GETTING **ACROSS** DEMENTIA

A DEMENTIA MANAGEMENT RESOURCE FOR GENERAL PRACTICE

ALZHEIMER'S ASSOCIATION VICTORIA
Sharing Dementia Care

SOUTHCITY GP services

A SSESSMENT

C OMMUNICATION

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Contents

Introduction

Education programs targeting the management and maintenance of frail and elderly people in their home, particularly those with dementia, have been identified as a priority by the membership of Southcity GP Services.

The *Getting ACROSS Dementia Program* has been undertaken in conjunction with Alzheimer's Association Victoria (AAV). Collaboration and support has also been provided by the steering committee for the project which included:

- Caulfield Aged Care Assessment Service (ACAS).
- Cognitive Dementia and Memory Service (CDAMS).
- Royal District Nursing Service (RDNS).
- Consumer representatives.
- Pfizer Pty Ltd.
- Local geriatricians and psychogeriatricians.
- Local general practitioners.

Role of the GP in Dementia Care and Management

It is estimated that there are 150,000 people in Australia who have moderate to severe dementia. There are a further 150,000 people in the community who may be in the early stages of dementia. Potentially, up to 50 people per day in Australia could be newly diagnosed as having dementia. The incidence of dementia increases exponentially with age, increasing in prevalence from one in 20 people in the 65 to 70 age group to one in four in those over 85.

Population projections indicate there will be a sixfold increase in the population aged 85 and over between 2000 and 2046. It is estimated that by that time there will be more than 1 million Australians with dementia. Younger people with dementia have also been identified as an increasing group.

The pace of advances in understanding of the nature and types of dementia, and their aetiology, is accelerating considerably and research into the effectiveness of acetylcholinesterase inhibitor medication for Alzheimer's disease, and other forms of dementia is continuing with favourable outcomes. In this environment, the general practitioner (GP) can be increasingly confident in the provision of meaningful diagnostic, prognostic and therapeutic information, and exhibition of an increasing range of evidence-based pharmacological and non-pharmacological interventions.

The general practitioner is perfectly placed, by way of background training, and a longstanding trusting relationship with the patient and family, to lead and coordinate the necessary comprehensive bio-psycho-social approach to the ongoing care of the patient with dementia and provide authoritative information and support to the caregiver. The advent of the Enhanced Primary Care initiative offers a potential reimbursement structure, allowing the general practitioner to more effectively embrace, promote and coordinate a bio-psycho-social management model.

The Getting ACROSS Dementia Kit

Diagnosis and management of patients with dementia is a complex matter which represents a challenge for general practitioners requiring support in the form of well considered continuing education and a practical guide to available resources.

This kit has been designed to address management and treatment issues to assist general practitioners to manage patients with dementia from early onset through to late stage nursing home care.

ACROSS

The "ACROSS" acronym was adopted for this program and kit as it provides a framework for a practical patient and caregiver centred approach to care and management of Alzheimer's disease and other dementias. It was developed by Barrett et al. to assist GPs to improve the quality of life for patients, their families and caregivers across all stages of Alzheimer's disease. However, it is equally applicable to other types of dementia.

This tool, provides an overview of the issues for people living with dementia and can be used as a simple guide for referral and support of patients and carers. From this basic level, the "ACROSS" framework is linked to progressively more detailed information sources and tools for those GPs who want to take a more proactive role in the management of their patients.

It should be noted that the ACROSS framework is not sequential, and should not be viewed as providing a linear management process. Apart from the Assessment section, (which deals with the process involved in obtaining a diagnosis), all other sections are applicable throughout the progression of the illness, and should be considered concurrently.

The information provided in each of the sections under the ACROSS acronym is in response to issues raised by people with dementia, their families and carers about the information and support they need to maintain well-being, independence and dignity through the progress of the condition. The information provided is intended to assist GPs to increase their effectiveness in treating dementia and includes suggested approaches to management issues.

A referral chart has been developed identifying referral options for patients and caregivers, (and sources of additional information for the GP), in response to specific presenting issues, and is located under the Referral section. This chart has been reproduced in a reduced format and laminated for easy access and reference.

A comprehensive index of support agencies, specific to Southcity's geographic region, is included in the Referral section.

Appendices

The appendices contain practical tools suitable to the primary care setting, and additional information, which are referred to throughout the kit. These include:

- History, examination and investigation, and caregiver check-lists.
- Brief introduction to dementia management in the nursing home setting.
- The Global Deterioration Scale.

Where necessary, recent developments, especially current trends in pharmacotherapy, not covered in the core reference materials, have been added.

Key References

The core reference for the kit is Barrett et al- "Alzheimer's Disease Patients and Their Care Givers: Medical Care Issues for the Primary Care Physician" – which provides a user-friendly and practical introductory reference to patient and care giver centred dementia management, and more details on the ACROSS framework.

An article by Brodaty – "The Role of the GP in the Management of Alzheimer's Disease" also provides a valuable resource for GPs, relating specifically to the Australian context.

A third principal resource - "Grey Matters" dementia notebook sponsored by Pfizer, offers a more broadly-based but succinct summary of the topic, including aetiology and differential diagnosis.

These three documents are included with this kit.

Additional Resources and Further Reading

A list of other sources of information has also been included. These resources include:

- **Websites**, which provide updated information on research and treatments, and carer resources. Some also provide the opportunity to discuss, with other GPs and experts in the field, issues you are dealing with in your own practice.
- **Articles**, which provide additional information about dementia and management issues in the primary care setting.
- **Books and videos**, which present issues from the perspective of people diagnosed with dementia, families and carers.

Assessment

Early Diagnosis

- The benefits of an early diagnosis of dementia should not be underestimated. It contributes to maximising the independence and dignity of the person with the diagnosis and enables the patient and family members to work together in making and adjusting plans for the future.
- It is essential that concerns of family members about changes in behaviour or other potential symptoms (including forgetfulness and confusion in the patient), should be treated seriously.
- The GP should act promptly on their own suspicions, or reports from the patient or family members, to ensure there is not an unwarranted delay in obtaining a diagnosis.

