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Managing dementia-related cognitive decline in patients and their caregivers

Background

There are over 332 000 Australians living with dementia. On average, families notice symptoms 3 years before a firm diagnosis is made. These symptoms are chronic and typically progressive and terminal.

Objective

To address some key aspects of providing person-centred care for a patient diagnosed with dementia, including considerations for family and caregivers, from a general practitioner's (GP) perspective.

Discussion

GPs play a crucial part in managing the needs of people with dementia and caregivers by providing ongoing support and by facilitating access to evidence-based care. Scheduled, regular reviews of people with dementia and their caregivers should become standard practice, and psychosocial interventions that can assist both parties should be offered.

Keywords

dementia; family caregivers; patient participation



Symptoms of dementia are chronic and typically progressive and terminal. These symptoms vary with the type of dementia, making diagnosis of underlying pathology important. People living with dementia are not a homogenous group; they have unique experiences. *Table 1* summarises some key facts regarding dementia in Australia.

GP-led dementia-focused care

Despite increasing prevalence and, arguably, improving awareness of dementia, it remains a stigmatising condition. The needs of people with dementia often parallel those of others with chronic illness: they want respect and understanding, they seek solutions and they tend to oscillate between acceptance and compensatory tactics.² General practitioners (GPs) should schedule a regular review to monitor health and wellbeing, and consider additional referral.³ Best practice primary care includes positively reframing dementia with a focus on abilities retained, encouraging information use, supporting caregivers, symptom management and structured case management.⁴ Case management refers to a coordinated approach to accessing required services (the GP, practice nurse or other health professionals may fill this role). Unfortunately, although people with dementia might be aware of their impairments, they are often excluded from active consultation by health professionals and family members.⁵ Although it is likely that a person with dementia will experience diminishing cognitive capacity over time, it is no less important that their wishes be ascertained and that they be included in discussions and decisions. People with dementia must be the primary focus of their appointments; they should be consulted and included accordingly and be maximally involved in their own health decisions.

Young onset dementia

Literature and experience show that people with dementia and their caregivers are often frustrated by lengthy diagnostic pathways, misdiagnoses and a sense that their needs are not being met.² This



Table 1. Alzheimer's Australia's key facts and statistics 2014¹

- More than 332 000 Australians have dementia
- The number of Australians with dementia is expected to increase to 400 000 in less than 10 years and to about 900 000 by 2050
- Each week there are 1700 new cases of dementia in Australia; by 2050 this number is expected to increase to 7400
- About 24 700 people in Australia have younger onset dementia (a diagnosis of dementia at ≤ 65 years, including people as young as 30 years)
- Three in 10 people >85 years, and one in 10 people >65 years has dementia
- About 1.2 million Australians care for someone with dementia
- Dementia is the third leading cause of death in Australia and the third cause of disability burden overall
- On average, symptoms of dementia are noticed by family members 3 years before a firm diagnosis is made

seems especially so for those diagnosed with young onset dementia (also known as younger or early onset dementia), whose experience typically differs from that of older people by their extreme sense of loss, employment issues (eg. pressure to improve work performance), financial pressures (eg. mortgage), family issues (eg. children, partners and elderly parents may become caregivers) and often increased concerns about genetic risk (many familial dementias are young-onset).⁵⁻⁷ The need for individualised dementia care through case management has been realised in part with the recent appointment of Younger Onset Dementia key workers by Alzheimer's Australia and the Federal Government. Many patients diagnosed with young onset dementia turn to social media, with secondary gains being education of care providers (eg. Facebook's Young Onset Dementia Support Group). Timely, appropriate referral for specialist support is particularly important for these patients.

GP support for a patient with dementia

GPs are well placed to develop (or sustain) a therapeutic relationship with people with dementia and their caregivers through regular, respectful, check-ups, which establish trust.⁸ GPs can be role models of adaptive attitudes, and monitor the need for a healthcare plan for referral to multidisciplinary, specialist services.⁸ Educational material can help to bridge information gaps in a variety of areas.⁹ This may include financial advice,¹⁰ information for children¹¹ and specialised support for minority communities.¹² Multicomponent interventions, such as education, support groups and practical training, are helpful for people with dementia¹³ and their caregivers.¹⁴ Early interventions can reduce future depression, communication challenges and caregiver burden.¹⁵ *Table 2*¹⁶ lists further points to consider at check-ups for patients with dementia.

