GPSA
GENERAL PRACTICE SUPERVISION AUSTRALIA

FAQ
FREQUENTLY ASKED QUESTIONS

PODCAST WEBINAR

Teaching your registrar to manage stage three (advanced) dementia

Stage three dementia is vastly different to the earlier stages of dementia: however, registrars have limited exposure to this advanced stage of the illness, and therefore less chances to learn about management.

This resource shows GP supervisors how you can increase a registrar's learning opportunities about the advanced stage of dementia; teach how to apply goals of care and minimise the impact of responsive behaviours; and develop a structured approach to a patient's care by using a GP Management Plan.

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

As our future generation of family doctors who will be treating an ageing population, registrars need to learn about the trajectory and management of dementia.

The management of late-stage dementia is vastly different to the early stages, when the patient may still be living independently or with family. Discuss each of the stages with your registrar, including symptoms and goals of care.

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	• 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	• Progression of cognitive deficits • Declining function
Third stage: Diminished quality of life	Dignity through providing comfort	• Increasing loss of independence; dressing, feeding, bathing • May have behaviours of concern • Usually physical decline • Limited communication • Profound memory loss

For more information about the stages and trajectory of dementia, see Managing Dementia Care FAQs at https://gpsupervisorsaustralia.org.au/frequently-asked-questions-more/

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How can I give my registrar exposure to patients with late-stage dementia?

By stage three dementia, patients have usually transitioned into nursing home care because their needs have become so great. For this reason, registrars often have limited exposure to patients with late-stage dementia, and therefore less opportunity to learn how to treat patients and build a relationship with the patient's family and carers during the palliative care phase of the disease.

However, you can expose registrars to stage three dementia by bringing them with you on your nursing home visits. After observing you treat nursing home patients for a week or two, you can pass over their care – under your supervision – to the registrar.

Is it reasonable to ask a registrar to take over the care of a patient I have treated for a long time, including before they moved into residential aged care?

While you may have known the patient for a long time, you will find patients and families are often very receptive to having a younger doctor also become involved in the patient's care. If your registrar is nervous to take over the care of a patient you have looked after for many years, reassure the registrar there are clinical benefits to having a fresh pair of eyes looking at the patient's condition. Remind them that as supervisor, you are still very much involved in the patient's care through case discussion and mentoring the registrar throughout the treatment of the patient.

You can also help your registrar "get to know" the patient, by telling stories about their life before their dementia diagnosis. For example, *"I remember when I first met this person, and he/she was the chair of the bowling club and also doing a lot of other things."*

How can I teach my registrar to ensure patient-centred care is maintained during late-stage dementia, when that patient is no longer able to communicate their wishes?

While it is important for registrars to have exposure to patients with late-stage dementia, equally they need opportunities to treat patients with early stage dementia. In doing so, your registrar should be taught:

- Diagnosis of dementia.
- The trajectory of dementia.
- How to explain the trajectory of dementia to a patient and their family during the early stage of the illness.
- Management of dementia (all stages).
- The importance of an advance care plan, and the role a treating GP plays in ensuring a patient puts in place an advance care plan early in their illness.

For more information about the trajectory of dementia, see Managing Dementia Care FAQs at https://gpsupervisorsaustralia.org.au/download/4879/

What are the key points I need to discuss with my registrar about advance care planning?

Discuss with your registrar the following:

- Advance care planning is the cornerstone of care for patients with dementia.
- Advance care planning aligns treatment with goals of care.
- Advance care planning educates the patient and carers about the natural history of the illness.
- Advance care planning assists patients (and family/carers) to anticipate the patient's needs.
- Advance care planning provides better outcomes for people with dementia.

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How can I demonstrate to my registrar that late-stage dementia is more than just memory loss?

The domains of dementia model can be helpful when teaching registrars about advanced dementia.

In stage three dementia the patient is often transitioned into nursing home care because of their increasing loss of independence with dressing, feeding and bathing. Behaviours may occur if their needs are not being met. Late-stage dementia patients have limited communication, profound memory loss and are probably not recognising their loved ones anymore.