Diagnostic Process

- A simple diagnostic evaluation process should include:
  - A focussed clinical history. *See History Checklist and Review*
  - Physical and mental status examination. *See Examination and Investigation Checklist and Review.*
  - Appropriate follow-up testing.
  - Referral of complex cases to specialty consultants.

  It is recommended that the patient and family member be interviewed separately to obtain a comprehensive clinical history.
- The diagnosis of dementia remains partly a process of exclusion of other conditions. There are a number of dementing illnesses and their differential diagnosis is sometimes complex.
- It is advisable to contact the Caulfield Cognitive Dementia and Memory Service (CDAMS) or enlist the support of a geriatrician, psycho-geriatrician or neurologist in complex cases.

Re-assessment

Where results are inconclusive, regular re-assessment should be undertaken, in conjunction with, and in addition to, the Annual Health Assessment process.

For specialist consultation in complex areas or additional advice and support regarding the diagnosis and management of dementia, contact:

Caulfield - CDAMS (Cognitive Dementia and Memory Service)
Mondays and Tuesdays only
Phone: 9276 6010 or
Email E.Rand@CGMC.org.au

Communication of Diagnosis and Other Information to Patient and Family

The rights and dignity of the person with dementia should be maintained at all times, respecting the patient's right to identify people to be informed and involved in the care relationship. Although the person with the diagnosis will continue to be the primary patient, the relationship between the doctor and the patient will necessarily change as the condition progresses. The caregiver, or other significant people in the patient's support network, should be seen as integral to the primary care relationship, and included in the treatment and management process. It is important to understand that many people will not see themselves as 'carers', especially in situations of younger onset and early stage dementia.

Telling the Patient and Family

- Make an appointment allowing adequate time for discussion. Provide the opportunity for patient and family members to see you separately for a feedback meeting, although couples may prefer to attend together.
- Give the patient the opportunity to indicate whether he/she wishes to know the diagnosis, for example, "There is a problem with your memory, which may get worse. Do you have any questions you would like to ask about this?"
- Allow patient/family to lead the unfolding specifics of the dialogue, keeping in mind the impact of the disclosure of a diagnosis or suspected dementia on the patient and family member.
- Allow terminology to progress from 'memory problems', 'difficulties with thinking', 'aged related degenerative conditions' to 'possible dementia' and 'Alzheimer's disease.'

Follow-up Meetings

- It is advisable to arrange a follow-up meeting, to allow the patient and family members time to absorb the initial information.
- Patients with early stage dementia should be given the opportunity for frank discussion about their condition.
- Take care not to be too dogmatic - and use terms such as "possible" and "probable", leaving room for hope, both diagnostically and with research and improving knowledge. *See Notes on Diagnostic Likelihood.*
- Remain sensitive to psychological and cultural family dynamics.

Providing Other Information

- Be ready to provide general and broad prognostic information. People often want to know about issues such as progression of disability, life expectancy and inheritance.
- The patient and family members are also likely to want information about the practicalities of coping as the condition progresses. Information should be provided on issues such as Enduring Power of Attorney, Enduring Guardian, Medical Power of Attorney, driving and continuing with work.
- Patients and families may also want to know about treatment options and to find out about services if or when they are needed.
- It is advisable to provide written information, for people who have been diagnosed with dementia and for members of their family.
- Alzheimer's Association Victoria has an extensive range of help sheets that address a number of issues that people with dementia and their families and carers may face, providing practical information and strategies, as well as other resources that may be useful. GPs may also find these a valuable source of information. *See Help Sheet Index included in the pack.*
- Alzheimer's Association Victoria also provides a range of information and support services, for people who are newly diagnosed and for members of their family:
  - Regular information sessions are conducted for families and friends who want to learn more about dementia and how to help that person, as well as services available in their community.
  - Support groups for people with early stage dementia provide opportunities for both people with dementia and family members to obtain information and talk through issues in a group program. These groups generally meet weekly for four to six weeks.

For specialist consultation in complex areas or additional advice and support regarding the diagnosis and management of dementia, contact:

Caulfield - CDAMS (Cognitive Dementia and Memory Service)
Mondays and Tuesdays only
Phone: 9276 6010 or
Email E.Rand@CGMC.org.au

Refer patients, their families and carers to Alzheimer's Association Victoria for additional support and information:

Dementia Helpline

Freecall 1800 639 331

Referral

This section has been divided into parts. The first consists of a table which addresses the different types of behaviours and the appropriate referral. The second part consists of an index of some of the local support agencies. This list was devised to serve as a guide and a list of psychogeriatricians, geriatricians and neurologists may be found in the Medical Directory of Australia. Southcity GP services has a CD copy of the Medical Directory of Australia which is available for use on the premises.

Support Services Key

AAV	Alzheimer's Association of Victoria	1800 639 331
MAPS	Mobile Aged Psychiatry Service	9276 6012
PGAT	Psycho Geriatric Assessment Team	9276 6012
ACAS	Caulfield Aged Care Assessment Service	9276 6314
CRCSR	Carer Respite Service Southern Region	9276 6400 or 1800 059 059
CAV	Carer's Association of Victoria	9650 9966
Continence Clinic		9276 6124
CDAMS	Caulfield Cognitive Dementia and Memory Service	9276 6010
VicRoads		1300 360 745
OPA	Office of the Public Advocate	9603 9500
VCAT	Victorian Civil and Administrative Tribunal	9628 9911

