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Supporting patients living with behaviours in dementia in regional areas – A clinical approach

This webinar will start soon.

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Hybrid event – Wednesday 29 July 6.30pm - 8pm

Acknowledgement of traditional owners

We acknowledge the Tasmanian Aboriginal people as the traditional owners and ongoing custodians of the land on which we are meeting today. We pay our respects to Elders past and present.

We would also like to acknowledge Aboriginal people who are joining us today.

Some housekeeping

Tonight's webinar is being recorded:
https://learning.primaryhealthtas.com.au

Please use the Zoom Q&A feature to ask questions

Please don't forget to register for your next webinar at:
https://www.primaryhealthtas.com.au/for-health-professionals/events/

Evaluation Survey

Evaluation survey - Behaviours in dementia in regional areas

Presenter

Dr Katie French
Geriatrician

Behavioural and psychological symptoms of dementia:
Supporting patients living in regional areas.

Dr Katie French

Consultant Geriatrician

Illawarra Shoalhaven LHD, South Coast NSW

Director, South Coast Specialist Health Care, Nowra and Kiama, NSW

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QUEENSLAND
NEW SOUTH WALES
VICTORIA
SOUTH AUSTRALIA
AUSTRALIAN CAPITAL TERRITORY
JERVIS BAY TERRITORY
STURT NATIONAL PARK
WILLANDRA NATIONAL PARK
145°
150°
30°
35°
Murwillumba
McPHERSON RANGE
Lismore
Ballina
Tenterfield
Casino
Moree
Inverell
Glen Innes
Grafton
Coffs Harbour
Armidale
Nambucca Heads
Kempsey
Port Macquarie
Taree
Wauchope
Tamworth
Narrabri
Gunnedah
Coonabarabran
Coonamble
Bourke
Barwon
Namoi
Darling
Macquarie
Cobar
Wilcannia
Broken Hill
Menindee Lake
WARRUMBUNGLE RANGE
NEW ENGLAND RANGE
GREAT DIVIDING RANGE
Dubbo
Scone
Muswellbrook
Maitland
Forster
Wellington
Orange
Singleton
Raymond Terrace
Parkes
Lithgow
Newcastle
Forbes
Bathurst
Gosford
Lachlan
Murray
West Wyalong
Cowra
Katoomba
Richmond
Griffith
Sydney
Hay
Balranald
Temora
Young
Botany Bay
Murrumbidgee
Cootamundra
Goulburn
Camden
Wollongong
Wagga Wagga
Junee
Yass
Bowral
Kiama
Nowra
Gundagai
Tumut
Deniliquin
Murray
Ulladulla
Corowa
Albury-Wodonga
Queanbeyan
Moruya
Cooma
Mount Kosciuszko 2228 m
Bega
Eden
Cape Howe
Snowy
Tasman Sea
PACIFIC OCEAN
0
75
150 mi

Illawarra/Shoalhaven, South Coast NSW

- Total population of 400,000; Shoalhaven 112,000
- 20% of the region’s population is aged 65 years and over
- 26% of Shoalhaven's population is >65, coastal villages as high as 37%.
- High socioeconomic disadvantage/high Indigenous population of 3.5%.
- Shoalhaven Hospital 245 beds, soon to become 490
- 3FTE geriatricians.
- Hospital waitlists 12-18 months, private 6-12 months
- GIP (Geriatrician In Practice) model of care.
- OneCare Umina Park, Burnie pilot using GIP model in RACF.
- Quarterly in person visits, focus on collaboration and case conferencing with GPs.

Supporting People with Behavioural Dementia in Regional Locations: Learning Objectives

At the completion of this session participants should be able to:

- Recognise uncommon presentations and behavioral symptoms associated with dementia.
- Apply evidence-based prescribing and deprescribing principles for people living with dementia.
- Determine when clinical investigations are appropriate to support diagnosis and management of dementia-related presentations.
- Apply best-practice approaches to capacity assessment, supported decision-making, and the consideration of restrictive practices within a regional care setting.

Why does this matter?

