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16 June 2022

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RE Official Information Act request CDHB 10894

I refer to your letter dated 8 June 2022 and received in our office on 13 June 2022 requesting the following information under the Official Information Act from Canterbury DHB (being a follow up request to our response to OIA CDHB 10870). Specifically:

1. **Can you please advise the date that the HealthPathway for Cognitive Impairment came into force and was first issued / published by CDHB?**

The HealthPathway for Cognitive Impairment went live on Canterbury DHB HealthPathways on 13 June 2019.

2. **Can you please forward a copy of further information referred to in the HealthPathway for Cognitive Impairment, in the links to:**
 - a. **Behavioural and Psychological Symptoms of Dementia (BPSD)**
 - b. **Complex long term disorders**
 - c. **About cognitive impairment**

Please find attached as **Appendices 1 – 3**.

I trust that this satisfies your interest in this matter.

Please note that this response, or an edited version of this response, may be published on the Canterbury DHB website after your receipt of this response.

Yours sincerely



Ralph La Salle
Senior Manager, OIAs
Canterbury DHB & West Coast DHB

Behavioural and Psychological Symptoms of Dementia (BPSD)

Background

About behavioural and psychological symptoms (BPSD)

About behavioural and psychological symptoms of dementia (BPSD)

Significant BPSD challenges arising in dementia are:

- common, affecting practically all people with dementia at some stage.
- distressing for people with dementia and their carers.
- associated with higher use of health care resources and with institutionalisation. ¹

Management

Practice point

Always try non-pharmacological approaches first

Pharmacological approaches carry the risk of harm and should not be first line. Any treatment trial (pharmacological or non-pharmacological) should aim to improve the quality of life and safety of everyone affected.

1. Ask about behavioural and psychological symptoms and determine the degree of impact that these symptoms are having on the patient and carer.

Psychological symptoms

- Anxiety
- Depression
- Psychosis, e.g. hallucinations, persecutory delusions, delusions of infidelity

Behavioural symptoms

- Aggression
- Agitation
- Apathy
- Inappropriate eating, dressing, or toileting behaviour
- Sexually inappropriate behaviour

- Sleep disruption
 - Vocally disruptive behaviour
 - Wandering
2. Explore expectations. A reasonable treatment goal is reduction, rather than cessation, of the challenging behaviour.
 3. Take a person-centred approach:

- Promote the idea that most behaviours the carer finds challenging arise from the patient's needs.
- Discuss with the carer the underlying purpose of the behaviour, exploring:
 - What need is the patient trying to communicate with their behaviour?

Needs

Needs may be biological, e.g. thirst, hunger, tiredness, continence issues, and pain. Commonly, needs are emotional, e.g. to feel respected, valued, loved, and needed (contributing).

Recognising this may enable carers to reframe BPSD into something more accurate, e.g. agitation might be understood as frustration and anxiety in the afternoons because the person feels they need to "go home" to prepare dinner.

- How can the carer assist the patient to have their needs better met?
 - Encourage attempts at meeting the need through trial and error.
 - Always ask: for whom is this behaviour or state a problem? If it is not the patient, management is unlikely to be best targeted towards them.
4. Take a behavioural approach:
 - Ask the carer to keep an ABC chart to capture a range of episodes of the behaviour.
 - Explain that the carer's responses to behaviour can shape that behaviour.
 - Review the ABC chart with the carer.

Review the ABC chart

Ask:

- What environmental factors are contributing?
- Is there a pattern of antecedents that might be making the behaviour more likely?
- Is there a pattern of consequences that might be making the behaviour more likely to happen again?

- Are there situations when the behaviour does not occur that are partly similar to the times it does? If so, what is different?
- Encourage attempts at meeting the need through trial and error.
- Advise the carer to avoid restraining the patient.

5. If other strategies are ineffective, a psychotropic medication may be appropriate:

- Psychotropics should never be used as the sole management strategy. They are not very effective for behaviours that challenge carers, carry a high risk of significant side effects, and can leave the legitimate needs of the patient unmet.
- Use only as a last resort other than in exceptional circumstances.

Exceptional circumstances

Earlier use of psychotropics may be reasonable:

- in true emergency situations, typically for very short term or one-off use.
- if ongoing high risk of serious harm to the patient or others.
- if the carer is so stressed that they cannot participate in the non-pharmacological, collaborative approach.
- if reasonable non-pharmacological strategies have proved to be ineffective or unavailable.
- in recurrences of a situation in which the patient derived clear benefits and insignificant side-effects from a particular psychotropic.
- If the patient lacks capacity to consent to (or refuse) treatment, discuss with the formal proxy decision-makers or, if none exist, the next of kin.

