any chronic disease it is essential that the GP has a role in ensuring the needs of the patient are identified and met. It is essential that an individual case plan, involving referral to relevant agencies, service providers and organisations be undertaken and implemented.

GPs need to receive professional reports from all those involved in the patient's treatment and rehabilitation program, enabling monitoring, effective management and follow up. This is especially relevant when a patient moves to different accommodation or care arrangements.

One of the key aspects of management of the AMD patient is to ensure patients receive both medical treatment and rehabilitation. This is all too often **not** the case, with patients "falling between the gaps" of the medical and rehabilitation areas. Patients may be told "there is nothing else that can be done to help your AMD" by a medical professional, but may not know there are vision rehabilitation services available. The seamless flow of referral requires the GP to undertake a central role, as an important communication link for the patient's ongoing well being.

Medical treatment for AMD is undertaken by an ophthalmologist and/or retinal specialist. The impact of the disease, including the emotional, social and economic consequences of vision impairment, is assessed by a range of professionals and various rehabilitation pathways can be recommended. In addition, many other professionals can be involved such as an optometrist, orthoptist, psychologist, occupational therapist; orientation and mobility instructor, low vision therapist, or care provider.

The GP is the professional most likely to be acting as the entry point for community-based care and involved in servicing those in all levels of residential care. As such, the GP plays a pivotal role in ensuring relevant referrals are made to meet individual's vision rehabilitation needs.

5. Types of Vision Health Care Services

Two types of services are required by people who have vision impairment due to AMD:

a) Medical Treatment Services
b) Vision Rehabilitation Services

Both types of services should be considered for financial support under the new Aged Care Framework. Medical treatment will be most likely be delivered through an Ophthalmologist or Retina Specialist with the referral from an Optometrist or GP. It is essential that the GP be informed and involved to review treatment and provide referrals as required.

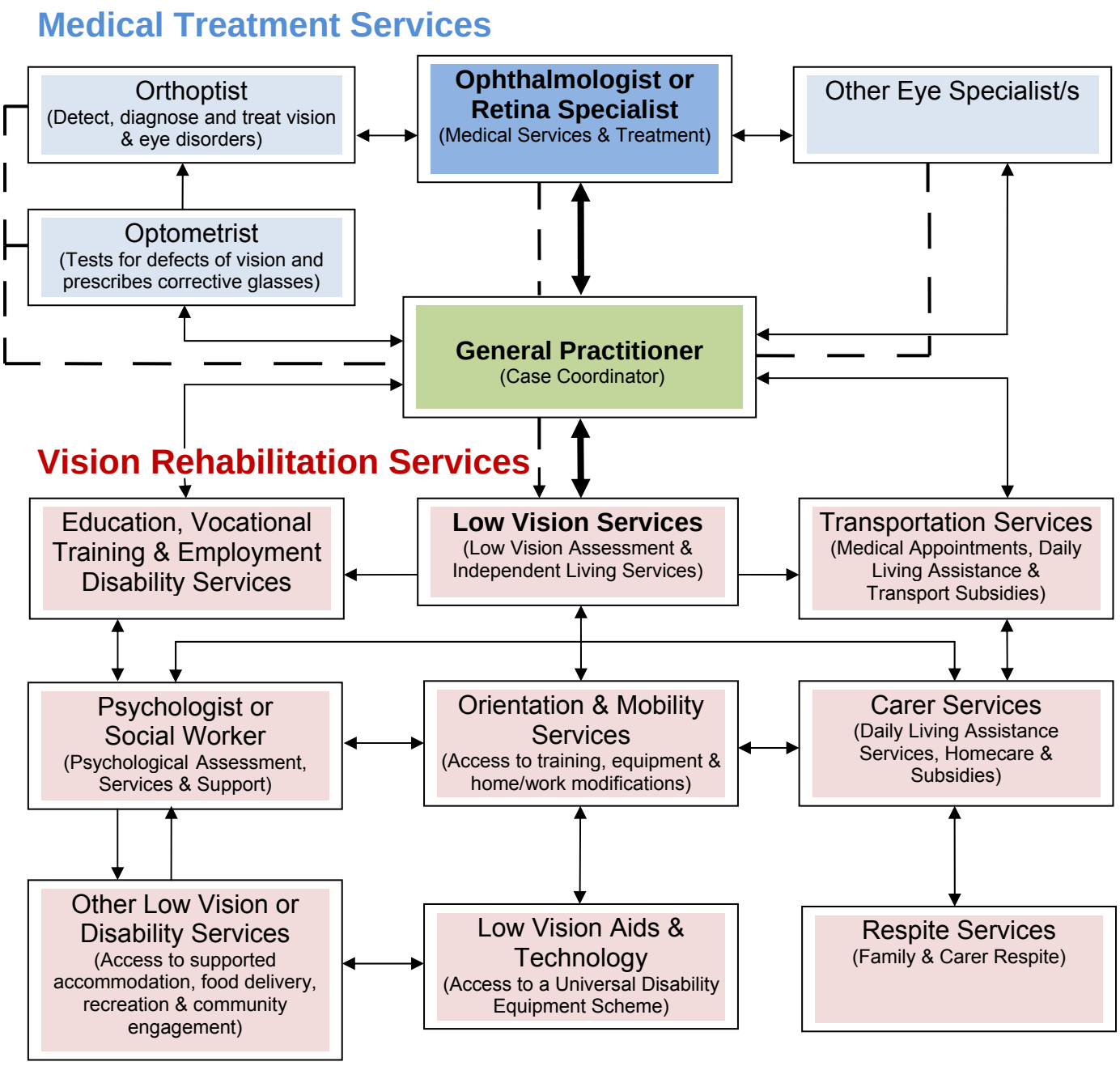
Social and other services and subsidies required by an individual with vision impairment or blindness are covered within the vision rehabilitation services category. All services should be equitable and available to those who the meet the selection criteria of having a physical disability due to vision loss.