- 433,000 Australians living with dementia
- Leading cause of death in Australia (9.4%).
- Estimated >1.1 million Australians involved in caring for someone with dementia.
- **Tasmania has the oldest and fastest-ageing population structure** of any Australian state or territory (21% over 65)
- "hyper-ageing" in regional communities, NW Tas 30%
- Limited access to specialist geriatric services

Dementia

DSM-5 Definition: Major Neurocognitive Disorder characterised by:

- Significant cognitive decline
- Interference with independence
- Not explained by delirium
- Not better explained by another psychiatric disorder

My Comprehensive Geriatric Assessment (CGA)

- Social- Place of birth, childhood, education, career + retirement age, marital status, children (and where they live).
- Functional status, driving, finances, EG/POA, wills
- Mobility, falls
- Smoking, etoh, drugs, head injuries
- PMH
- Medications
- Sleep, mood, cognition, delirium, recent surgeries, weight, continence, swallow
- Examination- postural bp, neurological, eye movements, CVS
- Cognitive Ax- RUDAS V MoCA V MMSE V ACE

Investigations

Pathology

- Reversible causes of cognitive loss- TFT, B12 etc, atypical screen when appropriate (VDRL, HIV/HEP B), vasculitic/autoimmune screens, antineuronal APOE genotype, Notch 3 gene,

Imaging

- CTB
- MRI
- FDG-PET
- Amyloid PET

LP

Prevalence of Dementia Type

Dementia	Approximate prevalence
Alzheimer's disease	60–70%
Vascular dementia	15–20%
Lewy Body Dementia	10–15%
Frontotemporal Dementia	5–10%
Parkinson Disease Dementia	3–5%

Characteristics of Dementia by subtype

Alzheimer's	Lewy Body	Vascular	Frontotemporal
Memory	Visual hallucinations	Stepwise decline	Behavioural change
Language	Fluctuating cognition	Executive dysfunction	Disinhibition
Navigation	Parkinsonism	Gait disturbance	Loss of empathy

What are Behavioural and Psychological Symptoms of Dementia?

Behavioural

- Aggression
- Agitation
- Wandering
- Calling out
- Sleep disturbance
- Sexual disinhibition
- Resistance to care

Psychological

- Depression
- Anxiety
- Delusions
- Hallucinations
- Apathy

Why do behaviour's occur?

The **Unmet Needs Model** postulates that behavioural changes in dementia are not deliberate or random acts, but are actually meaningful expressions of **unmet physical, emotional, or environmental needs**

- Pain
- Fear
- Confusion
- Loneliness
- Overstimulation
- Hunger
- Thirst
- Fatigue
- Boredom

Non-pharmacological management

- **Australian Clinical Practice Guideline Recommendations**
- Assess before treating
- Identify reversible causes
- Individualise interventions
- Involve carers
- Reserve psychotropic medications for severe distress or immediate risk of harm

“Behaviour is communication”

BEHAVIOR OCCURS: A STEP-BY-STEP CLINICAL PATHWAY

BEHAVIOR OCCURS

Observe and document the behavior (ABC Chart: Antecedent, Behavior, Consequence).

EXCLUDE DELIRIUM

Rule out acute medical causes (Infection, UTI, dehydration).

ASSESS PAIN

Use pain assessment tools (e.g., PAINAD, Abbey Pain Scale).

REVIEW MEDICATIONS

Check for side effects, drug interactions, or over-medication.

REVIEW RESPONSE

Evaluate effectiveness and update care plan.

ASSESS ENVIRONMENT

Identify overstimulation, noise, or physical or over-medication.

IDENTIFY TRIGGER

Determine unmet needs, fear, or sensory overload.

IMPLEMENT NON-PHARMACOLOGICAL INTERVENTIONS

Use Validation Therapy, activities, music, or sensory engagement.

ONLY IF SEVERE DISTRESS OR IMMEDIATE RISK...

CONSIDER SPECIALIST ADVICE

Consult dementia specialists (e.g., DBMAS).

CAUTIOUS PSYCHOTROPIC THERAPY

Use as a last resort, "start low and go slow", with regular review.

Note: This is a conceptual guideline and does not replace professional medical advice.

Referral Pathways for Behavioural Dementia

Dementia Support Australia (DSA)

- National behavioural advisory service
- Telephone consultation
- Outreach assessment
- Residential aged care support
- Behaviour support plans

My Aged Care

- Home support assessment
- Package referral
- Respite services

Older Persons Mental Health Services

- severe psychosis
- depression
- diagnostic uncertainty
- complex behavioural disturbance

Escalating Care

Most BPSD can be managed without medication; however, escalation is required when there is:

- Immediate risk of harm to the patient or others
- Severe distress despite comprehensive non-pharmacological interventions
- Persistent psychosis causing significant suffering
- Behaviour preventing essential medical or personal care
- Failure of first-line behavioural strategies

Restrictive practice

A restrictive practice is an intervention that restricts a person's movement or rights. Including:

- Physical restraint
- Mechanical restraint
- Environmental restraint
- Chemical restraint

***Use of medication primarily to influence behaviour rather than treat a diagnosed medical condition*.**

- Documentation is as important as the prescribing decision itself.