Emphasise to your registrar that **the goal of care during stage three dementia is dignity through providing comfort.**

Refer to the five domains (listed in the table below) of general practice as a teaching tool for registrars to show that dementia is more than memory loss.

DEMENTIA – STAGE 3 (ADVANCED)
Diminished quality of life

Domain	Patient problem	Goal of care
Cognition	• Limited cognition	Dignity through providing comfort
Function	• Full-time care	Dignity through providing comfort
Psychiatric	Psychiatric conditions may include: • Depression • Anxiety • Hallucinations • Delusions	Dignity through providing comfort
Behaviours	• Unmet needs/pain/distress may cause responsive behaviours	Dignity through providing comfort
Physical	• Very limited mobility • Eating/swallowing difficulties	Dignity through providing comfort (Reducing physical complications with comfort in mind)

For more information about dementia, see Dementia - Management FAQ at https://gpsupervisorsaustralia.org.au/download/4879/

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What responsive behaviours should my registrar be aware of when treating a patient with stage three dementia?

Explain to your registrar that throughout the course of the illness about 90 per cent of people with dementia will show symptoms of responsive behaviours, formerly called BPSD (behavioural and psychological symptoms of dementia). Responsive behaviours can occur at any time during the course of a dementia, but are more likely to be seen as the disease progresses. During the terminal phase of the illness, where significant physical decline often occurs, there may be a reduction in responsive behaviours.

Responsive behaviours can include:

- Aggression
- Screaming
- Restlessness
- Repetitive questioning
- Shadowing
- Wandering
- Hoarding
- Ruminating
- Sexual disinhibition
- Apathy
- Withdrawal

Your registrar also needs to be aware that depression, anxiety and psychotic symptoms such as hallucinations and delusions can also be evident.

How can I help my registrar better understand assessment and management of responsive behaviours in dementia?

Discuss the following assessment and management steps with your registrar:

1. Identify if there are reversible causes of the behaviours. For example, is there a delirium, infection, pain, constipation, hunger and thirst?
2. If potentially reversible causes are identified, they should be treated, and the behaviour reassessed.
3. If no reversible cause is found, further investigation of the reason for the behaviour is needed.
4. Ask staff in the residential care facility or a primary health care nurse (if the person lives at home), to conduct a comprehensive assessment of the behaviour. The assessment aims to look for possible causes and triggers in the person's personal story, medical condition, and past history. This information should be gathered in consultation with the patient's family. The CAUSEd model provides a structured approach to guide nurses and care workers to ask question which might identify the reason for the behaviour.
5. Once a trigger for the behaviour is identified, interventions can be put in place to minimise the risk of the behaviour reoccurring.

What is the CAUSEd model?

COMMUNICATION
ACTIVITY
UNWELL
STORY
ENVIRONMENT
dementia

The CAUSEd model is a structured approach to gathering information. CAUSEd guides nurses and care workers to ask questions which might identify the reason for the behaviour or what the person may be responding to.

Once a reason or trigger for the behaviour is identified, interventions can be put in place to minimise the risk of the behaviour reoccurring.

A detailed behaviour description chart is useful to identify patterns and triggers. For example, does the behaviour occur at a particular time of day or with certain people. The description chart also assists in determining how effective the chosen intervention has been.

The CAUSEd model includes recording the date and time and accurate description of the behaviour, a detailed description of any attempted intervention used and its outcome.

This assessment should be regularly reviewed, looking at patterns and causes.

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CAUSEd BEHAVIOUR CHART

Date	Time	Description of behaviour	Intervention	Outcome of intervention

What do I need to teach my registrar about pharmacological intervention for responsive behaviours?

Pharmacological intervention for responsive behaviours should only be considered under the following circumstances:

- If pain is the likely cause.
- If the person, family or carer are severely distressed.
- If there is imminent risk of harm to the person with dementia or others.

PAIN

If the assessment indicates pain may be the cause of the responsive behaviours, appropriate pain relief measures should be introduced. Pharmacological management should complement, not replace, non-pharmacological approaches.