Any Framework should allow for choice, whereby those with a 'disability' and/or their carer/s are able to choose and access services that best meet their needs.

Aged care service providers and workers are crucial to the effectiveness and access to appropriate medical treatment and low vision rehabilitation services.

It is the aged care worker who can initiate and facilitate access to care and support services required by people with AMD and potentially save the sight of elderly people and help them to retain independence and quality of life.

Flow Chart 2: Mapping a Seamless Referral Pathway for AMD



6. Medical Assessment and Treatment

Medical services must be affordable, accessible and operate on the premise of prevention, early intervention and effective treatment to save sight, and maintain independence and quality of life.

Those with AMD are often required to attend regular appointments with an optometrist, orthoptist, ophthalmologist, and other eye specialist/s. The medical treatment services should be coordinated by the treating ophthalmologist and feedback from medical assessments and treatment discussed by the GP with the patient.

MD Foundation Core Message:
"Get your eyes tested regularly and make sure your macula is checked".

Currently, medical assessments, tests and treatment are covered under Medicare. Appointments with eye health professionals to monitor and treat AMD can be costly and expensive. The expenses from these services should continue to be available with appropriate Medicare rebates. Where ongoing frequent medical fees are not currently covered by Medicare (ie: Optical Coherence Tomography), it is critical to ensure that that costs do not prevent ongoing treatment which could result in blindness and subsequently cost the community and the patient far more economically, socially and emotionally.

The more severe form of AMD is sudden and dramatic and caused by weak blood vessels growing into the retina and leaking blood and fluid - it is called Wet AMD. This form of AMD is the only one for which there is presently an effective treatment. However with Wet AMD, patients require immediate and frequent treatment to give the best possible chance of preserving sight[36].

The treating physician should explain the medical diagnosis and discuss treatment options with the patient. The Ophthalmologist should refer patients to vision rehabilitation services. However where this does not occur, the GP can coordinate referral to relevant rehabilitation services.

