

FAQ

FREQUENTLY ASKED QUESTIONS

Managing Dementia Care

With an ageing population and expected increase in dementia diagnoses, registrars need to become equipped in managing patients with dementia in general practice and supporting their carers.

As a GP supervisor you have a responsibility to teach your registrar how to diagnose dementia with certainty, deliver a diagnosis, and then how to care for the patients at different stages of the disease. This resource addresses frequently asked questions about teaching the management of dementia.

How can I teach my registrar to diagnose a dementia with certainty and conveying the diagnosis?

Diagnosing a dementia with certainty is a challenge for experienced GPs, so imagine the difficulty it will pose a registrar. For more information on how to teach identifying dementia with greater certainty and delivering a diagnosis, see:

- Teaching the Diagnosis of Dementia – FAQs
<http://gpsupervisorsaustralia.org.au/frequently-asked-questions-more/>
- Teaching Dementia Care – A structured approach for your registrar
<http://gpsupervisorsaustralia.org.au/webinars/>
- GPSA teaching plans
<http://gpsupervisorsaustralia.org.au/teaching-plans/>
 - Diagnosing Dementia
 - Understanding Dementia
- Dementia Training Australia videos:
 - GP Consent for a Collaborative History
<https://vimeo.com/262114049>
 - GP Taking a Collaborative History
<https://vimeo.com/262115486>
 - GP Conveying Dementia Diagnosis
<https://vimeo.com/262115048>
 - 3-GP conveying progressive deterioration to a person with dementia and how it might be managed
<https://vimeo.com/298314458>

What are the main take home messages I need to give my registrar about dementia management?

Whether your registrar diagnoses a dementia, or takes on the care of a patient with an existing diagnosis, they should adhere to the following objectives:

- Develop a structure of managing dementia based on the stages and domains of the disease.
- Create a patient-centric management plan for people with dementia.
- Recognise the impact of dementia on the carer and where to access support.

What summary can I give my registrar about dementia?

Dementia is an umbrella term that describes a syndrome of symptoms that are caused by disorders affecting the brain. It is not one specific disease.

Dementia affects thinking, behaviour, ability to perform everyday tasks. Diminishing brain function also impacts on normal social and working life.

Your registrar should be aware of the different types of dementia. These are:

- **Alzheimer’s disease** - the most common type of dementia, 40 to 70 per cent of all dementias.
- **Vascular dementias** - second most common type of dementia, 15 to 25 per cent of all dementias.
- **Lewy body dementia** - 2 to 20 per cent of all dementias.
- **Fronto temporal dementias** - 2 to 4 per cent of all dementias.
- **Other dementias** - dementia associated with Parkinson’s disease, Huntington’s disease, head trauma, human immunodeficiency virus (HIV), alcohol-related dementia, Crutzfeldt-Jakob Disease, corticobasal degeneration and progressive supranuclear palsy.

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What types of dementias are most commonly managed in general practice, and therefore need to be best understood by registrars?

As GPs, we know our patients best. For this reason, supervisors need to teach registrars how to take ownership of the common forms of dementia; Alzheimer's and vascular (or a combination of both). Teach your registrar to reserve the less common dementias for geriatricians and the old-age psychiatrists to manage.

What stages of care do I need to teach my registrar?

