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Supplementary Material

Best-practice recommendations to inform general practice nurses in the provision of dementia care: a Delphi study

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Supplementary File S1 Recommendations endorsed as extremely relevant in each Component of Care in The Guidelines (19) and the level of consensus (%) reached in which survey round.

Number of recommendations endorsed as extremely relevant in each component of care (% of total)	**Components of care** (number of recommendations within this component of care)	**Recommendations endorsed as highly relevant to role of the primary care nurse** (Recommendation no. in The Guidelines)	**Agreement as extremely relevant** (Round reached consensus)
3 (100%)	Principles of care (3)	Health and aged care professionals should provide person-centred care, by identifying and responding to the individual needs and preferences of the person with dementia, their carer(s) and family. The 10 Principles of Dignity in Care should be used as the standard by which care is delivered and evaluated (1)	94% (1)
		Improving quality of life, maintaining function and maximising comfort are appropriate for people living with dementia throughout the disease trajectory, with the emphasis on particular goals changing over time (2)	94% (1)
		Health and aged care professionals should use language that is consistent with the Dementia Language Guidelines and the "Talk to me" good communication guide for talking to people with dementia (3)	100% (1)
4 (100%)	Ethical and Legal Issues (4)	Valid informed consent should always be sought from the person with dementia for decisions regarding financial affairs, health care and living arrangements. If the person lacks the capacity to make a decision, the relevant state and territory laws in respect of substitute decision making for financial and personal and health matters must be followed (4)	82% (1)
		Health and aged care professionals should inform the person with dementia, their carer(s) and family about advocacy services and voluntary support, and should encourage their use. If required, such services should be available for both the person with dementia and their carer(s) and family independently of each other (5)	88% (1)
		Health and aged care professionals should discuss with the person with dementia, while he or she still has capacity, and his or her carer(s) and family the use of: • an Enduring Power of Attorney and enduring guardianship • Advance Care Plans. Advance Care Plans should be revisited with the person with	82% (1)

		dementia and his or her carer(s) and family on a regular basis and following any significant change in health condition or circumstance. Advance Care Plans should be completed or updated at the time of assessment undertaken by the Aged Care Assessment Team (6)	
		Information provided by the person with dementia should be treated in a confidential manner. Health and aged care professionals should discuss with the person any need for information to be shared. Only in exceptional circumstances (e.g., where the professionals have a duty of care) should confidential information be disclosed to others without the person's consent. However, as the condition progresses and the person with dementia becomes more dependent on family or other carers, decisions about sharing information (with other health professionals or substitute decision makers) should be made in the context of the person's capacity to make decisions. If information is to be shared, this should be done only if it is in the best interests of the person with dementia (7)	82% (1)
6 (100%)	Barriers to access and care (6)	People with dementia should not be excluded from any health care services because of their diagnosis, whatever their age (8)	94% (1)
		If language or culture is a barrier to accessing or understanding services, treatment and care, health and aged care professionals should provide the person with dementia and/or their carer(s) and family with: • information in the preferred language and in an accessible format • professional interpreters • interventions in the preferred language (9)	100% (1)
		Health professionals should consider the needs of the individual and provide information in a format that is accessible for people with all levels of health literacy and considering the specific needs of people with dysphasia or an intellectual disability (10)	100% (1)
		Hospitals should implement strategies to maximise independence and minimise the risk of harm for patients with dementia as identified by the Australian Commission on Safety and Quality in Health care (11)	75% (1)
		Organisations in primary, secondary and tertiary care settings should consider the needs of people with dementia when designing health and aged care services and	81% (1)

		facilities. In particular, services should be structured to complement existing services in the local area (12)	
		People with younger onset dementia have unique needs; organisations should tailor their services in order to ensure that they are age appropriate and address the needs of the person with younger onset dementia and their carer(s) and family (13)	88% (1)
4 (100%)	Information and support for the person with dementia (4)	Health and aged care professionals should be aware that people with dementia, their carer(s) and family members may need ongoing support to cope with the difficulties presented by the diagnosis (50)	100% (1)
		Following a diagnosis of dementia, health and aged care professionals should, unless the person with dementia clearly indicated the contrary, provide them and their carer(s) and family with written and verbal information in an accessible format about: • The signs and symptoms of dementia • The course and prognosis of the condition • Treatments • Sources of financial and legal advice, and advocacy • Medico-legal issues, including driving (51)	75% (1)
		People with a diagnosis of dementia, particularly those living alone, should be provided with information about how to join a social support group (52)	87% (1)
		Health and aged care professionals should ensure that the person with dementia and their carer(s) and family are provided with written and verbal information regarding appropriate services available in the community (including those affected by Alzheimer's Australia, Carers Australia, Aged Care Assessment Teams, and My Aged Care). Any advice and information given should be recorded (53)	88% (1)
7 (100%)	Support for carers (7)	Carers and families should be respected, listened to, and included in the planning, decision-making and care and management of people with dementia (99)	100% (1)
		Carers are at an increased risk of poor health and their needs should be assessed and reviewed regularly by their own health practitioner. Carer and family needs should be addressed regularly, including if the person with dementia has entered residential care, and after their death (100)	94% (1)
		The person with dementia, their carer(s) and family should be offered respite appropriate to their needs. This may include in-home respite, day respite, planned activity groups and residential respite (101)	88% (1)