There has been, for some patients, a “disconnect” between the visit to the ophthalmologist and referral to rehabilitation with the medical model failing to engage and connect with the rehabilitation side of vision loss. Some patients currently ‘fall between the gaps’. It is essential that all professionals, especially the aged care workers and the GP are aware of the critical importance of this side of AMD patient management.

AMD is related to modifiable risk factors such as smoking, maintaining a healthy weight, protecting eyes from sunlight fitness, blood pressure, cholesterol and diet (limiting intake of fats) [37]. It is crucial to create awareness of AMD risk factors so individuals can change their behavior to reduce the risk of developing AMD or slow the progression of the disease. There are diet and lifestyle changes people can make to help slow the progression of AMD[38].

Evidence suggests the earlier a person is diagnosed with AMD, the greater the opportunity of saving sight. Information, education and awareness campaigns directed at behavior modification for prevention, early intervention and treatment for AMD (such as the AMD Foundation’s activities and programs) should be supported under the new Aged Care Framework.

Mapping the Natural History of Macular Degeneration

7. Vision Rehabilitation Services

Vision rehabilitation services aim to help people minimise the health, social, emotional and economic impacts of vision impairment, so people can lead as close to normal life as possible with their remaining vision, use of other senses and with aids and technology. The goal is to maintain independent living and quality of life for people with low vision.

(i) Services Required

There is a fundamental need to ensure services cover most of the individual care and support needs of a person with vision impairment throughout their lifetime according to need. There are a number of vision rehabilitation services that can be identified as required by a person with vision disability including:

a) **Low vision services** (including information, assessment and training in independent daily living);

b) **Orientation and mobility services** (including mobility at home, work or within the local community);

c) **Low vision aids and technology** (including low vision equipment and any training required in the use of aids and assistive technology);

d) **Carer and respite services** (including assistance with daily living activities and respite services available for family or carers);

e) **Education, vocational training and disability employment services** (to increase skills and provide support to find and maintain worthwhile education, training and employment);

f) **Transport services** (including to medical or rehabilitation appointments and daily living transportation needs to support independence and allow people to stay within their homes longer);

g) **Emotional support** (including psychological and social services, information and education);

h) **Community participation** (including leisure and recreation); and

i) **Other disability services** (supporting independent living and community participation).

The vision rehabilitation services should be accessible and supported by an Aged Care Framework.

Aged Care workers must be aware of these services, provide information about vision rehabilitation options, direct people with AMD to seek a low vision assessment and ensure the involvement of the GP for ongoing central co-ordination and referrals.

Those with MD should be provided information on service options and empowered (where possible) to determine which services to access.

(ii) Barriers to Service

Rehabilitation services can reduce the impact of vision loss, however studies show that many Australians could benefit from these services but fail to use them. Current barriers to accessing low vision rehabilitation services include:

a) A lack of awareness in services offered among people with vision impairment and referring professionals;

b) A misconception that rehabilitation services are only for people who are blind;

c) Confusion with the referral process;

d) Problems with using transport to access rehabilitation services; and

e) Personal factors such as co-morbidities[39].

It is crucial that aged care professionals refer people with a vision disability to seek assessment and rehabilitation services. The GP can play a critical role as case coordinator in identifying needs and referring people with low vision to rehabilitation services.

Greater capacity for people to manage and take control of their vision loss can promote confidence, reduce stress and improve overall quality of life.

The Aged Care Framework should focus on improving the uptake of rehabilitation services by people with a vision disability and remove barriers to services to promote independent living for people with a disability due to AMD.

It is evident that a variety of services are required to assist people with severe low vision including; medical, low vision, aids and technology, care and respite, psychological and emotional support, education, vocational training or employment, transportation, and community participation.

Referral pathways must be strengthened through improving the knowledge of AMD and of vision rehabilitation amongst aged care and health professionals.

(iii) Low Vision Services Standards

Like most major service providers service standards through guidelines and/or accreditation are essential and should be considered through any new scheme. A seamless referral network is critical to an efficient and effective service.