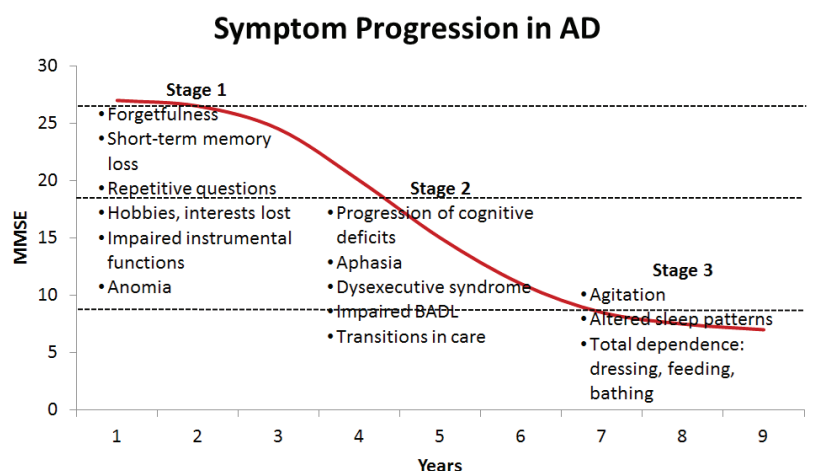
STAGES OF CARE FOR PEOPLE WITH DEMENTIA

Stage	Goal of care	Symptoms
First stage: Still at Home	Dignity through maintaining independence and enjoyment	<ul style="list-style-type: none"> • Short-term memory loss • Repetitive questions • Hobbies, interests lost • Impaired instrumental functions
Second stage: Now needing 24-hour care	Dignity through keeping safe and maximising any quality	<ul style="list-style-type: none"> • Progression of cognitive deficits • Declining function
Third stage: Diminished quality of life	Dignity through providing comfort	<ul style="list-style-type: none"> • Increasing loss of independence; dressing, feeding, bathing • May have behaviours of concern • Usually physical decline

How do I teach my registrar to identify what stage of dementia their patient falls into? In turn, how can the registrar educate the patient's carer about the stages and trajectory of dementia?

The following graph can be used as a teaching tool for your registrar, dementia patient and their carer. The graph provides a general application for the stages and trajectory of the most common dementia, Alzheimer's Disease. You could print, laminate and display the graph in every room of your training practice as a guide for registrars, patients and their carers.

Note: While the graph provides a clear delineation between stages one, two and three, explain to your registrar that the graph is a general guide, because the stages are very nuanced until becoming evident at a certain point in time. Teach your registrar that dementia patients can move in different areas across the stages. That is, a patient is not neatly in stage one today, and in stage two tomorrow; the progression of the illness is subtle and nuanced.



BADL= basic activities of daily living.
Modified from Feldman et al. *Clinical Diagnosis and Management of Alzheimer's Disease*. 1st ed. 1998

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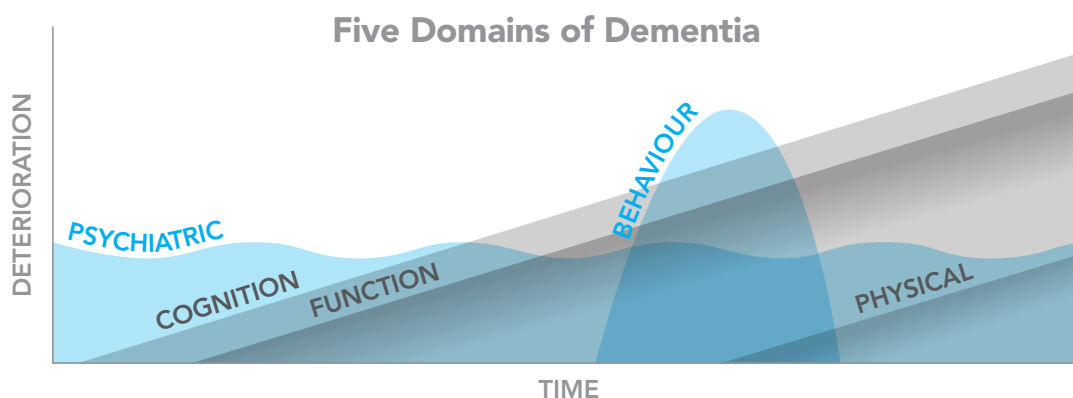
What should I teach my registrar about the domains of dementia?

There are five domains of dementia: psychiatric, cognition, function, behaviour and physical. When discussing the above graph (Dementia Stages and Trajectory) with your registrar, you could also discuss the graph below (Five Domains in Dementia).

You can see in the Five Domains in Dementia graph that the decline in **cognition** and **function** domains start early in the dementia and tend to parallel each other.

Note with your registrar how the **psychiatric** illnesses come and go out of that domain across the course of the dementia (for example, hallucinations and delusions at various stages).

Then note with your registrar that while the **behaviour** and **physical** domains develop at end-stage dementia, this is often when the patient and a distressed or concerned carer will present at the practice. For example, the patient may be wandering; aggressive; shouting out; or questioning repetitively.



What else can my registrar learn from the two graphs (Dementia Stages and Trajectory; and, Five Domains in Dementia)?

Spend time in a planned teaching session with your registrar using the graphs as a reminder about the importance of early diagnosis of dementia.

Explain that sometimes the registrar may not see a patient until end-stage dementia because this may be when a distressed family may first present. Discuss with your registrar that whether they see the patient in early or late stage dementia, they need to understand and guide the patient and their family/carer through the trajectory and domains of dementia for best management of the illness.

How can I prepare my registrar to give anticipatory guidance after conveying a dementia diagnosis to a patient (early stage) and their family/carer?