Antipsychotics

- **Risperidone** is the only antipsychotic specifically approved in Australia for:
  - Persistent aggression in Alzheimer's disease
  - Severe behavioural disturbance
  - Failure of non-pharmacological management
  - Recommended for **short-term use (up to 12 weeks)** where possible.

- Quetiapine
- Olanzapine
- Haloperidol
- Aripiprazole (less commonly)

Antidepressants

- **When Are They Useful?**
- Depression coexists
- Anxiety predominates
- Mild agitation associated with anxiety
- Emotional distress

Common agents

- Sertraline
- Citalopram
- Mirtazapine (selected patients)
- Duloxetine

Sodium valproate

- Evidence demonstrates no clinically meaningful benefit
- Notable side effects including sedation, confusion, hepatotoxicity, pancreatitis, blood dyscrasias.
- Despite this it is not uncommonly used and anecdotally is beneficial in certain situations.

Cholinesterase Inhibitors & Memantine

- May modestly improve behavioural symptoms in some patients by addressing underlying cognitive disease rather than acting as direct behavioural treatments.
- Donepezil for anxiety
- Rivastigmine for hallucinations
- Memantine for agitation, sleep disturbance in later stages of dementia.
- When to stop?

'MAJOR RISKS AND MANDATORY PROTOCOLS FOR PSYCHOTROPICS IN OLDER ADULTS.'

SEVERE CLINICAL HARMS

INCREASED MORTALITY
Statistically Significant Risk across all age-related psychotropics.

FALLS
Due to orthostatic hypotension & coordination impairment.

PNEUMONIA
Compromised swallowing reflexes and aspiration risk.

PARKINSONISM
Dopamine blockade causing Drug-Induced EPS (Extrapyramidal Symptoms).

STROKE
Elevated Cerebrovascular Adverse Events (CVAE).

FRACTURES
Often resulting from falls (Hip, Pelvis, Wrist).

SEDATION
Excessive drowsiness, reduced quality of life, mobility.

COGNITIVE DECLINE
Accelerated deterioration in memory and function over long-term use.

THESE HARMS DEMAND STRICT COMPLIANCE WITH LEGISLATED PROTOCOLS.

PSYCHOTROPICS ARE REGULATED AS CHEMICAL RESTRAINT.

Typical drugs involved: Risperidone, Olanzapine, Quetiapine (Antipsychotics); Diazepam, Lorazepam (Benzodiazepines).

RESTRICTIVE PRACTICE

RESTRICTIVE PRACTICE MANDATORY FLOWCHART

1. **Step 1: EXHAUST ALL NON-PHARMACOLOGICAL STRATEGIES** (Behavioral interventions, environmental mods).
2. **Step 2: DOCUMENT FAILURES OF NON-DRUG INTERVENTIONS. INFORM KEY PERSONNEL.**
3. **Step 3: CONSULT & OBTAIN INFORMED CONSENT FROM RESIDENT OR MEDICAL SUBSTITUTE DECISION MAKER (MSDM).** **INFORM OF HARMS** (stroke, falls, mortality risk).
4. **Step 4: IMPLEMENT PSYCHOTROPIC BEHAVIOR SUPPORT PLAN (BSP).**
5. **Step 5: REGULAR CLINICAL REVIEW & MANDATORY DOSE REDUCTION (TAPERING).**

MANDATORY DOCUMENTATION:
Behavior Support Plan, + Regular Support Plan, Reduction, Informed Consent Regular Review,' and 'Informed Consent.

Dementia as a terminal illness

“Complete resolution of behaviours is uncommon. Improvement is usually modest. Medication should always be combined with ongoing non-pharmacological care”

- The aim is **symptom reduction**, not sedation. However, if sedation is the only way in which to reduce symptoms how are we unable to justify treatment?
- Advanced dementia is a terminal illness.
- Are we in fact treating terminal symptoms of a debilitating disease? Distinguishing terminal delirium in dementia is difficult.