Presenting Issue Referral Chart

Presenting Issue	Support Service	Advice/support to		
		GP	*Client*	*Carer*
Challenging behaviours such as: Wandering Agitation Aggression Hallucinations/Delusions Sexual Inappropriateness Resistance to Care	AAV(carer support additional information) Psycho geriatrician MAPS/PGAT	✓ ✓ ✓	A A A	✓ ✓ ✓
Carer stress/illness/failure to care for patient appropriately (including prevention of)	AAV ACAS CRCSR CAV Local Government		 A 	✓ ✓ ✓ ✓ ✓
Unclear diagnosis Suspected dementia Differential Diagnosis Depression Delirium Psychosis Poly-pharmacy Anxiety	**Respective referral service** CDAMS, geriatrician, psychogeriatrician Geriatrician, neurologist, CDAMS Psychogeriatrician, PGAT, CDAMS Geriatrician PGAT, psychogeriatrician Geriatrician Psychogeriatrician, CDAMS	 ✓ ✓ ✓ ✓ ✓ ✓ ✓	 E E A A A A E	 ✓ ✓ ✓ ✓ ✓ ✓
Accommodation issues Respite/permanent Nursing Home or hostel	 ACAS AAV	 ✓ 	 A A	 ✓ ✓
Difficulty managing daily tasks eg Maximising living environment Activities of daily living Continence	 AAV Local Government (Meals on Wheels, Home Help, personal care) Community Health Service (occupational therapy, physiotherapy, A Community Health nurse) ACAS (for complex needs) Continence Clinic RDNS	 ✓ ✓ ✓ 	 E A A A A A	 ✓ ✓ ✓ ✓ ✓ ✓
Social isolation	Day centres SPAS	 ✓	A A	✓ ✓
Driving competency	Vic Roads (refer attached form) CDAMS	✓ ✓	A A	✓ ✓
Financial and lifestyle issues Forward planning Competency unclear Power of Attorney Legal issues Decision Making	 Psychogeriatricians Geriatricians OPA Victorian Civil & Administrative Tribunal (VCAT) ACAS (if house bound) AAV	 ✓ ✓ ✓ ✓ ✓ 	 A A A A A E	 ✓ ✓ ✓ ✓ ✓

E - early, A- all stages of dementia

Index of Support Agencies

Caulfield Aged Care Assessment Service - ACAS

Caulfield General Medical Centre
Monday to Friday 8.30am-5pm
Phone: 9276 6314

The Aged Care Assessment service provides a comprehensive assessment of the needs of elderly persons and some younger disabled persons with significant disability. In conjunction with the assessment, advice and information, referral is provided on a range of community services, rehabilitation and eligibility regarding residential care and Community Aged Care Packages. Limited aged care specialist medical opinions are also available, including assessments of a person's capacity to make lifestyle and or financial decisions.

Albert Road Clinic

31 Albert Road, Melbourne
Phone: 92568377

The Albert Road Clinic is a fifteen bed Psychogeriatric Unit. Psychogeriatricians attached to this unit are Dr Peter McArdle, Dr Harry Hecht and Dr Glenn Sutcliffe.

Alzheimer's Association Victoria - AAV

98 Riversdale Road, Hawthorn, 3122
Phone: 9818 3022, Freecall 1800 639 331

Alzheimer's Association Victoria offers a comprehensive range of support services for people with all forms of dementia, their families and carers, providing sensitive and flexible support throughout the course of the illness. The Association is a statewide service with staff providing support at the local level.

The Dementia Helpline 1800 639 331 (freecall), is a telephone information and support service that is free of charge. It is staffed by trained and experienced volunteer advisers who can provide understanding and support, practical information, up-to-date written material about dementia and information about other services. Other services available include:

- Counselling and individual support.
- Information and education courses.
- Support for people with early stage dementia.
- Support groups.
- Help sheets and other resources.

Caulfield Continence Service

Caulfield General Medical Centre
Phone: 9276 6124

The Caulfield Continence Service provides a multidisciplinary approach to the assessment, investigation, management, education and research of urinary and faecal incontinence in adults. The service aims to improve quality of life and promote independence of the individual while meeting the needs of carers and health professionals.

Cognitive Dementia & Memory Service (CDAMS)

Caulfield General Medical Centre
Mondays and Tuesdays only – please leave a message on other days.
Phone: 9276 6010

CDAMS provides a comprehensive multi-disciplinary assessment of people with cognitive problems and advice on their management / care throughout the pathway of dementia. The team consists of a psychiatrist, neurologist, geriatrician, neuropsychologist, occupational therapist and social worker. The service is not age restricted and can see people in the cities of Port Phillip, Stonnington and the old city of Caulfield (it does not cover the whole of Glen Eira).

Community Health Services - CHS

Caulfield Community Health Service
Phone: 9523 6666

East Bentleigh Community Health Service
Phone: 9579 2333

Home Based Allied Health Service (Parkdale)
Phone: 8587 0198

Inner South Community Health Service

- Prahran
  Phone: 9525 1300
- St Kilda
  Phone: 9534 0981
- Southport (South Melbourne)
  Phone: 9690 9144

Community Health Services offer a range of occupational therapy and physiotherapy assessments for provision of aids and advice to maximise independence. Community Health Nurses and Social Workers are available for a variety of monitoring and care co-ordination. Podiatry and dietician services are also available. Some services may include speech therapy, counselling and psychology services.

City of Glen Eira

Caulfield Adult Day Activity & Support Service
Glenhuntly Road, Caulfield
Phone: 9524 3220

Centre based social and recreational activities providing respite for carers. Meals are included and transport can be arranged.

Carer Respite Service Southern Region (CRCSR)

Caulfield General Medical Centre
Phone: 9276 6400 Monday to Friday 8.30-5pm or
1800 059 059 - 24 hours a day, 7days a week

The Carer Respite Service provides support to carers who are defined as 'someone providing unpaid care for a relative or friend with care or support needs'. Support provided is through advice and information, assistance and advocacy to link in with other services, planning advice, counselling in relation to the caring role and some assistance with the cost of emergency short-term care (dependent on individual circumstances).

- Carer Support Worker Program.
- CareLine- 24 hours.
- Residential Respite Program.
- Carer Mental Health Program.
- Service System Development.
- Promotion and Education.
- Dementia Support.