- You could role play with your registrar how and when to use the graphs (Dementia Stages and Trajectory; and, Five Domains in Dementia).
- Watch and discuss learning points in Dementia Training Australia video *GP Conveying Dementia Diagnosis* <https://vimeo.com/262115048>

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What consequences of not recognising and diagnosing dementia early do I need to teach my registrar?

An early diagnosis allows the patient to stay at the centre of decision-making while they still have the ability. In educating and listening to the patient, the registrar (and the patient's family/carer) are able to honour the patient's wishes to the best of their ability.

So, emphasise to your registrar the consequences of not recognising dementia early include:

- Failure to intervene symptomatically.
- Failure to give assistance for ADL dysfunction.
- Missed opportunities regarding acetyl-cholinesterase-inhibitor (ACHEI) treatment; power of attorney; will; and advance care planning.
- Dangerous decision-making.
- Struggling families, misunderstanding. (Early diagnosis allows time for GPs to educate families about behaviours which may happen and strategies to manage them).
- Delays in placement and long-term planning issues, and opportunity for patient to be at centre of decision-making (for example, power of attorney, guardianship, will, advanced care directive).

What examples can I give my registrar on things to consider when seeing a patient with a psychiatric illness which may be part of an early stage dementia?

Given the early trajectory of decline of cognition and function domains and the nature of psychiatric illness coming in and out of the psychiatric domain of dementia, teach your registrar to ask himself (and seek counsel with you) questions such as the following examples:

- *"Is this a concurrent or a depression that I am seeing, as part of the work up?"*
- *"Is it an anxiety that I'm seeing, or is the psychiatric illness a part of an actual dementing illness?"*
- *"If my patient has been travelling along with his declining cognition function and has now suddenly really declined, could he have developed a dementia within that?"*

What responsive behaviours should a registrar educate families to be prepared for, so as to develop strategies which will help management?

Responsive behaviours which may develop, or come and go, may include:

- Wandering
- Aggressiveness
- Shouting out
- Repetitive questioning

What physical decline can a registrar expect to see as responsive behaviours start to drop off the trajectory?

When discussing the trajectory with your registrar, you can teach them as the patient moves towards the end of the trajectory, physical impacts which may start to set in include:

- Decreased mobility – falls
- Decreased ability to swallow – prone to aspiration, pneumonia
- Incontinence

While the behaviours decline on the dementia trajectory, teach your registrar some responsive behaviours may still occur. For example, an end-stage dementia patient may show unusual behaviour if they are constipated or have an infection.



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What does a registrar need to learn to consider in a dementia patient's management plan?

Remind your registrar they need to base the management plan on the five domains and trajectory of dementia. For example, in an early stage diagnosis your registrar needs to understand the goal is to help the patient maintain independence and enjoyment, so it is important to manage everything which can contribute to declining cognition – and that also entails actively managing any other conditions the patient may also have. For example, cardiovascular risk factors, hypertension or diabetes.

Your registrar needs to learn the importance of encouraging patients in early stage dementia to maximise their social interactions. For example, your registrar could tell their patient:

"An early diagnosis of dementia gives you the time to enjoy your family as much as you can. You can do all the things you like doing on a social level to keep engaged and happy, but you may need to adapt your social interactions to stay well. For example, if you find going to a big party or restaurant too noisy or confusing. If you can't find the toilet or remember how to pay the bill, that could be stressful for you."

How can I teach my registrar to manage questions about dementia from their patient and carer?

Teaching dementia management to your registrar, includes teaching them how to educate their patient (early stage) and carer (every stage) about what to expect, and what may need to be put in place for quality care.

You could practise question and answer scenarios with your registrar – and explain to them that the education of their patient and carers will happen over a period of appointments as they are able to process the information and come back with more questions.



VIDEO RESOURCE: Patient Anna

During a planned teaching session with your registrar view and discuss the fourth video about Anna in the Dementia Training Australia videos,

GP conveying progressive deterioration to a person with dementia and how it might be managed

<https://vimeo.com/298314458>

In this video, Anna and her daughter return to their GP after an earlier diagnosis of dementia.

Anna says: *"I have been to the solicitors and have my papers in order; but what is going to happen to me?"*

The doctor answers: *"It's difficult to give a definite answer, but what I can do is tell you about what's likely, or might, happen. Everyone's experience with dementia is different ... but what I can tell you from my experience is that people with dementia like yourself will progressively deteriorate."*

Later in the conversation, Anna says: *"But I want to stay at home."*

The doctor responds: *"My goal is to honour your wishes as best as I can. There may come a time where for both of you (Anna and daughter), it wouldn't be safe for you to be in your home ... you will not be able to care for yourself adequately and the demands (to daughter) for you to care for your mum at home will be so great ..."*

View the full video with your registrar for an example how this conversation with the patient and and carer may progress.