People who have a vision disability due to AMD require support and help from a range of health professionals and services. The Centre for Eye Research Australia (CERA) found

that up to 85% of people with low vision and visual acuity of < 6/12 in Australia could benefit from accessing low vision rehabilitation[40].

Low vision services and access to rehabilitation programs can assist people with vision impairment by lessening emotional distress[41] and increasing the ability to participate in daily activities unassisted thereby increasing independence[42].

Low vision organisations such as Vision Australia, Royal Society for the Blind South Australia, Queensland Blind Association, and Guide Dogs (to name a few), are crucial in providing a variety of low vision services aimed at assisting the person with low vision in their home, work or local community. It is important for people with vision impairment to access vision rehabilitation services to promote independence and maintain quality of life.

Access to low vision service providers is crucial for people affected with AMD to demonstrate skills to best use their remaining vision and other senses to continue daily living activities, as well as to introduce low vision aids or technology that will further support independence. These service organisations meet a need for the low vision community, and as such should be an integral part of any seamless referral system.

There are some key areas that could be improved and addressed in the development of the new Aged Care Framework:

a) Aged Care providers and workers are required to have a level of knowledge of AMD and low vision through mandatory participation in education and training to meet service standards.

b) Service organisations are required to fulfill a minimum level of expectations with service delivery standards. This would allow for equity to access in the provision of a standard level of service, thereby addressing the current trend that individuals can receive different services and service standards across organisations and states;

c) A requirement of service standards, or an accreditation process, is to review and improve the existing referral process between low vision service organisations and other service providers. This will minimise the current risk of people getting ‘lost in the system’ or ‘falling through the gaps’. This is particularly relevant in creating greater coordination between agencies to ensure the individual needs of the client are met satisfactorily and to avoid duplication of services; and

d) The level and quality of low vision services should ensure people who have vision impairment living in rural or remote areas, receive equitable service delivery, which can be facilitated by aged care service providers or workers.

8. Low Vision Aids and Technology

A recent audit of low vision aids and equipment carried out by the Foundation in August 2010 found that there is no standard subsidy across the states and territories that provide equitable access to subsidies for low vision aids and technology[43]. The Department of Health in several states (QLD, SA, NT and VIC) have no subsidy scheme available for purchasing low vision aids or assistive technology. Where subsidies do exist, the criteria involved to access the schemes are severely limiting requiring means testing, DVA membership, or pension concession card or senior card holder status. Existing subsidies are inadequate and do not provide for the low vision aids and technology needs for people with a vision disability across this country in an equitable manner.

Access to low vision aids and technology is valued by users and increases independence and quality of life for people who are vision impaired[44]. The Aged care Framework must focus on ensuring the provision aids and technology to people who are identified as having a vision disability.

Costs associated with aids and technology can limit the availability of assistive equipment for many people with low vision. A national program must be developed and supported by Governments enabling low vision aids and technology to be affordable and accessible.

A hearing aid is currently subsidised and made affordable and accessible for people within an aged care setting. Mobility aids are also available and facilitated through ACAT or residential care facilities. It is as important for low vision aids and technology to be subsidised and made affordable and accessible for people with a vision disability.

Training in the use of the low vision aids and/or technology is essential for maximum use, and as such should be covered by the Framework[45].

Mechanisms for remote, rural or socially isolated people with a vision disability should be addressed. A communication platform must be available and accessible to convey the types and choices of low vision aids and technology, as well as the method and means to obtain them under the Aged Care Framework. Where cost remains a barrier for the purchase of low vision aids and technology, long-term loan and recycled equipment schemes should be supported under the Framework.

Aids and technology must be a major component of the Aged Care Framework as they provide the central pathway for independence and quality of life for people with a vision disability.

MD Foundation client Jo Thomas uses low vision aids and Technology everyday to continue to access information.