Putting it all together. Real cases and experiences.

Mrs AO

- 73 year old retired nurse with increasing anxiety and subjective cognitive loss.
- No significant medical hx including IHD, chronic pain, diabetes
- Progressive amnestic cognitive loss and functional decline
- Anxiety predominant disease, predating cognitive symptoms for years, triggered retirement. Commenced on Venlafaxine 75mg several years ago with good effect.
- Sleep not an issue.
- Lived at home for 2 years, son moved in to provide 24 hour support
- Transitioned to RACF 12 months before death approx. 8 years after initial symptoms (anxiety).
- Late stage symptoms included pacing, extreme anxiety.

Management decisions -AD

- How to treat anxiety in this setting?
- Maintained on Venlafaxine prior to review. Do we change or increase dose?
- Choice of CI- commenced on Donepezil with modest response and stabilization of function for ~2yrs.
- Increasing behavioural features- pacing, anxiety
- Add memantine v stop donepezil
- Ongoing anxiety- added olanzapine- falls and postural hypotension.
- NOF# Sx v Non-Sx?
- No surgery, stopped cognitive enhancers, died within 2 weeks.

Mr RJ

- 85 year old Macedonian man, retired steel worker
- 5 year history of progressive behavioural changes and cognitive impairment with significant decline following CABG and CVA.
- Hx of IHD, CABG, AF, R CVA,HTN, Ex smoker, moderate ETOH
- On Apixaban, statin, ACE-I, BB blocker
- Depression after CABG 10 years ago, mood lability an issue Wife unable to manage his care needs, transitioned to RACF
- Increasing aggression, predictable at times of personal care.
- MRI showed extensive microvascular changes, old infarct.
- FDG PET- generalized hypometabolism, early AD changes suggest repeat imaging in 12 months.

Management decisions - VD

- Selecting appropriate cognitive tests to suit education.
- Blood pressure targets in this age group
- Treatment of depression post stroke/cardiac intervention and subsequent mood lability
- Sertraline 25 mg up to 50 mg mane, rarely more.
- No evidence for CI, may increase mood lability and psychological symptoms.
- Be careful not to miss seizure activity. If suspected, in this case a trail of Sodium valproate is reasonable- to treat a suspected medical condition.
- If ongoing agitation particularly in the evenings. I would opt for low dose IR Seroquel nocte (rather than the guidelines).

Mr BP

- 71 year old retired vet presents with a 2 year history of falls, cognitive change and sleep disturbance.
- History of several trip and falls with slow gait.
- Wife now sleeps in separate room due to injury at night, hitting/kicking in sleep for the last 5 years.
- Cognitive change that fluctuates, high cognitive baseline over same period.
- Intermittent visual disturbances of animals, tiger in the bedroom progressing to ants on the floor.
- Progressive development of parkinsonism with unilateral UL tremor, masked faces, constipation and urinary incontinence.

Management decisions DLB

- Early initiation of rivastigmine 5 up to 10 and then 15 if tolerated in younger patients.
- Sleep- melatonin, mirtazapine at low dose
- Mood disturbance- apathy, distress
- When to treat parkinsonism- careful risk v benefits- what symptoms are most disruptive to life cognition/psych v motor
- Persistent, threatening hallucinations Quetiapine 12.5 mg up to 25 mg IR night, use SR during the day if can tolerate dose. Avoid haloperidol and risperidone.
- Early driving review due to visuospatial issues.

Mr AB

- 67 yo retired school teacher with 4 year history of cognitive decline and speech deficits.
- Non-smoker, heavy EtOH as young man, minimal now.
- Significant concussion history with over 30 years of rugby league, front row position. At least 3 loss of consciousness.
- Significant car accident at 20 with head injury.
- Father died in 70s from dementia, brother in late 60’s with similar symptoms. Both played league.
- Mood changes more frustrated and increasingly ”hot headed”. Depression and erratic behaviour in 20-30s.
- Sleep disturbed for 5+ years- enacting football in his sleep

Mr AB

- MRI- SWI microbleeds, haemosiderin, cavum septum pellucidum, atrophy- frontotemporal lobes.
- FDG PET- hypometabolism mainly in the fronto-temporal cortex, with limited parietal involvement
- Slow cognitive decline, functional independence until 2 months prior to death
- Mood predominant issues in the last 6 months- erratic, aggressive, hallucinations, delusional thoughts.
- Last 2 months- physical violence, unpredictable.
- Died in hospital with no accepting facilities including specialist behavioural units due to extreme, unpredictable behaviours.
- Autopsy findings- severe (Stage IV) CTE, Alzheimer's pathology.