Psychological support

Psychosocial therapies such as cognitive behavioural therapy are effective for people with mild-to-moderate dementia¹⁷ and a referral to a psychologist should be considered. A person with moderate dementia may be forgetful and confused, become easily disoriented in unfamiliar surroundings, neglect hygiene or diet, become more repetitive and show agitation and frustration. Evidence supports the use of reality orientation, memory strategies and cognitive reframing.¹⁷ Reframing to focus on strengths can be useful in addressing unhelpful terminologies and catastrophic thoughts.¹⁸ As negative perceptions may be antagonists of life satisfaction and healthy relationships, psychosocial support may be helpful.

For people with dementia and their caregivers, group-based psychological therapies can enhance quality of life in a cost-effective manner. Perhaps the most important concept is the promotion of human potential, adaptation, wellbeing and pleasure.¹⁹ Peer support programs that seek to address dementia education and social needs can be beneficial²⁰ and may be available where group-based psychological therapies are not. Alzheimer's Australia conducts various programs accommodating the person with dementia, the caregiver or both (eg. Living With Memory Loss Program).

Behavioural and psychological symptoms of dementia

A person with dementia may at times show behavioural and/or psychological symptoms or changes associated with dementia. Rather than perceiving behaviour as negative and ignoring or punishing the person, behaviour reflects unmet needs and may be the only means of problem solving available for the person. Unmet needs may include issues associated with comorbid illness, pain or discomfort, low mood, reduced cognition, impaired self-efficacy, isolation and boredom.³ In understanding the person's needs, GPs must understand the person: the correlates and antecedents of behaviours; the type of dementia and associated cognitive and functional losses; the person's history, personality, abilities, interests, values, culture, sexuality, routines and traumas, and perspective. Underlying organic illness should always be ruled out and triggers considered (eg. physical, emotional, intellectual and/or spiritual causes for the person's presentation). The increased likelihood of depression and/or delirium should be considered and symptoms regularly reassessed. The benefits of counselling and occupation or respite services should also be considered. Contemplate cultural or gender/sexuality factors, which may warrant specialised support.³

Drugs and dementia

When considering pharmacological management of the cognitive and behavioural symptoms of dementia, it is important not to miss opportunities for stabilisation of symptoms, such as those produced by mood disorders. As with all medications, there is a pressing need to balance efficacy with potential side effects and this is especially true of the cognitive-enhancing medications (eg. cholinesterase



Table 2. Points to consider at check-up for people with dementia¹⁶

| | |
|-----------------------------------|--|
| Safety | <ul style="list-style-type: none"> • Consider safety and environment factors |
| Social/emotional | <ul style="list-style-type: none"> • Discuss diagnosis with person and caregiver • Monitor signs of depression/anxiety • Discuss behaviour changes • Encourage supportive routine and pastimes • Communicate quietly and clearly • Facilitate understanding between the person with dementia and their caregiver |
| Care plan | <ul style="list-style-type: none"> • Develop a care plan in conjunction with the person with dementia and their caregiver that maintains independence as much as possible • Establish a routine for regular check up and review of goals • Establish information-sharing agreements • Complete/review Advance Health Directive (AHD) • Appoint a case manager if possible (Home and Community Care (HACC) provide valuable input in many areas) |
| Medication | <ul style="list-style-type: none"> • Review medications, consider Webster pack or nursing service |
| Activities of daily living | <ul style="list-style-type: none"> • Monitor participation in activities of daily living (ADLs) and personal activities of daily living (PADLs) |
| Nutrition | <ul style="list-style-type: none"> • Ensure the person has access to food and fluids • Engage dietician and/or speech pathologist if required |
| Legal/financial | <ul style="list-style-type: none"> • Encourage completion of enduring power of attorney (EPOA) and AHD (solicitors or public trustees can assist if required) |
| Driving | <ul style="list-style-type: none"> • Consider referral for an occupational therapist driving assessment (in some cases driving schools can provide feedback) |
| Practical | <ul style="list-style-type: none"> • Domestic, personal care and respite accessible via HACC, Aged Care Assessment Team (ACAT) or Department of Veterans' Affairs (DVA) |
| Caregiver support | <ul style="list-style-type: none"> • Consider the history of the caregiver/care recipient relationship • Consider the caregiver's perception of the health and functional status of the person with dementia • Understand the caregiver's values and preferences • Assess strain/burden, depression, suicide risk (see Resources) • Assess psychosocial needs and available resources • Assess knowledge and provide information or refer on, eg. Alzheimer's Australia's National Dementia Helpline or Dementia Behaviour Management Advisory Service (DBMAS) • Encourage/facilitate family conference to discuss support • Access service coordination (home caregivers will require visiting services due to barriers eg. isolation, transport, immobility, culture/language) |
| Respite | <ul style="list-style-type: none"> • Encourage use of respite if appropriate • Monitor need for referral to ACAT for residential respite |
| Residential care | <ul style="list-style-type: none"> • Support the caregiver in making decisions regarding alternative care when appropriate |