9. Care and Respite

People with a vision disability due to AMD may require the support of family, friends and carers. When independent living is no longer possible it is the role of the carer to undertake activities that can no longer be performed by the person who has low vision. Where possible, the Foundation supports programs for carers allowing the person with low vision to maintain living as independently as possible within their own home.

Care should support independent and daily living and personal care needs. Participatory independent care plans need to be developed and implemented by carers and relevant service providers covering objectives, care activities, roles and responsibilities. Any carer scheme should allow for equity of access and regular monitoring and evaluation of services to ensure the delivery of quality services accountable to the client[46].

Where a person is living in residential care, it is the responsibility of aged care service provider to ensure appropriate and adequate care and support is given to a person with AMD, taking into consideration the unique needs of people with low vision. Access to medical treatment and vision rehabilitation services must be facilitated. The quality of life for a person with vision impairment should be a paramount consideration, and all efforts must be directed to ensure the accessibility of services.

Where the carer is a family member or friend, access to appropriate local respite services must be an integral part of an Aged Care Framework.

10. Emotional Support

Studies have shown that people with AMD experience depression at the same rate as people with cancer or heart disease[47]. Depression is a serious illness and can have effects on physical and mental health, affecting independence and quality of life[48]. It is vital that people with AMD have access to appropriate psychological services which are easily accessible and affordable.

Depression must be recognised in order to be treated effectively by a health care professional. Having a GP act in the role of case coordinator will ensure regular assessments are completed to identify depression (and/or other mental illness) experienced by a person with a vision disability, thereby promoting early intervention for psychological support. Emotional support must be included as a necessary service option for people with a vision disability and included within the Aged Care Framework.

The GP can identify and provide referral to appropriate local psychological services. Clients can be supported according to their individual needs, and fees should be covered by Medicare as allocated under the GP Mental Health Care Plan as part of the *National Action Plan on Mental Health 2006-2011*[49].

Aged care service providers should facilitate access to appropriate psychological services identified as a need for a person with AMD.

11. Community Participation

Wherever possible any scheme should encourage and support community participation. Healthy living should be promoted within any aged care setting, especially to reduce the impact of co-morbidity. Regular exercise and leisure activities can help people with low vision remain active and engaged in the community. It is important to reduce social isolation and maintain confidence to continue to participate in activities[50].

Low vision doubles the risk of falls[51], and central vision loss associated with AMD can result in impaired balance and increased risk of falls. Most falls are preventable, with about 50 per cent of falls occurring within homes or immediate surroundings[52]. Community aged care service providers (such as ACATs and relevant HACC service providers) have a role to play in actively supporting reduction in slips, trips and falls.

Residential aged care service providers must ensure facilities are appropriate for a person with low vision as a part of the duty of care.

Physical activity keeps us healthy and reduces the risk of falls. When considering community participation the information and education of falls prevention, and the participation in orientation and mobility training, is important and should be included within the Aged Care Framework.

12. Education, Vocational Training and Employment

There are those who sit within the aged care system who desire to continue or start education, vocational training or employment, and so should be considered within a Framework.

There are high productivity losses from reduced labour market participation through lower employment, greater absenteeism, and premature mortality associated with low vision and blindness[53]. Labour force participation for people with disabilities is 53 per cent, with Vision Australia reporting that 63 per cent of people who are blind or vision impaired are underemployed or unemployed[54]. Lost earnings for visually impaired are estimated to cost the Australian economy $1.8 billion in 2004[55].

Participation in education, vocational training, and/or employment by people who have a vision disability boosts their level of productivity and positively impacts quality of life. It is important when developing the Aged Care Framework that support is given, for those who so choose, to access to appropriate education, vocational training and Disability Employment Services.

The individual Vision Rehabilitation Plan should give information about education, training and employment options and services, including subsidy or support schemes such as the Employment Assistance Fund[56]. Full participation by people with a vision disability should be encouraged and promoted where possible through the Aged Care Framework.

13. Transportation Services

A national transport scheme is an important consideration under the Aged Care Framework to enable access to appropriate local medical and rehabilitation services for people with a disability due to AMD.