Day Centres

City of Stonnington
Stonnington Community Care – Adult Day Activity & Support Service (ADASS)
Phone: 9522 3224

A centre based program aimed at adults with intellectual or psychiatric disability and residents who find themselves socially isolated from their community. The service offers a wide range of activities and recreational artistic and therapeutic opportunities to assist in the development and maintenance of independent living and social skills.

Chris Gahan Senior Citizens Centre – Stonnington Community Care
Phone: 9522 3224

A supported program of activities designed to maintain and enhance the physical well being of older people are offered at the centre. A hot midday meal is available and transport can be arranged to and from the program.

John Macrae Centre - Toorak Uniting Church
603 Toorak Road, Toorak
Phone: 9826 6130

A day centre program for frail older people and for those with dementia. Assessment is necessary. A meal and transport are provided.

MECWA Day Centre
56 Burke Road, East Malvern
Phone: 9571 2828

Socialising small groups for frail and isolated older persons and a more structured program for people with memory loss, confusion and dementia and people with a disability.

Montefiore Day Centre Programs – Alan Rabinov Centre
14 Eastbourne Street, Prahran
Phone: 9529 6666

Includes a socialisation program for frail aged and dementia specific programs. Covers cities of Port Phillip, Glen Eira and Stonnington.

City of Port Phillip

Napier Street Adult Day Activity Support Service.
179 Napier Street, South Melbourne
Phone: 9696 9229

Support and social interaction activities are offered to assist frail older individuals to live in the community. Meals are included and transport can be arranged.

Burra Club – PO Box 439, Port Melbourne
Phone: 9646 1570

Provides respite for carers of people with dementia and support for carers through an Alzheimer's Association Support Group.

Eroke Club – Betty Day Centre
67 Argyle St, St Kilda
Phone: 9209 6717

A program especially for older, frail residents of the City of Port Phillip. Some days specifically designed for people with memory loss. A team of experienced staff provides participants with the opportunity to take part in a diverse range of activities and outings.

Geriatricians, Psychogeriatricians and Neurologists

A complete list of local physicians may be found in the Medical Directory of Australia. GPs are welcome to use the copy of the program available at Southcity GP Services, phone 9276 3256.

Local Government Agencies - LGAs

City of Glen Eira
Phone: 9524 3247

City of Port Phillip - St Kilda
Phone: 9209 6792

South Melbourne
Phone: 9209 6346

Port Melbourne
Phone: 9209 6580

City of Stonnington
Phone: 9823 1333

Local Governments provide a range of in-home support, including personal care, home help, Meals On Wheels, in-home respite and some basic home maintenance and shopping assistance. An assessment officer from the council will visit the person at home and advise each person on an individual basis regarding the service available and associated cost.

Mobile Aged Psychiatry Service (MAPS)

Caulfield General Medical Centre
Monday to Friday
Phone: 9276 6012

MAPS is available to see people aged over 65 with a mental illness (for example, depression, delusions) or behavioural problems associated with dementia (aggression, hallucinations, persistent wandering) who are living in their own homes in the areas of Port Phillip, Stonnington and the Caulfield Malvern portion of Glen Eira (this includes those living in hostels, nursing homes).

Physicians in Aged Care Outpatients Clinic
Caulfield General Medical Centre
Phone: 9276 6800

Physicians in Aged Care Consultants have a broad range of skills in geriatric medicine. They provide a comprehensive medical assessment of older patients at the following clinics:

- General Aged Care and Dementia.
- Bone Health and Falls Prevention.
- Continence.

Royal District Nursing Service (RDNS)

Caulfield
Phone: 9509 0666
Moorabbin
Phone: 9555 6755

The Royal District Nursing Service provides a range of nursing services including wound care management, medication administration, palliative care, hygiene assistance, (where health needs warrant a nurse) and continence assessment and advice. Other complex nursing procedures may also be provided, often in conjunction with a hospital within the area.

Southern Psychogeriatric Activity Service (SPAS)

Central Bayside Community Health Services
Phone: 85870200

SPAS is a service, which aims to assist older people with psychiatric problems or dementia to participate in local social and recreational activities. The service is available for residents of Port Phillip, Stonnington, Glen Eira, Bayside and Kingston (including those living in SRSs, boarding/rooming houses and private hotels).

The team is staffed by occupational therapists and community psychiatric nurses who work one-to-one with a client on a gradual process of integration into a socialisation. This continues with support and follow up until the person feels comfortable and is able to participate independently.

The service is also available as a point of contact for advice as to suitable activity or socialisation groups in your clients' area. It is recommended that they be your first point of contact when seeking a group for your client.

Ongoing Evaluation and Management

Working With the Patient and Family Caregiver

- It is essential that the GP develops a collaborative relationship with both the patient and the family caregiver, to ensure effective monitoring of the wellbeing of both. Families and carers bring valuable information about the person with dementia, their history and their cognitive and behavioural changes.
- Ongoing monitoring and management should encompass both the person with dementia, and the family caregiver, throughout the course of the condition. This should include six-monthly and more comprehensive yearly evaluations and reassessments. *See Patient Examination and Investigation Checklist & Review. See Caregiver Evaluation.*
- View the patient's and family's situation wholistically. If they are seeing you for other conditions or problems, ask how things are going in relation to the dementia and link to other supports if necessary.
- Be sensitive to the needs of both the patient and carer, ensure that adequate time is allocated for consultations with both. The carer may be able to talk more openly if they see the physician without the person with dementia. In the early stages in particular, the patient may feel more comfortable talking to the physician alone about any issues and concerns.

Depression

- Depression is a significant issue for people with dementia and their carers and should be considered in all evaluation and management processes.

Progression of the Illness

- As the dementia progresses, impairments become increasingly severe, affecting the patient's independence and the demands and responsibilities on the carer:
  - Instrumental activities in daily living (IADL) e.g. handling finances, taking medication.
  - Behaviour e.g. waking at night, wandering, repetitive questions and behaviours, aggression, and poor communication.
  - Personal activities of daily living (ADL) e.g. self-care, dressing, bathing.