AGITATION

If treatment of agitation is necessary, selective serotonin reuptake inhibitors could be offered on a trial basis. Currently the best evidence for people with dementia displaying agitation is for **Citalopram**.

The effectiveness of the trial should be reviewed within two months, and if there has not been significant improvement, consider de-prescribing in a gradual manner.

The risks of withdrawal and other side effects should be made clear to the patient, family or carer from the outset.

DISTRESSING BEHAVIOURAL OR PSYCHOLOGICAL SYMPTOMS

If people with dementia show distressing behavioural, or psychological symptoms, it may be necessary to use anti-psychotic medication.

The risks and benefits of anti-psychotic treatment need to be explained in detail to the person with dementia, their carers and family. Using anti-psychotics is considered a chemical restraint.

Benefits	Risks
Reduction in responsive behaviours	Worsening cognition Falls Hospitalization Stroke Death
Reduction in distress	

CO-MORBID CONDITIONS

Co-morbid conditions, such as depression, delirium and pain, also need to be considered.

- **Risperidone** shows the strongest evidence for treating psychosis in people with dementia.
- **Risperidone** or **Olanzapine** may be used for agitation or aggression.

Risperidone prescribing can be given under a PBS Authority but is restricted in use - the patient must have Alzheimer's dementia and have psychotic symptoms and aggression, initial authority is for up to 12 weeks if non-responsive to non-pharmacological methods and the maximum use over 12 months is 12 weeks.

LEWY BODY DEMENTIA

People with Lewy body dementia may have particularly severe adverse extrapyramidal effects from anti-psychotics, with double or triple the mortality rate, and such treatment should be avoided if possible.

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IN-PRACTICE TEACHING EXERCISE: RESPONSIVE BEHAVIOURS

Consider this case example with your registrar as a teaching tool.

- Jack, a 78-year-old retired farmer, has had dementia for eight years. He was recently admitted to full-time care in a residential aged care facility. Since moving from the family home, Jack was wandering the halls of his aged care facility at night in an agitated state.
- A detailed behavioural assessment showed that Jack, being a farmer, would check all the farm gates at the end of the day. Therefore, it was thought that this may be the reason for his agitated wandering at night in the residential aged care facility. Jack's carers and family supported recommendations from the responsive behaviour assessment.
- The nursing staff agreed to take Jack with them while they did their evening medication round. Jack responded well to this approach becoming less agitated in the evenings.
- It was agreed that the care team would regularly review Jack's progress with Jack and his family, and the next review was scheduled for two months' time.

Jack's case forms part of the video Responsive Behaviours in Dementia (8:18 mins). The video provides an easy-to-understand tutorial about the assessment and understanding of responsive behaviours, and offers a range of management options. Watch the video with your registrar as part of your teaching session at https://www.dropbox.com/s/3r3fdrasecywpzc/UTAS_WickingDementiaResponsiveBehaviour sM_720p%20%281%29.mp4?dl=0

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What teaching opportunities may emphasise to my registrar the importance of referring to the goal of care for a patient with late-stage dementia?

In previous GPSA dementia resources, we 'met' Anna during her dementia diagnosis and early management of the disease. So, let's once again refer to Anna's case as our example.