Ask your registrar: *"What does the doctor do well? Are there any particular questions/statement that you like? Did you notice how the doctor keeps Anna at the centre of the consultation, while also answering the needs/queries of her daughter?"*

Discuss that each patient and carer will have a different capacity to understand, act on care issues, or be involved in the decision making.

Then explore scenarios, such as: *"How could you approach these conversations if the carer was not as attentive/observant/educated as Anna's daughter?"*

"How can you encourage /teach the patient/care to be observant of behavioural/physical changes and to prioritise regular visits to the doctor as part of their dementia management?"

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How can I teach my registrar What does my registrar need to be taught about a GP dementia management plan?

Teaching points for your registrar include:

A management plan helps guide a clear pathway for management of a patient with dementia.

A management plan must be based on the five domains of dementia; cognition, function, psychiatric, behaviour and a physical.

A management plan needs to take into the account goals for each stage of dementia. For example:

- **Stage 1** - Still at Home.
- **Goal of care** - Dignity through maintaining independence and enjoyment.
- **Domain** - Cognition.
- **Care** - Manage elements which may contribute to decline in cognition, such as cardiovascular risk factors, hypertension, diabetes, maximising/adapting social interactions; review medications which may be impacting the patient's cognition; Acetylcholinesterase inhibitors (AChEIs); and encourage mental stimulation.

GENERAL PRACTICE MANAGEMENT PLAN - ITEM 721

DEMENTIA - STAGE 1			
DOMAIN	PATIENT PROBLEM	TREATMENTS/SERVICES/ PATIENT & FAMILY ACTION	ARRANGEMENTS FOR TREATMENTS/ SERVICES (who, when) – as needed
Cognition	<ul style="list-style-type: none"> • Forgetfulness • Short-term memory loss • Repetitive questions 	<input type="checkbox"/> AChEI <input type="checkbox"/> CV risk factor assessment and management <input type="checkbox"/> Power of attorney <input type="checkbox"/> Advanced Care Directive <input type="checkbox"/> Family education	<ul style="list-style-type: none"> • Practice nurse • General practitioner • Geriatrician • Family meeting – six monthly
	Goal of care: Maintain independence and optimise function		
Function	<ul style="list-style-type: none"> • Impaired instrumental functions 	<input type="checkbox"/> Driving assessment <input type="checkbox"/> Home hazards assessment <input type="checkbox"/> Family education	<ul style="list-style-type: none"> • Practice nurse • General practitioner • ACAT assessment • Care package • Community physiotherapy/OT/ social work • Home help • Meals on Wheels
	Goal of care: Maintain independence and optimise function		

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Psychiatric	<ul style="list-style-type: none"> • Depression • Anxiety • Delusions • Hallucinations 	<input type="checkbox"/> Screening of mental health in patient <input type="checkbox"/> Screening of mental health in carers <input type="checkbox"/> Facilitation of transition in to care <input type="checkbox"/> Collaboration between care staff/family/GP	<ul style="list-style-type: none"> • Practice nurse • General practitioner • Psychologist
	Goal of care: Maintain independence and optimise function		
BEHAVIOUR	<ul style="list-style-type: none"> • Social withdrawal • Frustration • Sleep disturbance • Wandering • Hoarding 	<input type="checkbox"/> Carer education and increased support <input type="checkbox"/> Routine <input type="checkbox"/> Increased social engagement <input type="checkbox"/> Facilitation of transition in to care <input type="checkbox"/> Collaboration between care staff/family/GP	<ul style="list-style-type: none"> • Practice nurse • General practitioner • Family meeting – three monthly • Alzheimer's Australia
	Goal of care: Maintain independence and optimise function		
PHYSICAL	<ul style="list-style-type: none"> • Failure to maintain physical health care needs 	<input type="checkbox"/> Home Medication Review with emphasis on rational prescribing of medication <input type="checkbox"/> Nutritional assessment <input type="checkbox"/> Dental review <input type="checkbox"/> Continence assessment <input type="checkbox"/> Falls assessment <input type="checkbox"/> Immunisation - influenza, pneumococcus <input type="checkbox"/> Facilitation of transition in to care <input type="checkbox"/> Collaboration between care staff/family/GP	<ul style="list-style-type: none"> • Practice nurse • General practitioner • Pharmacist • Community dietician
	Goal of care: Maintain independence and optimise function		