Any scheme must address the physical accessibility and affordability of transport services for all but especially rural and remote clients, who may require treatment and rehabilitation services.

14. Costs

The Aged Care Framework must be equitable and appropriate, covering costs associated with a vision disability and the care required. Access to the service should not be hindered due to cost and the financial system for people with a vision disability must be simple and easy to use.

15. The E-health System

The implementation of the proposed E-health system, involves records being shared across health professionals via an Individual Electronic Health Record (IEHR), allowing healthcare providers to make better decisions about health and treatment advice, and greater transparency and sharing of information[57]. This will be of great value to the GP for co-ordination and efficiency in the management of patients with a vision disability. Furthermore, it will allow aged care health service providers greater transparency of individual treatment plans allowing for enhanced coordination of services.

The MD Foundation supports healthy and independent aging.

16. Conclusion

Those with AMD need clear, accurate and appropriate information about their disease. The ready availability of this information for people with AMD and their families and/or carer is essential for effective care. This includes information about the risk factors for AMD, treatment, the low vision rehabilitation pathway, and safe and independent everyday living.

The Macular Degeneration Foundation supports the AMD community and health professionals by providing information through professional education, Continuing Professional Development (CPD) approved publications, and via our website and helpline.

The Foundation has an ongoing, critical and necessary role in any scheme; especially in supporting the General Practitioner and aged care service providers and workers in their roles.

A pilot project with General Practitioners in NSW conducted by the AMD Foundation through a grant funded by the Federal Department of Health and Ageing (in 2009 and 2010); highlighted the need for ongoing professional development and support for GPs in diagnosis, treatment and rehabilitation of AMD.

A similar educational and training program could be developed for use within the aged care sector as a mandatory induction requirement for workers and as an ongoing component of professional development.

The not-for-profit sector has an extremely important role in providing advice, information, education, support, advocacy and education for individuals, families and carers affected by AMD, and as such should be recognised and included in the Aged Care Framework.

The objective of the reform directions under the *Aged Care Framework* is for people with a vision disability due to AMD to have needs based planning to enhance their quality of life, participation and independence as valued members of the community.

The MD Foundation's submission highlights the following:

1. AMD is primarily a disease of the ageing and is the leading cause of blindness and vision loss in this country; maintaining vision, quality of life and independence are key objectives for those with AMD;

2. Nearly one quarter of Australia's population will be aged 65 and over by 2050, compared with 13.5 percent today[58]. Without greater prevention and treatment the number of Australians who are vision impaired due to AMD will increase from 64,685 in 2010 to 135,808 by 2030[59].

3. It is critical to acknowledge, understand and include those with AMD in an Aged Care Framework;

4. The medical, emotional, social and economic needs of people with a disability due to AMD must be given consideration in any Aged Care Framework;

5. It is important to have a simple, easy and accessible framework with input in design and evaluation from the very people who will use the services;

6. The need to include prevention, early intervention, treatment and rehabilitation needs for people with a vision disability due to AMD in any national Aged Care Framework

7. There is an important role for education and training of all people within the aged care community in order to provide effective and appropriate levels of support and care for people with AMD;

8. There is a wide range of professionals supporting a person with AMD and this should include the General Practitioner;

9. A well structured, seamless, equitable and accessible referral process is critical to ensure both medical and rehabilitation services are included in aged care and support;

10. There is an imperative in providing equity of access to a range of appropriate services acknowledging both medical and rehabilitation needs;

11. Services should have standards, guidelines and protocols, with consideration of an accreditation process;

12. People who are blind or have low vision need to be consulted and empowered in the development of an accessible Aged Care Framework, involved in decision making, and have ongoing input into the growth and maturity of an Aged Care Framework;

13. Aged care service providers and workers have an important role to play in promoting prevention, ensure regular testing for AMD, and facilitating early intervention. It is crucial that the medical and rehabilitation requirements of people with AMD are considered and included within the Aged Care Framework.