EXAMPLE: STAGE 3 DEMENTIA	
Patient Case: Anna	
• Anna, is now 80-years-old, and living in a residential aged care facility. • She has stage three Alzheimer's disease (the most common form of dementia). • Today she developed a temperature of 38.3°C, a moist cough, and a respiratory rate of 28 breaths per minute. • The nurse phones your registrar to ask whether Anna should be hospitalised.	
SCENARIO 1: Anna has a temperature	
Registrar:	*"The nursing home has rung me to go and see Anna as she has a temperature and a cough. She probably has a chest infection. The nurse wants me to send Anna to hospital but I am not really sure what to do?"*
Supervisor:	*"We've already discussed the events plan with the patient and family in the advance care plan: our goal of care is really to keep the patient comfortable.* *"Unplanned hospital transfers are common amongst the elderly, particularly those in residential aged care. But a patient with a cognitive or functional impairment is at increased risk and has poorer outcomes by being transferred into hospital care. Anna is a high-risk patient because of her advanced dementia.* *"I don't think this patient should go to hospital; there is nothing to be gained. It is not in our goal of care for this patient to go to hospital. We want to keep her comfortable and minimise her suffering.* *"Maybe the nurse doesn't know Anna or the plan, so it is important for you to communicate that element with the nursing home and the family."*
SCENARIO 2: Medication review	
Registrar:	*"When I went to review Anna, I noticed that she is still on quite a few medications. She's not taking much orally at the moment and I am not sure whether to cease them for now or permanently. What should I do?"*
Supervisor:	*"Given Anna is in late-stage dementia, and is acutely unwell, that is certainly a trigger to do a medication review. Let's have a look together if any medications can be removed. We need to keep the goals of care in mind as we review the medication in detail."*
SCENARIO 3: After Anna recovers, the registrar receives another call from the nursing home and seeks advice from this GP supervisor	
Registrar:	*"Anna is calling out a lot, she's agitated and disturbing other residents. The nursing staff think Anna might need something to calm her down. What medication should I prescribe?"*
Supervisor:	*"Before considering medication, we need to work out why Anna is calling out. Is this a new thing for Anna to be doing, or has she been doing it for much longer. There could be many things wrong: maybe she is in pain, or has a urine infection, or just a stone in a slipper. If something is agitating her, we need to work out first if that is the underlying cause for her calling out.* *"We may not find anything; maybe it's just the stage she is up to in her illness, and if that's the case we can think about using medication – but that is not our initial step. The initial step is really to ask a few questions – take a history, examine it, work out what is going on."*
Outcomes:	Anna recovers from her chest infection, and it is discovered she had a stone in her slipper. Once the stone is removed, Anna is no longer agitated and stops calling out.

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* For earlier teaching examples of Anna's case, see these Dementia Training Australia videos:

- GP Consent for Collaborative History at https://vimeo.com/262114049
- GP Taking a Collaborative History at https://vimeo.com/262115486
- GP Conveying a Dementia Diagnosis at https://vimeo.com/262115048
- 3-GP conveying progressive deterioration to a person with dementia and how it might be managed at https://vimeo.com/298314458

When reviewing a stage three dementia patient's anticholinergic load, what information may help my registrar?

At any stage of dementia it is important to review medications and in particular any that may be contributing to or impacting on the person with dementia's cognition. The following table has the pneumonic Acute Changes in M(ental)S(tate) to prompt us to remember some of the more common medications to think about deprescribing if it's appropriate. It's then important to remind the registrar to reassess the patient after any medication changes. A home medication review may be useful in this setting and may in fact be the first time your registrar may have utlilised one of these.

ANTICHOLINERGIC LOAD

ACUTE	CHANGE	IN	M(ental) S(tate)
Antiparkinsonian	**C**ardiac (antiarrhythmics)	**I**nsomnia medications	**M**uscle relaxants
Corticosteroids	**H**2 blockers (cimetidine)	**N**arcotics	**S**eizure medications
Urologic (antispasmodics)[1]	**A**nticholinergics NSAIDs		
Theophylline	**G**eropsychotropic[2]		
Emesis (antiemetics)	**E**toh		

[1] Urologic (antispasmodics) such as oxybutynin or tolterodine
[2] Geropsychotropic medications (such as antidepressants, antipsychotics, sedatives)

How can I help my registrar be prepared for a patient's palliative care phase of dementia?

Talk to your registrar about a general practice management plan, specific to each stage of dementia.

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 physical.
- A management plan needs to work towards goals for each stage of dementia.

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As a teaching example, let's look at Anna's case again.

PATIENT CASE: ANNA	
Registrar:	*"Anna has stopped eating and drinking and the staff are unable to even get her out into a chair anymore. Her daughter is really worried. I am not sure what to do now."*
Supervisor:	*"You have been doing a really good job looking after Anna, and you have a good relationship with the family. You should explore with Anna's daughter exactly what she is worried about.* *"The daughter knows her mother is dying, so it's an emotional time. Talk to Anna about our goals of care for her mother – dignity through providing comfort – and how this underpins our GP Management Plan during Anna's illness, including this palliative phase.* *"In talking to the daughter, you may discover she is worried her mother is not comfortable because she is not eating or drinking. So, you need to reassure her that you are keeping her mother comfortable, and that she actually just no longer wants to eat and drink."*

Show this example GP Management Plan for stage three dementia, as a teaching tool during an in-practice teaching session with your registrar.