  See Global Deterioration Scale
- It may be useful to identify issues as short, medium or long term, and as early stage (e.g. early intervention) or late stage (e.g. need for palliation).
- Co-morbidity with other illnesses, and risk of delirium (e.g. UTI's), creates complex care issues for the caregivers and may require urgent response from the GP (e.g. brief hospitalisation).

Family and Carer Support

- The caregiver's need for information and support will increase as the dementia progresses, and the person with dementia becomes more dependant. The later stages of the illness may be the most difficult for the caregiver as the need for placement in residential care and palliation is approached.
- Provide or assist the patient and carer to access information, emotional and practical support, including respite. Referrals to, and information about, appropriate services throughout the course of the illness will assist the caregiver to cope with changes in the person with dementia and prevent crisis situations developing.

  See Referrals Index. See Referral Chart

Transition to Residential Care

- While some people remain living in the community throughout the progression of the dementia, most will require long-term residential care. The decision and process of moving to residential care can be very difficult for families and carers, requiring additional understanding and support.
- The GP can be very influential at this time, with families relying on the doctor's advice and assessment. GPs should be aware of the important role they play.
- The GP's role in the care of the dementia patient should not cease with the placement of the patient in residential care. The caregiver often continues to need support during and after the transition to care. If possible, on going involvement by the GP in the care of the patient in this later stage of the condition and sensitivity to management issues in residential care, can contribute significantly to the wellbeing of the patient and their family.

  See Management of Patients with Dementia in the Hostel and Nursing Home Setting.
- In instances where the patient moves away from the area, the GP may need to be sensitive to the difficulties involved in transferring care to other medical practitioners.

Refer patients, their families and carers to Alzheimer's Association Victoria for additional support and information:

Dementia Helpline
Freecall 1800 639 331

Further information about dementia, and the AAV's services is available from the Association's website:
www.alzvic.asn.au

Solutions to Patient and Care Giver Issues

In many cases there are no easily identifiable or implemented solutions to the issues that arise for people with dementia, their families and carers. However, the GP has a significant role to play in working with the patient and families to address difficulties and care issues.

Behavioural Problems

- GPs need to have knowledge of both pharmacological and behavioural interventions for dementia patients

  See Recent Trends in the Pharmacological Management of Behavioural and Psychological Symptoms of Dementia (BPSD).

- Caregivers often find behavioural problems associated with dementia such as:
  - Wandering.
  - Agitation.
  - Becoming angry.
  - Sleeplessness.
  - Appearing sad.

  more stressful than impairments in self-care skills (e.g. dressing).

Problem Solving Approach and Collaboration

- A close collaborative relationship with the caregiver is important in addressing behavioural problems effectively. The caregiver can provide valuable information about the problematic behaviour, triggers and consequences, and their co-operation is essential in implementing any strategies or treatment.
- When dealing with behavioural issues a problem solving approach with families and carers is most effective. In many situations it may be more effective to make modifications in the environment rather than focussing on the person.
- It may also be necessary to inform and educate the carer about the progression of the condition and assist them to identify appropriate coping strategies, to deal with changed behaviours. Referral to services which can assist in this manner may be useful.

Referrals to Prevent Crisis Situations

- It is advisable to ensure that caregivers are aware of services that can provide assistance when necessary. Respite and other forms of support are essential in preventing carer stress and the development of crisis situations.

  See Referral Index

- In many cases, early signs of carer stress and decompensation are detectable and referral to appropriate services should be made to assist families and carers to deal with specific problems and issues.

  See Referral Chart

Support for the Caregiver and the Person with Dementia

- Alzheimer's Association Victoria (AAV) provides a range of support services for families and caregivers, including:
  - Counselling and Individual Support.
  - Telephone Outreach Program.
  - Library and Information Services.
  - Practical Education Programs and Workshops for Families and Carers.
- AAV has an extensive range of help sheets that provide practical information and strategies on specific issues that caregivers may face, including:
  - Caring for Someone with Dementia.
  - Young People and Dementia.
  - Changed Behaviours.
  - Taking Care of the Carer.
  - About Dementia.
  - Information for People with Dementia.
  - Early Onset Dementia.

  GPs may also find these a valuable source of information.

  See AAV Help Sheet Index provided in package.
- The **Dementia Helpline** is a telephone information and support service that is free of charge. It is staffed by trained and experienced volunteer advisers. Many of the advisers have personal experience in dementia care.
- Many people find great comfort and practical assistance in attending meetings with others who know what it is like to care for and live with a person with dementia. Alzheimer's Association Victoria coordinates a large number of local carer support groups across Victoria.

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Sensitivity to Caregiver Issues

Caregiver Stress

The evaluation of caregiver stress and depression and their ability to cope with increasing demands, requires great sensitivity. The health and ability of the carer to maintain the caring role will significantly determine the quality of care of the patient.

Support for the Caregiver

- Sensitivity and collaborative support from the GP will considerably alleviate patient and caregiver distress and concerns and may improve the quality of life for those involved in the care-giving situation.
- Carers greatly appreciate willing, focussed and flexible response to the emotional and practical needs of other family.
- Acknowledgment of the value of the caregiver role and validation of the caregiver's feelings is important in alleviating the isolation and the frustrations they commonly experience.

Family and Cultural Issues

- Cultural issues should be considered when dealing with patients and family members. Cultural issues will influence the approach at each stage of a dementing illness, since there is a wide variety in the meaning and response to dementia according to culture and this also impinges on the caregiver role.
- Individual values and beliefs should also be taken into consideration and respected when identifying care options and interventions.
- Socioeconomic and educational background within a culture may also affect the way in which the patient and the family is best managed. However, care should be taken not to culturally stereotype individuals and families, nor assumptions made about people's values and preferences.

Later Stages of Dementia

- Caregivers may find the later stages of the illness particularly difficult, including the need to consider transfer to residential care. GPs should be alert to signs of grief and depression in the caregiver.
- The GP may have a significant role to play in alleviating caregiver guilt and justification of the decision to place the person with dementia in long term care.
- GPs should be particularly sensitive to caregiver values and cultural issues in relation to management in the residential care setting and palliation.