inhibitors and memantine) and other psychotropic medications (eg. neuroleptics and antidepressants). current treatments may modify the clinical manifestations but not the disease itself.²¹ There is increasing evidence that neuroleptics such as risperidone and haloperidol have significant physical and cognitive side effects, including increased risk of mortality,²² and non-pharmacological treatments should remain first-line management of behavioural and psychological symptoms.

It is important for people with dementia and their caregivers to discuss the implications of commencing and ceasing therapies with their GP or specialist. Regular reviews of medication should remain a

keystone in primary care management and special regard should be given to medications that may be worsen or mimic cognitive symptoms, such as drugs with anticholinergic or sedating effects.

Caregiver support

Providing support to a person with dementia can be physically and emotionally demanding. Caregiver stress results when caregivers perceive that the demands of caring outweigh their ability to cope, leaving them at increased risk of depression, burden and ill-health.²³ Caregivers tend to be reluctant to seek help²⁴ and GPs should routinely



screen for mental health, including perceived burden, guilt, blame, self-efficacy, fears, strengths and resources.²⁵ It is acknowledged that caregiver support may be complicated by the person with dementia and their caregiver having different GPs. Importantly, reframing behaviours in the context of cognitive decline rather than personality (eg. 'He's not being stupid, the task is difficult for him now') can play an important part in improved coping strategies for caregivers, and GPs can demonstrate this practice.²⁶ GPs can also encourage self-care and discuss referral to counselling services, practical support (eg. home aids and service coordination via Home and Community Care or Aged Care Assessment Team) and/or respite. Utilisation of non-pharmacological, positive, practical, psychosocial support (eg. psychology, speech pathology, social work, occupational therapy, volunteering) has the potential to delay a person's requirement for nursing home accommodation.

Summary

A person diagnosed with dementia, or their caregiver, is first and foremost a person, a unique individual with a life story who is striving for respect and autonomy. Understanding the person behind the diagnosis, as well as their caregivers, is potentially complex but critical. GPs, practice nurses, service providers and specialist support colleagues are pivotal partners in care. They should focus on the patient's abilities, encourage active use of information, manage symptoms, and access case management where available. Systematic follow up of people with dementia and their caregivers should be integrated into primary care where possible, and non-pharmacological, positive psychosocial interventions are important elements for consideration.

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Resources

- Alzheimer's Australia:
website: www.fightdementia.org.au
helpline: 1800 100 500
- Dementia Behaviour Management Advisory Service [DBMAS]:
1800699 799 (24 hours)
DBMAS BPSD manual: www.dementiaresearch.org.au/images/dcrc/output-files/328-2012_dbmas_bpsd_guidelines_guide.pdf
- American Psychological Society
assessment tools:
www.apa.org/pi/about/publications/caregivers/practice-settings/assessment/tools/index.aspx

- Australian Psychological Society:
suicide risk assessment tools:
www.psychology.org.au/ATAPS/resources/
- Carers Australia:
www.carersaustralia.com.au/
- Cognition/Dementia Care System General Practitioner Education Package for people with dementia living in the community 2008 (QUT):
www.health.qld.gov.au/caru/networks/docs/dementia-package-gp.pdf Includes screening tools (eg. dementia, depression, delirium, burden)
- Commonwealth Respite and Carelink Centres:
www9.health.gov.au/ccsd/
Telephone: 1800 052 222
- Queensland Health Chronic Disease Guidelines 3rd Edition 2010
www.health.qld.gov.au/cdg/docs/cdg_demen_gdline.pdf
- Young Onset Dementia Support Group (Facebook):
www.facebook.com/YoungOnsetDementiaSupportGroup

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