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GENERAL PRACTICE MANAGEMENT PLAN – ITEM 721, 731, 732

DEMENTIA STAGE 3			
DOMAIN	**PATIENT PROBLEM**	**TREATMENTS/SERVICES PATIENT AND FAMILY ACTION**	**ARRANGEMENTS FOR TREATMENTS/SERVICES (who, when) – as needed**
Cognition	• Cognition significantly impaired	• Likely to lack capacity. Care as per enduring Guardian/Advance Care Directive	• RACF staff or/ home care community providers if home care provided • General practitioner • Geriatrician • Family meeting – 6 weekly
	Goal of care: Dignity through providing comfort		
Function	• Impaired instrumental functions	• Impaired functions of daily living	• Dependence for maintenance of functions of daily living • RACF/home care staff • General practitioner • My Aged Care • Care package
Psychiatric	• Depression • Anxiety • Hallucination • Delusions	• Heightened awareness for symptoms or psychiatric conditions • Screening for mental health issues in carers • Family education	• General practitioner • Geriatrician • Psychogeriatrician • Family meeting – 6 weekly • Dementia Support Australia www.dementia.com.au
	Goal of care: Dignity through providing comfort		
Behaviour	• Sleep disturbance • Agitation • Calling out • Wandering • Hoarding	• Carer education and increased support • Consider comprehensive behaviour assessment, e.g. CAUSEd model Non-pharmacological interventions based on comprehensive assessment • Pharmacological treatment where non-pharmacological measures have failed or patient/carers/family at risk of harm • Family education	• RACF/home care staff • General practitioner • Geriatrician • Psychogeratrician • Family meeting – 6 weekly • Dementia Support Australia www.dementia.com.au
	Goal of care: Dignity through providing comfort		
Physical	• Continence • Falls • Swallowing • Pain	• Cease all medications other than those for comfort • Nutritional assessment • Continence assessment • Falls assessment • Pain assessment • Family education • Review advance care plan and achieve agreement for end-of-life care including in the terminal phase	• Clear outline for dealing with deficits over a 24-hour period • RACF/home care staff • General practitioner • Pharmacist
	Goal of care: Dignity through providing comfort		

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What item numbers can be used in developing a GP Management Plan for stage 3 dementia?

MBS Items 721, 723 can be used for the development of a GP Management plan /TCA annually. These can be billed in conjunction with health assessment MBS Items 703-707 (depending on time).

An MBS Item 732 can be used for the review of a GPMP/TCA and can be done three-six monthly.

Resources

HELP LINES:

National Dementia Helpline (Alzheimer's Australia)
Phone 1800 100 500

Dementia Behaviour Management Advisory Service (DBMAS)
Phone 1800 699 799 (24 hours)

PUBLICATIONS AND WEBSITES

RACGP silver book at
https://www.racgp.org.au/silverbook

Dementia Australia at https://www.dementia.org.au/

Dementia Training Australia at https://www.dta.com.au/

https://gpsupervisorsaustralia.org.au/teaching-plans/

http://www.carersaustralia.com.au/

DEMENTIA TRAINING AUSTRALIA VIDEOS

GP Consent for a Collaborative History
https://vimeo.com/262114049

GP Taking a Collaborative History
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GP Conveying Dementia Diagnosis
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3-GP conveying progressive deterioration to a person with dementia and how it might be managed
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GPSA RESOURCES

Teaching plans:
- Diagnosing Dementia
- Managing Dementia

Webinars:
- Dementia Demystified: A Model for the Practice Team to Learn Together
- Part 1
- Part 2

FAQs:
- Teaching the Diagnosis of Dementia
- Managing Dementia

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