6. If a psychotropic is appropriate, discuss a trial of medication.

Trial of medication

Outline the parameters of the trial. Decide:

- who will assess success of the trial, how will success be determined, when will this be assessed, and who will communicate this to the prescriber.
- who will monitor for side-effects, and who will communicate this to the prescriber.
- when will dose and discontinuation reviews by the prescriber take place, even if the medication is tolerated and the trial is successful.

Make a plan for ending the trial period:

- Regularly-used psychotropics can nearly always be successfully withdrawn after 3 to 6 months.
- This does not apply in the same way to psychotropic medication used effectively for a formally diagnosed major depressive disorder, anxiety disorder, bipolar disorder, or psychotic illness in the context of dementia.

7. Decide on as-required or regular dosing.

As-required or regular dosing

Prescribe as-required dosing with caution because:

- carers (formal and informal) may lack a detailed understanding of when they might best be used.
- the behaviour that triggered the dosing is likely to end before the medication takes effect.
- higher doses, with more associated risk, are required for rapid reduction of high arousal states. Prevention with regular lower dosing is preferable.
- unwanted medication effects are likely to last for many hours.

As-required dosing is best used to help carers when a highly risky or distressing state is building up. Ensure directions for when to use it are very clear. Ask the carer to keep an accurate and accessible record of the times and amounts used.

Regular dosing can be used in lower amounts and is therefore safer and more readily monitored for effectiveness than as-required dosing. It is not advisable for:

- highly intermittent and/or very antecedent-responsive behaviours, e.g. rare physical aggression, or
- physical aggression that only occurs with provocation.

8. Choose an appropriate medication:

- Antidepressants

Antidepressants

Depression in the context of dementia is a key diagnosis not to miss. Consider antidepressants if non-pharmacological interventions are not effective or the depression is severe. Examples are:

- Citalopram 20 mg can be helpful for depressive states, anxious states, and also for isolated psychotic symptoms without depression
- Mirtazapine 15 to 30 mg can be particularly helpful for insomnia associated with depression or anxiety

Avoid antidepressants with anticholinergic activity including tricyclics, paroxetine, venlafaxine.

See Antidepressants for Older Persons.

- Cholinesterase inhibitors

Cholinesterase inhibitors

The strongest effect is for apathy, then some effect for psychotic symptoms, then least effect for anxiety and agitation. These drugs can cause neuropsychiatric side-effects, especially low mood.

See main Cognitive Impairment - Assessment and Management pathway.

- Benzodiazepines and zopiclone

Benzodiazepines

Benzodiazepines may be helpful for sedation for sleep or specific procedures, and for states of emotional arousal such as significant anxiety or anger. They are unlikely to cause problems with tolerance or dyscontrol in the context of dementia.

- Lorazepam 0.25 to 1 mg can be effective for short-term management of agitation and anxiety, as needed, but can be reasonably long acting.
- Avoid clonazepam due to its long half-life and risk of accumulation, especially clonazepam drops because of the extra difficulty of measuring out controlled doses.

Use benzodiazepines very cautiously:

- They cause sedation, confusion, impaired cognitive function, incontinence, dribbling of saliva, slurred speech, and increased risk of falls.
- They generally suppress the challenging symptoms, rather than providing relief to the underlying causes.

If given, review regularly as accumulation or heightened sensitivity can develop. Along with this, the target symptom can naturally reduce with time, meaning the medication may no longer be needed.

Zopiclone

Zopiclone 3.75 to 15 mg at night can be helpful for sleep.

- Antipsychotics

Antipsychotics

General considerations:

- Antipsychotics are most effective for psychotic or manic symptoms, and less effective for off-label indications such as anxiety, sedation, or sun-downing agitation.
- There is some limited evidence for the use of antipsychotics for short-term management if aggression, agitation, or other similar behaviour is challenging carers or associated with significant distress to the patient.
- If antipsychotics are used as required, they are not being used for their antipsychotic effect but for their tranquillising effect.

Risks, benefits, and contraindications:

- They have significant adverse effects (depending on the particular agent), especially sedation, postural hypotension, central and peripheral

anticholinergic symptoms, and extra-pyramidal side-effects (especially parkinsonism)

- They have been associated with an increased risk of adverse outcomes. Avoid use if stroke risk high.

Adverse outcomes

- Stroke
- Falls
- Over-sedation
- Pneumonia
- Mortality (all causes)
- Contraindicated in cases of parkinsonism (especially in Parkinson disease or Lewy body dementia) without specialist advice.
- Particularly useful if delirium develops with distressing psychotic symptoms.