		Carer(s) and family should have access to programs designed to provide support and optimise their ability to provide care for the person with dementia. Programs should be tailored to the needs of the individual and delivered in the home or at another accessible location. Programs should be delivered over multiple sessions and include: Education regarding dementia and its consequences Information regarding relevant services including respite Referral to support organisations such as Alzheimer's Australia or Carers Australia Development of individualised strategies and building carer skills to overcome specific problems experienced by the person with dementia as reported by the carer Training in providing care and communicating most effectively with the person with dementia Support and information regarding coping strategies to maintain their own well-being including stress management Training in the use of pleasant and meaningful activities as a strategy to engage the person with dementia (102)	81% (1)
		Consideration should be given to involving the person with dementia, as well as their carer(s) and family, in support programs (103)	81% (1)
		Health and aged care professionals should provide carers and families with information regarding how to join a mutual support group. Individual preferences for group composition may vary and groups of the preferred composition should be available (104)	75% (2)
		Carers and families of people with dementia should be supported to build resilience and maintain overall health and fitness. Where necessary, they should be offered psychological therapy, conducted by a specialist practitioner (105)	88% (2)
4 (80%)	Organisation of health services (5)	Health and aged care managers should coordinate and integrate, referral, transitions and communication across all agencies involved in the assessment, treatment, support, and care of people with dementia and their carer(s) and families, including jointly agreeing on written policies and procedures. People with dementia and their carers and families should be involved in planning local policies and procedures (54)	76% (1)

		Health system planners should ensure that people with dementia have access to a care coordinator who can work with them and their carers and families from the time of diagnosis. If more than one service is involved in the person's care, services should agree on one provider as the person's main contact, who is responsible for coordinating care across services at whatever intensity is required (55)	76% (1)
		Care coordinators should ensure that care plans are developed in partnership with the person and their carer(s) and family are based on a comprehensive assessment including the person with dementia's life history, social and family circumstance and goals and preferences, as well as the person's physical and mental health needs, routines and current level of functioning and abilities (56)	82% (2)
		Care coordinators should ensure that coordinated delivery of health and aged care services for people with dementia. This should involve: • A care plan developed in partnership with the person and their carer(s) and family that takes into account the changing needs of the person • Assignment of named health and/or aged care staff to operate the care plan • Formal reviews of the care plan at a frequency agreed between professionals involved and the person with dementia and/or their carer(s) and family (57)	81% (1)
4 (80%)	Training for staff and students (5)	Health and aged care organisations should ensure that all staff working with people with dementia receive dementia-care training (attitude, knowledge, and skill development) that is consistent with their roles and responsibilities. Training should reflect programs that have been shown to optimise care for people with dementia. Effective programs tend to be: delivered face-to-face by someone experienced in dementia care; scheduled over several training sessions; involve ongoing mentoring or support from someone experienced in dementia care; and, utilise active learning techniques such as problem solving, case based training and role plays (59)	76% (2)
		Training programs should be comprehensive and have a strong focus on communicating effectively with the person with dementia and his or her carer(s) and family and recognising, preventing, and managing behavioural and psychological symptoms of	76% (2)