17. References

[1, 6] Arnold JJ, Heriot W., 2006, *Clinical Evidence*: 15, 1-3.
[2] Mitchell P, Taylor HR, Keeffe JE, Vu H, Wang JJ, Rochtchina E, Pezzullo LM, 'Vision Loss in Australia' *Medical Journal of Australia* 2005v12 (11) pp. 565-568
[3, 7, 11] VanNewkirk MR, Nanjan AMD, Wang JJ, Mitchell P, Taylor AMD, McCarty CA, 'The Prevalence of Age-related Maculopathy: The Visual Impairment Project' Ophthalmology 2000 (107): 1593-1600
[4] Smith W, Assink J, Klein R, Mitchell P, Klaver CC, Klein BE, Hofman A, Jensen S, Wang JJ, de Jong PT. 'Risk Factors for Age-related Macular Degeneration: Pooled Findings from Three Continents'. *Ophthalmology* 2001; 108(4): 697-704.
[5] Smith W., Mitchell P., "Family History and Age-related Maculopathy: The Blue Mountains Eye Study", *Australian and New Zealand Journal of Ophthalmology*, 1998, 26: 203-6.
[8, 9] Vision 2020, June 2010, Clear Focus: The Economic Impact of Vision Loss in Australia in 2009. Prepared by Access Economics for Vision 2020.
[10, 13, 14, 31, 39, 50] Centre of Eye Research Australia (2006) *Centrally Focused: The Impact of Age-Related Macular Degeneration*. Prepared by Access Economics for the *Centre of Eye Research Australia,* Melbourne.
[11, 12] Hooper *et al*, 2008, *Eyes on the Future*, May 2010, Prepared by Access Economics for the Macular Degeneration Foundation.
[15, 24, 59] Mitchell *et al*, 2009, *Eyes on the Future*, May 2010, Prepared by Access Economics for the Macular Degeneration Foundation.
[9] Arnold JJ., Heriot W., 2006, *Clinical Evidence*: 15, 1-3.
[11] Van Newkirk MR *et al*, "The Prevalence of Age-related Maculopathy: The Visual Impairment Project", *Ophthalmology*, 2000: 107: 1593-1600.
[16, 18, 19, 21, 33] *The Global Economic Cost of Visual Impairment* (2010), Prepared by Access Economics for the AMD Alliance International.
[17, 20, 22, 36, 39] Access Economics, *Draft: Eyes on the Future*, June 2010, Prepared by Access Economics for the Macular Degeneration Foundation.
[23] Mitchell, J. and Bradley, C., "Quality of life in age-related macular degeneration: a review of the literature", *Health and Quality of Life Outcomes*, 2006, 4:97.
[25] Williams RA, Brody BL, Thomas RG, Kaplan RM, Brown SI. *The Psychosocial Impact of Macular Degeneration.* Arch Ophthalmol 1998, 116:514-520.
[26, 29] Lotery a, Xu X, Zlatava G, Loftus J. *Burden of illness, visual impairment and health resource utilisation of patients with neovascular age-related macular degeneration: results from the UK cohort of a five-country cross-sectional study.* Br j Ophthalmol 2007, 91(10): 1303-7.
[27] Cruess A, Xu X, Mones J, Lotery A, Pauleikhoff A, Soubrane G, Zlateva G, Goss T. Humanistic Burden and Health Resource Utilization among neovascular age-related Macular Degeneration Patients: Results from a multi-country Cross Sectional Study. ARVO 2006.
[28] Owsley C, McGwin G, Scilley K, Dreer LE, Bray CR, Mason JO. *Focus Groups with Persons Who Have Age-Related Macular Degeneration: Emotional Issues. Rehabilitation Psychology* 2006, 1:23-29.
[30] Good G.A, La Grow S, Alpass F. *Activity and independence: A comparison study of older people with and without impaired vision.* Presented at The 9th International Conference on Low Vision, Montreal 2008.
[32] Lamoureuz EL, Pallant JF, Pesudovs K, Rees G, Hassell JB, Keeffe J.E. The Effectiveness of Low-Vision Rehabilitation on Participation in Daily Living and Quality of Life. Investigative Ophthalmology and Visual Science 2007, 48:1476-1482.
[34] Department of Health and Aging, 2010, *National Action Plan on Mental Health 2006-2011,* located at: http://www.health.gov.au/internet/main/publishing.nsf/Content/health-pcd-gp-mental-health-care-medicare
[35] General Practice NSW, 2010, *National Prevention of Type 2 Diabetes Program*, located at: http://www.gpnsw.com.au/programs/diabetes
[37] Mitchell P *et al*, *Arch Ophthalmol*, 2002, 120: 1357-63.