  See Management of Patients with Dementia in the Hostel and Nursing Home Setting.

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Appendices

Appendix 1

Global Deterioration Scale (GDS)

1. No subjective complaints of memory deficit. No memory deficit evident on clinical interview.
2. Subjective complaints of memory deficit, most frequently in following areas:
   (a) forgetting where one has placed familiar objects.
   (b) forgetting names one formerly knew well.
3. Earliest clear cut deficits.
   Manifestations in more than one of the following areas:
   (a) patient may have gotten lost when travelling to an unfamiliar location.
   (b) co–workers become aware of patient's relatively poor performance.
   (c) word and/or name–finding deficit become evident to intimates.
   (d) patient may read a passage or book and retain relatively little material.
   (e) patient may demonstrate decreased facility remembering names upon introduction to new people.
   (f) patient may have lost or misplaced an object of value.
   (g) concentration deficit may be evident on clinical testing.
4. Clear cut deficit on careful clinical interview. Deficit manifest in following areas:
   (a) decreased knowledge of current and recent events.
   (b) may exhibit some deficit in memory of one's personal history.
   (c) concentration deficit elicited on serial subtraction.
   (d) decreased ability to travel, handle finances etc.
   Frequently no deficit in following areas:
   (a) orientation to time and place.
   (b) recognition of familiar persons and faces.
   (c) ability to travel to familiar locations.
5. Patient can no longer survive without some assistance.
   Patient is unable during interview to recall a major relevant aspect of their current life, e.g.:
   (a) their address or telephone number of many years.
   (b) the names of close members of their family (such as grandchildren).
   (c) the name of the high school or college from which they graduated.
6. May occasionally forget the name of the spouse upon whom they are entirely dependent for survival. Will be largely unaware of all recent events and experiences in their lives.
   Retain some knowledge of their surroundings, the year the season, etc. May have difficulty counting by 1s from 10, both backward and sometimes forward.
   Will require some assistance with activities of daily living:
   (a) may become incontinent.
   (b) will require travel assistance, but occasionally will be able to travel to familiar locations.
   Diurnal rhythm frequently disturbed. Almost always recall their own name.
   Frequently continue to be able to distinguish familiar from unfamiliar persons in their environment.
   Personality and emotional changes occur. These are quite variable and include:
   (a) Delusional behavior, e.g. patients may accuse their spouse of being an imposter; may talk to imaginary figures in the environment or to their own reflection in the mirror.
   (b Obsessive symptoms, e.g. person may continually repeat simple cleaning activities.
   (c) Anxiety symptoms, agitation and even previously non–existent violent behavior may occur.
   (d) Cognitive abulia, e.g. loss of willpower because an individual cannot carry a thought long enough to determine a purposeful course of action.
7. All verbal abilities are lost over the course of this stage. Early in this stage words and phrases are spoken but speech is very circumscribed.
   Later there is no speech at all – only grunting.
   Incontinent - requires assistance toileting and feeding.
   Basic psychomotor skills (e.g. ability to walk) are lost with the progression of this stage.
   The brain appears to no longer be able to tell the body what to do.
   Generalized and cortical neurologic signs and symptoms are frequently present.

Source: American Journal of Psychiatry, Vol. 139, pp.1136-1139, 1982, the American Psychiatric Association. Reprinted by permission. The GDS is copyrighted.

Appendix 2

History Checklist and Review

Issue	- /+/++/+++	6/12 Reviews			
Cognitive Impairment + Decline					
● memory					
● problem solving					
● language					
● getting lost					
● using mechanical/electronic appliances					
● failure to recognise person/object					
● fluctuating confusion					
Behavioural/Psychological Symptoms					
● depression					
● appears sad most of time					
● nothing is pleasurable					
● expressed wish to be dead					
● withdrawal					
● aggression					
● agitation					
● false beliefs					
● hallucinations					
● sleep disturbance					
● loss of social graces					
● obsessive-compulsive					
Disability (in activities of daily living)					
Instrumental					
● financial/bill paying					
● driving					
● medication compliance					
● occupation/hobbies					
● domestic tasks					
● using telephone					
Personal					
● cleanliness					
● dressing					
● continence					
● mobility					
Risk (of coming to harm)					
● home - appliances					
● outside - falls - traffic - lost					
● nutrition					
● abuse-physical, financial, sexual					
● iatrogenic-medication					
Other					
● alcohol					
● family history					

Appendix 3

Examination and Investigation Checklist and Review

Issue	Finding	6/12 Reviews			
Examination					
Physical					
General					
● vascular signs					
● thyroid signs					
● other……..					
● other……..					
Neurological					
● hearing & vision					
● focal signs					
● parkinsonism					
● balance & gait					
● other ……					
● other ……..…….					
Mental State					
Cognitive					
● attention					
● speed					
● MMSE or AMTS					
● clock drawing					
● insight					
● other……..					
● other …….					
Psychological					
● mood					
○ feels sad					
○ nothing is pleasurable					
○ would rather be dead					
● hallucinations/delusions					
● social appropriateness					
withdrawal					
aggression					
agitation					
● other …….					
● other …….					
Investigation					
Screening blood tests:					
● FBE; TSH; B12& Folate; serology					
● other……..					
Imaging					
● CT brain					
● other……..					
Other					

Appendix 4

Caregiver Evaluation

Issue	Rating: - (No Problem)	+++ (Problem)
Health		
● Recurring illness		
● Declining Health		
● Injury – possible abuse by patient or self-abuse		
● Compliance with medication		
Behavioural/Psychological		
● Anxiety		
● Trouble sleeping		
● Depression		
● Suicidal ideation		
Emotional		
● Family support		
● External network of support		
● Accesses other services		
Personal		
● Maintaining personal hygiene/appearance		
● Upkeep of home/other daily activities		
● Poor/inadequate diet or irregular meals		
● Time to self		
● Maintaining interests/hobbies		
● Participation in social activities		
● Financial difficulties		
● Competency level for driving, decision making etc		
Care of Person With Dementia		
● Adequate care of person with dementia		
● Management of medication		
● Acceptance of caring role		
Other		
● Alcohol		
● Family history		

Appendix 5

Notes on Diagnostic Likelihood and Patient/Carer Centred Disclosure

Comprehensive assessment results in a spectrum of diagnostic likelihood

- Spectrum begins from “no objective evidence of impairment”, to “mild cognitive impairment”, to “possible dementia”, to “probable dementia”.
- The type of dementia is similarly often uncertain.
- There is often a need for review of progress and re-assessment after 9 to 12 months to improve diagnostic accuracy.
- There is about 12% annual conversion of those describes as “mild cognitive impairment” to “possible dementia”.