Management considerations –TBI/CTE

- Take a concussion history in all patients presenting with cognitive decline.
- If there is a significant Hx, consider traumatic brain injury when prescribing.
- Mood/sleep/pain/psychosis/memory
- Sertraline for mood, add lamotrigine if not settled
- High dose melatonin for sleep, Quetiapine if sleep is the most pressing issue
- Utilising the learnt behaviour of driven, physically fit, retired athletes to achieve goals of exercise, nutrition and cognitive training.
- Mood/sleep/pain/psychosis/memory
- Memantine v rivastigmine v donepezil

Contact Information

Connecting with Brain Donation Services and Concussion Support Networks

Australian Sports Brain Bank

- **Website:** brainbank.org.au
- **General Enquiries:** SLHD-brainbank@health.nsw.gov.au
- **Office Phone:** (02) 9351 0943
- **24/7 Urgent Page: 1800 551 898 (Imminent Brain Donation Only)**
- **Headquarters Address:** 94 Mallett Street, Camperdown NSW 2050

Concussion Legacy Foundation

- **Website:** concussionandcte.org/en-au
- **Support Email:** australia@concussionfoundation.org
- **Alternate Contact:** info@brainbank.org.au
- **Media Relations:** annittasiliato@concussionandcte.org
- **Postal Address:** PO Box 716, Pascoe Vale VIC 3044

Excellent dementia care is not defined by choosing the "right drug.”

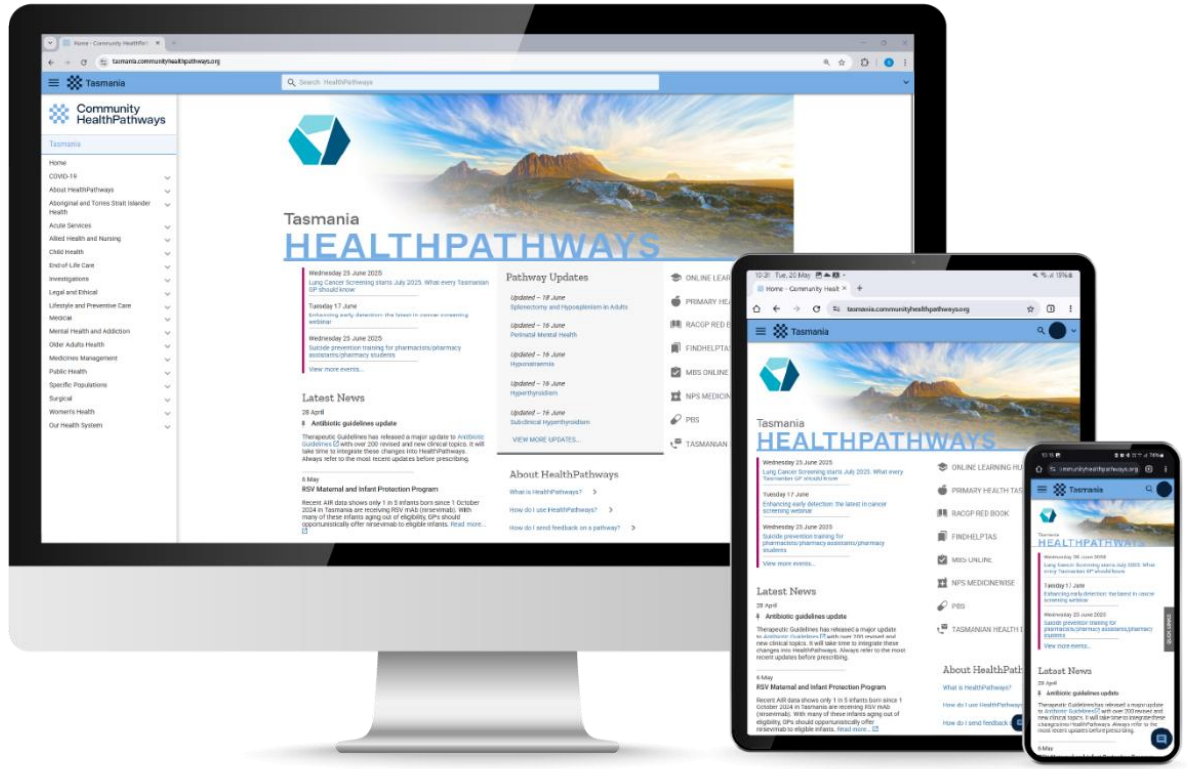
It is defined by:

- understanding the individual,
- supporting families,
- using multidisciplinary care,
- prescribing cautiously,
- and reviewing frequently.