[38] Age-Related Eye Disease Study Research Group (AREDS). *Arch Ophthalmol*, 2001, 119: 1417-36.
[40, 44, 45] O'Connor P, Keeffe J. *Focus on Low Vision*. Centre of Eye Research Australia 2007.
[41] Brody BL, Roch-Levecq AC, Thomas RG, Kaplan MK, Brown SI. *Self-management of Age-related Macular Degeneration at the 6- Month Follow-up*. Arch Ophthalmol 2005:123:46-53.
[42] Hinds A, Sinclair A, Park J, Paterson H, Macdonald M. *Impact of an interdisciplinary low vision service on the quality of life of low vision patients*. Br J Ophthalmol 2003, 87:1391-1396.
[43] Macular Degeneration Foundation, *Low Vision Aids and Technology Subsidies*, August 2010.
[46] Ageing, Disability and Home Care, Department of Human Services NSW, March 2010, *"New directions for disability respite services in NSW"*, Located at: http://www.dadhc.nsw.gov.au/NR/rdonlyres/50B41AD4-57B5-4BF3-8989-FD5A528FADE6/5168/NewdirectionsfordisabilityservicesinNSW.pdf
[47] Mitchell J, Bradley C. Quality of life in age-related Macular Degeneration: A review of the Literature. AMDAI White Paper. Royal Holloway University of London 2006.
[48] Chung Ting-Yiu R, Pang KLK, Tong YWJ. Survey on Socio-economic Impact of Age-related Macular Degeneration to Patients Families. Public Opinion Programme HKU 2007.
[49] Department of Health and Aging, the *National Action Plan on Mental Health 2006-2011,* located at http://www.health.gov.au/internet/main/publishing.nsf/content/health-pcd-gp-mental-health-care-medicare
[51] NSW Department of Health, 2004, Stay on Your Feet: Your Home Safety Checklist
[52] Australian Commission on Safety and Quality Healthcare, 2009, *"Preventing Falls and Harm in Older People: Best Practice Guidelines for Australian Community Care"*, located at www.safetyandquality.gov.au
[53] Binns et al 2009, Hooper et al 2008, Lamourex et al 2007 O'Connor et al 2008, Pollard et al 2003. In Access Economics, *Eyes on the Future*, May 2010, Prepared by Access Economics for the Macular Degeneration Foundation.
[54] Department of Families, Housing, Community Services and Indigenous Affairs, 2010, *SHUT OUT: The Experience of People with Disabilities and their Families in Australia,* located at: http://www.fahcsia.gov.au/sa/disability/pubs/policy/community_consult/Pages/2_4_cantgetajob.aspx
[55] Eye Research Australia, 2004, *The Economic Impact and Cost of Vision Loss in Australia*. Prepared by Access Economics for the *Centre of Eye Research Australia,* Melbourne.
[56] Department of Education, Employment and Workplace Relations, 2010, Employment Assistance Fund, located at: http://www.deewr.gov.au/Employment/Programs/DES/Employer_Support/Pages/EAF.aspx
[57] National E-health Transition Authority, 2010, located at: http://www.nehta.gov.au/
[58] Department of Treasury Australia, *Australia to 2050: Future Challenges*, Intergenerational Report (January 2010) at 9.