Patient and carer centred communication of diagnosis

- Make dedicated appointment with patient/caregiver/family with adequate time for discussion.
- Decide what information the patient can comprehend and process.
- In very early cases with insightful patient consider seeing patient alone, according to patient’s wishes.
- In more advanced cases decide whether to include or exclude patient from caregiver/family feedback meeting.
- If excluded, patient is entitled to some information - for example the fact that they “have memory problems which may get worse”.
- Allow patient/caregiver/family to lead the unfolding specifics of the dialogue.
- Remain sensitive to psychological and cultural family dynamics.
- Allow terminology to progress from memory problems, difficulties with thinking, age related degenerative condition, possible dementia, possible Alzheimer’s disease and other specific conditions to “probables”, if and when patient/caregiver/family are receptive.
- Take care not to be too dogmatic-keeping in mind the “spectrum of diagnostic likelihood” and always use terms like possible and probable, leaving room for hope both diagnostically and with research and improving knowledge.
- Be ready to provide general/broad prognostic information upon request - e.g. progression of disability; life expectancy; factors influencing inheritance.

Appendix 6

Management of Patients with Dementia in the Hostel and Nursing Home Setting

The residential care population

- The Commonwealth Government funds (with variable resident contribution) about 140,000 residential aged care beds in Australia - about 74,000 nursing home based (high care) and about 66,000 hostel-based (low care).
- In these settings the prevalence of dementia is 28% among the hostel residents and 60% among the nursing home residents. The prevalence of "cognitive impairment" is 54% and 90% respectively.
- People residing in hostels and nursing homes have the full spectrum from mild to moderate to severe dementia, but most of those in nursing homes will be in the latter category.

Some system related complexities in management of dementia in residential care

- The overall principles of diagnosis and management for people with dementia should not be different from that applicable to community-dwelling people, after taking into consideration co-morbidities and prognosis.
- In the residential care setting it is particularly the disabilities in performing instrumental and personal activities of daily living, as well has the behavioural and psychological symptoms of dementia (BPSD), which often have both originally precipitated the need for admission, and are paramount in the day to day task of caring for people with dementia, as faced by care staff.
- Staff charged with the "front line" responsibility of meeting society's (unspoken) expectation that the residential setting will provide all dementia care, once the illness becomes too severe to manage in the community, have lacked comprehensive training, nor has there been an adequate bio-psycho-social model for understanding and managing the extremely challenging manifestations of dementia seen in the residential setting.
- The medical inputs to dementia management in the Australian long term care setting have often been through the general practitioner being asked to prescribe tranquillisers for residents whose behaviours were considered unacceptable and unmanageable.
- A study of Sydney nursing homes in the mid 1990s revealed that Australia had possibly the world's highest reported rate of psychotropic drug use in residential care.
- There has been no organisational or remunerative structure for comprehensive medical care of nursing home residents, nor has there been a commitment to or structure for an overall multidisciplinary model of practice to guide evaluation and intervention.
- As the illness progresses there is a need to monitor and clarify the aims of treatment, but mechanisms for acquisition and recording of terminal care wishes and advance directives have not been well developed in most facilities, nor has there been a significant take up of statutory appointments of proxy guardian and medical decision making agents.
- EPC Case Conferencing in residential care is not yet well established. General practitioners will need to be cognisant of these complex system issues; well informed about diagnosis and management of dementia and adept at leading multidisciplinary team meetings if they are to have a meaningful positive impact.
- There should be a low threshold for enlisting support of a geratrician in more complex cases.

Appendix 6 - *Continued*

Improving the Management of Dementia in the Long Term Care Setting

The individual general practitioner is not in a position to address or overcome many of the complex hurdles described above. However, within the structural and systematic limitations described, the following practices and interventions are recommended:

- Establish appropriate professional relationships with the patient, patient's family, and nursing home staff.
- Regularly review and closely monitor all aspects of the physical and mental health of the patient, including the use of medication.
- Establish regular contact with the family for discussion and ascertainment of their expectations and wishes.
- Promote consideration and discussion of prognosis, the appointment of an Enduring Guardian and or Medical Power of Attorney, and advance directives, when appropriate.
- Request accurate and specific description, and ongoing monitoring and recording, of symptoms and behaviours which cause concern, preferably using established scales.
- The enclosed "Update On Pharmacological Treatment Of Dementia" remains relevant for long-term care patients. Recent nursing home trials suggest that the acetylcholinesterase inhibitor medications donepezil, rivastigmine and galatamine may be beneficial in improving activity of daily living function, and reducing behavioural disturbance, in institutionalised patients with moderate to moderately severe Alzheimer's disease. However, these are early data, and the cost of the medication will be an inhibiting factor since most patients will not qualify for PBS authority reimbursement.
- The enclosed "Recent Trends In The Pharmacological Management Of Behavioural And Psychological Symptoms Of Dementia (BPSD)" is particularly relevant to the long-term care population.
- Take time and acquire skill in discussing with nursing staff the psychological and social strategies for the management of behavioural disturbance, which could be applied instead of, or in combination with, pharmacological interventions. Nurses and allied health clinicians, over the last 20 years, have developed psychosocial approaches to care such as 'reality orientation'; 'validation therapy', and 'reminiscence therapy'. It is not yet clear, however, as to, how and for which residents these approaches are beneficial. Nevertheless, many nursing and allied health practitioners have developed significant experience and skill in enhancing interaction with people with dementia.
- As it becomes appropriate, and in the light of knowledge of the patient's and family's perspective, sensitively manage the transition to a palliative care approach to overall management, and recognise the need for grief counselling of the caregiver.