Questions?

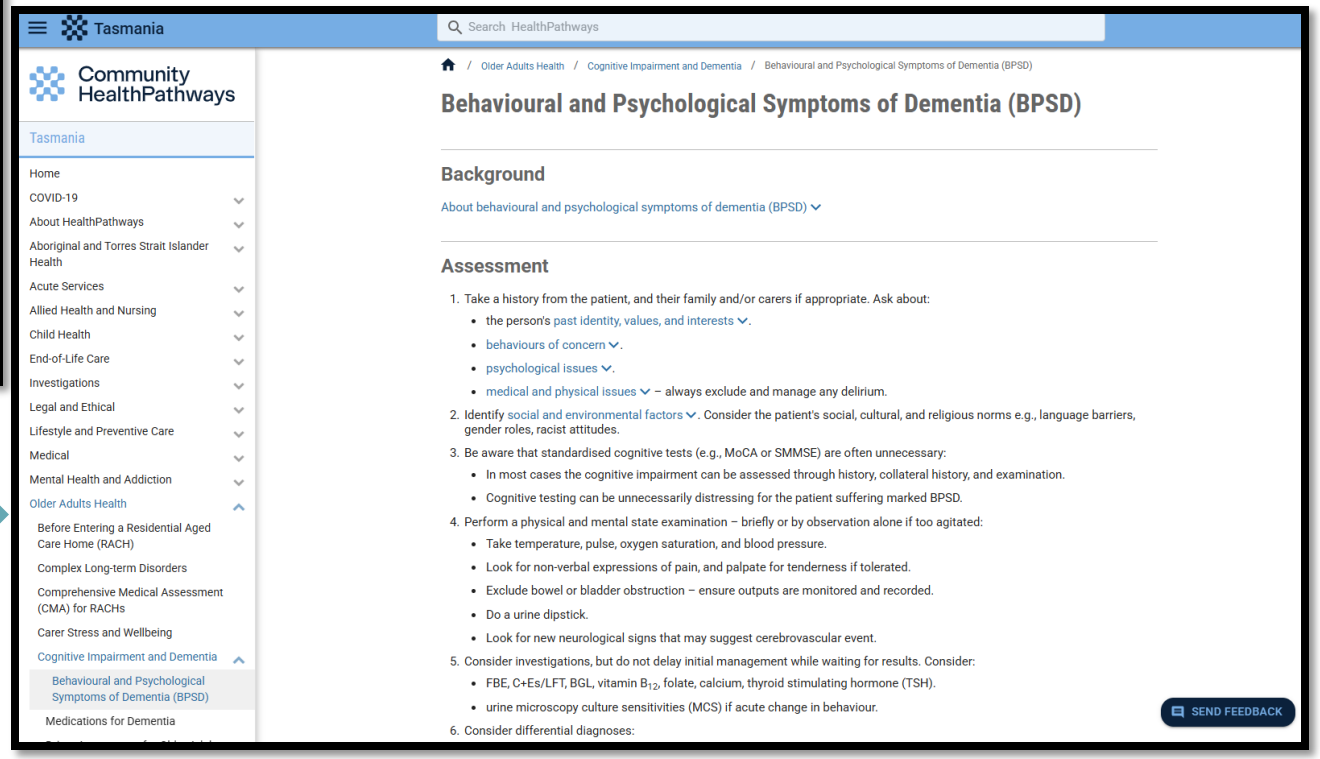
Community HealthPathways

Tasmanian HealthPathways is a web-based information portal developed by Primary Health Tasmania. It is designed to help primary care clinicians plan local patient care through primary, community and secondary healthcare systems.



For access to the Tasmanian HealthPathways, visit the homepage:

tasmania.communityhealthpathways.org



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Scan here

Some final words

- After the webinar ends, your browser will open a link to an evaluation survey.
- Statements of attendance will be emailed to participants.
- For event queries, please contact events@primaryhealthtas.com.au

Evaluation survey - Behaviours in dementia in regional areas

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