Antipsychotic options:

- Risperidone 0.25 mg to 0.5 mg a day (maximum 2 mg per 24 hours). Avoid use in context of parkinsonism.
- Quetiapine 12.5 mg to 25 mg once or twice a day. Beware postural hypotension and sedation.
- Haloperidol 0.25 mg to 0.5 mg a day (maximum 2 mg per 24 hours). Do not use in context of parkinsonism.

Prescribing considerations:

- In all cases, start with a low dose and increase very gradually (no less than weekly), depending on response and tolerance.
- If for a rest home resident, prescribe in the "short-term treatment" section for a fixed time trial, e.g. 2 to 4 weeks. An improvement should normally be noticed within a month, otherwise discontinue.
- As BPSD is usually transient, review the need for antipsychotics regularly. If no longer required, reduce and stop. Once symptoms are improved for three months, antipsychotics can usually be safely stopped gradually over 2 to 4 weeks.
- Watch for potential side-effects, e.g. extra-pyramidal side-effects (mainly parkinsonism), sedation, increased confusion, postural hypotension, and falls.

9. Review all patients at least every 3 months.

10. If symptoms are severe, associated with high risk, likely to lead to a move into a higher level of care, or are unresponsive to the interventions above, request Cognitive Impairment Specialised Assessment.

Request

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RELEASED UNDER THE OFFICIAL INFORMATION ACT

Complex Long-term Disorders

COVID-19 note

During COVID-19, it is important that we are prioritising our most at risk communities. See Canterbury Primary Response Group advice for supporting the health of vulnerable populations.

Last updated: 21 April 2020

This page is for patients with multiple co-morbidities or complex single diseases and focuses on aspects of care common to all complex conditions. It applies to all adults, but particularly those in the older age groups.

Assessment

1. Consider completing a wider health needs checklist. It may not be necessary to address all elements in the checklist as some may not be relevant, or may have already been addressed.
2. Identify areas of physical health that need further assessment.

Physical health

Areas of physical health to explore:

- Alcohol and drugs
- Cognitive impairment
- Continence
- Exercise
- Falls risk
- Frailty
- Hearing
- Immunisations
- Intellectual disability
- Nutrition
- Oral health
- Sleep
- Vision

3. Ask about the patient's current living situation and whether their needs are being met.

Current living situation

Areas of the patient's current living situation to explore:

- Mobility and transport
 - Home safety
 - Paid or unpaid carers
 - Whether they are caring for others
 - Any possible abuse
 - Access to food and warmth
4. Identify any emotional or psychological needs.

Emotional or psychological needs

Areas of the patient's emotional or psychological health needs to explore:

- Mood
 - Sexuality
 - Social connectedness
5. Respectfully enquire about the person's spiritual (or wairua) needs, acknowledging that this may be an important area of life for the patient.

Spiritual (or wairua) needs

In New Zealand there is considerable variation amongst people in their recognition of or holding to spiritual values. Many New Zealanders, particularly those of Polynesian or Māori descent, will draw strength and support from spiritual beliefs and values, while others may have little interest in this area of life.

6. Identify any cultural needs.
7. Identify any financial and legal assistance needs. Consider:
 - financial security.
 - future planning.

Management

1. Use an integrated patient/whānau approach, seeking permission to involve family/whānau where able.
2. Give education and support about the condition, taking the patient's level of health literacy into consideration. Consider referral to condition-specific support groups.

Education and support

- Helps reduce anxiety
- Allows informed decision-making
- Helps the patient make decisions for the future by building awareness of the progressive nature of some diseases

3. Discuss lifestyle self-management to maintain wellness and prevent worsening illness.

Lifestyle self-management

- Alcohol moderation:
 - HealthInfo – What is safe drinking?
 - Alcohol.org.nz – Information for older people about drinking alcohol
- Good sleep practices
- Foot problems & care in older adults
- Looking after teeth and gums
- Mental wellbeing
- Nutrition advice, including Community Nutrition Initiatives
- Physical activity, see Keeping active
- Smoking cessation

4. Discuss possible interventions to prevent future illness:

- Assess risk of osteoporosis and vitamin D deficiency and intervene as appropriate.
- Offer annual flu vaccination, pneumococcal vaccination, shingles vaccination, or other vaccinations.
- Consider any other possible interventions relevant to patient's condition.