		dementia. Staff should be trained in the principles of person- centred care and how these principles are applied in practice (60)	
		As people with dementia are vulnerable to abuse and neglect, all health and aged care staff supporting people with dementia should receive information and training about how to prevent and manage suspected abuse (61)	75% (1)
		All undergraduate curricula in the health sciences should contain significant stand-alone content about the assessment, treatment, support and care of people living with dementia. Content should include person-centred care and the health, social and legal implications of a dementia diagnosis for the person with dementia, their carer(s) and family (63)	81% (1)
2 (66%)	Early identification (3)	Concerns or symptoms should be explored when first raised, noted, or reported by the person, carer(s) or family and should not be dismissed as 'part of ageing' (23)	94% (1)
		Medical practitioners working with older people should be alert to cognitive decline, especially those aged 75 years and older (24)	94% (1)
3 (60%)	Considerations for Aboriginal and Torres Strait Islander people (5)	Health and aged care services working to improve the health and care of Indigenous Australians living with dementia should be culturally sensitive and informed and utilise translators and/or cultural interpreters where necessary, particularly during assessment, when communicating the diagnosis and gaining consent (15)	76% (1)
		Health and aged care professionals should consult with family and Indigenous community representatives when developing a culturally appropriate care plan. A case manager (who may be an Indigenous community-based staff member) can assist with accessing and coordinating services required and advocating for the person with dementia (17)	75% (1)
		As the transition to residential care is a particularly difficult step for the person living with dementia, their family and community, health and aged care professionals should display sensitivity and consider organising support from the community and Indigenous staff members at this time (18)	82% (1)
3 (60%)	Cognitive assessment (5)	Clinical cognitive assessment in those with suspected dementia should include examination using an instrument with established reliability and validity. Health and aged care professionals should take full	76% (1)

		account of other factors known to affect performance, including age, educational level, non-English speaking background, prior level of functioning, aphasia, hearing or visual impairments, psychiatric illness or physical/neurological problems when interpreting scores (38)	
		The Kimberley Indigenous Cognitive Assessment (KICA-Cog) of KICA-Screen tool is recommended for use with remote living Indigenous Australians for whom the use of alternative cognitive assessment tools is not considered appropriate (39)	88% (2)
		The Rowland Universal Dementia Assessment Scale (RUDAS) should be considered for assessing cognition in CALD populations (41)	82% (2)
2 (50%)	Communicating the diagnosis (5)	The medical practitioner should be honest and respectful and use a gradual and individualised approach when communicating the diagnosis to the person with dementia and their carer(s) family (46)	76% (2)
		Medical practitioners should be aware that people with a history of depression and/or self-harm may be at particular risk of depression, self-harm or suicide following the diagnosis of dementia, particularly in the first few months' post diagnosis. While such reactions are believed to be uncommon, counselling should be offered as an additional way to support the person during this time (49)	76% (2)
1 (50%)	Living well (2)	Health and aged care professionals should support the person with dementia to receive adequate nourishment and hydration through maintaining a healthy balanced diet. People with dementia should have their weight monitored and nutritional status assessed regularly. In cases of undernutrition, consultation with a dietician and/ or assessment by a speech pathologist may be indicated (64)	82% (2)
1 (30%)	Considerations for CALD populations (3)	Health and aged care services need to recognise and be responsive to the cultural and linguistic needs of CALD people living with dementia, their carer(s) and families. Services should utilise a range of communication tools, including working with bilingual bicultural staff or professional interpreters across the whole service pathway, particularly during assessment, when communicating the diagnosis and gaining consent (20)	82% (1)
1 (30%)	Promoting functional independence (3)	People with dementia should be strongly encouraged to exercise. Assessment and	94% (1)

		advice from a physiotherapist or exercise physiologist may be indicated (68)	
3 (15%)	BPSD (20)	Health and aged care staff and carers and family should identify, monitor, and address environmental, physical, and psychological factors that may increase the likelihood of the person with dementia experiencing distressing behavioural and psychological symptoms. These factors include: • Unmet needs (e.g., pain, hunger, need to eliminate, lack of privacy, lack of meaningful activities, communication) • Lowered stress threshold (e.g., conflicts or poor communication within the family or between staff, carer stress) (77)	81% (1)
		Health and aged care staff should attempt to minimise the impact of behavioural and psychological symptoms of dementia by providing person-centred care (care that is consistent with the 10 Principles of Dignity in Care) (82)	81% (2)
		To assist the carer(s) and family help the person with dementia who is experiencing behavioural and psychological symptoms of dementia, carer(s) and family should be offered interventions which involve: • Carer skills training in managing symptoms and communicating effectively with the person with dementia • Meaningful activity planning • Environmental redesign and modification to improve safety and enjoyment • Problem solving and management planning (85)	75% (2)
1 (10%)	Diagnosis of dementia (10)	At the time of the diagnosis of dementia, and at regular intervals subsequently, assessment should be made for medical comorbidities and key psychiatric features associated with dementia, including depression and psychosis, to ensure optimal management of coexisting conditions (29)	82% (2)