Appendix 7

Update on Pharmacological Treatment of Dementia

Acetylcholinesterase Inhibitor Medications

Donepezil (Aricept); rivastigmine (Exelon) and galatamine (Reminyl) are currently approved for the treatment of mild to moderate Alzheimer's disease in this country. Tacrine has a difficult side effect profile and has been replaced by the newer agents.

There is increasing evidence from a number of clinical trials that these medications result in modest improvements in cognition, functional capacity, and behaviour, compared to placebo.

There are preliminary data suggesting that earlier prescription and maintenance of these medications may have modest favourable longer term outcomes.

There is early evidence that acetylcholinesterase inhibitors may also be beneficial in dementia with Lewy Bodies and in mixed vascular–Alzheimer's dementia. There is a possible benefit in vascular dementia and in the dementia of Parkinson's disease.

Frontotemporal dementia and other focal degenerative disorders usually do not respond to acetylcholinesterase inhibitors.

The medications are included as Authority only items in the Pharmaceutical Benefit Scheme and are otherwise expensive, in the order of $100 to 200 per month or more, depending on the dose and degree of pharmacist discounting.

Evolving changes in PBS Authority criteria are outlined in the current Schedule of Pharmaceutical Benefits.

Other Medications

There is one randomised controlled trial showing a mild protective effect for vitamin E in Alzheimer's disease. This study used a high dosage of 1000 international units twice daily and it is unknown whether lesser doses have the same benefit. There are also some grounds for recommending multivitamin supplements, including folic acid.

There is a lack of sufficient data to achieve confidence or consensus about the role of other medications in treating dementia.

Many patients are given *Gingko biloba*, but studies of this agent have yielded inconsistent results. There are also concerns about the precise contents of the products marketed as *Gingko biloba*, leading to its non-recommendation by the American Psychiatric Association.

There are accumulating data supporting active cardiovascular risk factor control in vascular dementia and earlier data suggesting that this may also be important in Alzheimer's disease prevention and management.

Appendix 7 - *Continued*

Recent Trends in the Pharmacological Management of Behavioral and Psychological Symptoms of Dementia (BPSD)

Psychological and behavioural symptoms are now regarded as integral manifestations of the dementing illnesses, rather than co-morbidities. Psychological symptoms including depressive symptoms are very common in the presentation and early stages of common forms of dementia including Alzheimer's disease. Behavioral manifestations become extremely common in the intermediate stages of Alzheimer's disease, and also occur at various stages in other types of dementia.

The common types of behavioural symptoms are outlined in the core references within this package.

In general:

- pharmacological interventions should be regarded as a possible component of the management of some of these symptoms and features, in conjunction with selected non-pharmacological interventions, including psychological and social strategies instituted through the caregiver.
- accurate description and assessment of the target symptom is crucial. Scales which specify and quantify the symptom or behaviour, and measure changes with intervention and time, are increasingly being used, and underline the need for objective practice.

Recent trends in pharmacological management of BPSD include the following:

- the former practice of wide-spread prescription of low dose conventional ante-psychotic agents such as haloperidol was never satisfactorily evidence-based, and is now less favoured: especially with the common extrapyramidal side effects of haloperidol; and the sedative and anticholinergic side effects of these drugs.
- dementia with Lewy Bodies is recognised as a particular contraindication to the use of the major tranquilizer-neuroleptic group of agents (including the newer atypical antipsychotics): due to the extreme sensitivity and sometimes catastrophic neurological effects seen in these patients.
- a trial of one of the newer [non-tricyclic] antidepressants is often initiated if there is reasonable likelihood of the symptom or behaviour having an underlying depressive aetiology. The nature of the symptoms and their severity, including sleep disorder, anxiety, and obsessive-compulsive features, influences the choice of antidepressant.
- in Alzheimer's disease (and possibly dementia with Lewy Bodies) acetylcholinesterase inhibitors may have a beneficial effect on behavioural manifestations, perhaps especially in moderate to moderately severe stages of the illness, and may be better tolerated than alternative therapies.
- the atypical neuroleptic agents risperidone, olanzipine and quetiapine have been shown in some trials to be effective in management of some behavioural disturbances in dementia: with a reduction in psychotic features and aggression. Although often better tolerated than conventional anti-psychotics these medications are not free of significant side effects: with risperidone causing some measure of sedation and extrapyramidal effects; olanzipine having significant anticholinergic activity; and quetiapine causing drowsiness and postural hypotension.
- there are data suggesting that some anti-epileptic agents, especially carbamazepine, in low dosage, is effective in reducing behaviours characterised by motor overactivity and aggression.

Appendix 8

Further Reading and Resources

1. Ancill, RJ, Holliday SG, Thorpe l, Rabheru K (eds) Treating Dementia- Cognition and Beyond. 2000. Canadian Academic press, Vancouver British Columbia, Canada.
2. Brodaty, H. Managing Alzheimer's Disease in Primary Care. 1999. Science Press
3. Bochner F et al Psychotropic Therapeutic Guidelines, Version 4, 2000. Therapeutic Guidelines Limited. Victoria, Australia.
4. Finkel, SI. BPSD IPA Education pack. 1998. Gardiner-Caldwell Communications Ltd International Psychogeriatric Association

Recommended Websites

International Psychogeriatric Association	http://www.ipa-online.org
Alzheimer's Association of Victoria	http://www.alzvic.asn.au

Video Resources

Living with Alzheimer's Disease-Memory Matters (Pfizer/Alzheimer's Associations Australia)
More information about this and other resources available from the **AAV Helpline 1800 639 331**.

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