5. Utilise the appropriate care plans:

- Medical care plans

Medical care plans

- Acute plan for decision making in acute situations
- Medical care guidance plan for patients who lack mental capacity
- Personalised care plan for planning and actioning long-term health care goals
- End of life and legal considerations

End of life and legal considerations

- Encourage setting up Enduring Power of Attorney. See Mental Capacity.

- Review any advance directive that the patient may have or may wish to make.
- Initiate discussions on Advance Care Planning regarding:
 - aged residential care.
 - resuscitation.

Resuscitation

- Information for doctors about resuscitation decisions – CDHB Palliative Care Guidelines
- Information for patients about resuscitation – Deciding about Cardiopulmonary Resuscitation
- attitudes to limiting future medical interventions.
- dying with dementia.

6. Assist patient to manage their medications:

- Check compliance.

Compliance

Consider why the patient and doctor are not concordant with treatment:

- Cost of health care
- Side-effects of medications
- Complexity of treatment regimens
- Access to pharmacy, general practice, and hospital
- Lack of knowledge and understanding about the disease and its treatment
- Social and cultural factors
- Carer stress or neglect
- If patient is on multiple medications, consider medication management review. In older adults, see also Deprescribing and Prescribing in Older Adults.
- For patients with medicine adherence problems, consider referral to the community pharmacy.

7. Stabilise any mental health conditions and advise about options for mental health community support.

8. Discuss impact on quality of life, and the types of support available for:

- optimising the home environment.

Optimising the home environment

Consider:

- occupational therapy assessment of home safety and function through community and home-based intervention.
- home and heating support.
- needs assessment and service coordination (NASC) for home help.
- maintaining or returning to meaningful activity or work.

Meaningful activity or work

For support with returning to daily activities and employment, consider:

- occupational therapy support with employment through work assessment and rehabilitation, or with meaningful activity through community and home-based intervention.
- employment and activity providers:
 - Catapult Employment Services Trust
 - Emerge Aotearoa – if patients need higher level of support to find and sustain employment
 - Work and Income NZ
 - Workbridge – self-referral for high-functioning patients
- community support worker for people with mental illness.
- strategies for living with chronic illness such as conserving energy or managing everyday activities.
- for mental health patients, requesting employment service support or supported activity.
- addressing financial concerns.

Financial concerns

Consider:

- budgeting advice:
 - Christchurch Budget Service
 - Work and Income
- social work support – mostly community-based providers.
- funding options:
 - Services to Improve Access (SIA)
 - Work and Income:
 - Disability Allowance
 - Disability Certificate – Counselling

- Enhanced Capitation to reduce medical costs
- Carer Support
- End of life care funding through the primary health organisation (PHO)
- Financial Support for Health Costs
- driving and transportation.

Driving and transportation

- Discuss the possibility that future disease progression could affect driving. See Fitness to drive.
- If appropriate, refer for an occupational therapy driving and vehicle assessment.
- Mobility parking cards are available for those who meet the criteria.
- Complete the Environment Canterbury disability declaration for patients eligible for the Total Mobility taxi voucher scheme – See list of approved operators.
- If driving is no longer possible, suggest Age Concern Life Without a Car course.
- When planning to travel, remind patients to make an appointment for a travel consultation.
- parenting and family relationships.

Parenting and family relationships

For support with parenting and family relationships, consider:

- family and carer support, including the potential need for respite care.
- child and parenting community support.
- children of parents with mental illness.
- social connectedness.

Social connectedness

Social isolation is common and debilitating.

- Suggest involvement in family, social, or cultural activities, joining community groups or condition-specific support groups. A range of activities for older adults are listed in the Christchurch City Council's Information Directory for Older Adults Living in Riccarton/Wigram, and Hagley/Ferrymead Activity Guide for Older Adults.
- Begin with a "start where you are at" approach. Make goals realistic and start small, gradually increasing social contact with time, with the aim that any changes are beneficial and can be sustained.

- See Getting back into community-based activities.
- cultural needs.

Cultural needs

If appropriate, consider referral to:

- Community Māori or Pacific health providers.
- Interpreter Services.
- Migrant and Refugee Services.
- spiritual (or wairua) needs.

Spiritual (or wairua) needs

Encourage the patient to discuss any spiritual concerns they may have with trusted support people, whanau, priest or other providers of faith-based counsel.

9. Consider additional supports. If:

- intensive nursing input for condition is required, refer to community nursing or specialised hospital based nursing.
- difficulties maintaining physical fitness, or would benefit from physical rehabilitation, request physiotherapy assessment or enrolment in a programme such as PhysioFITT or Green Prescription.

PhysioFITT programme

PhysioFITT is a targeted physical activity and exercise programme provided by all private physiotherapists for patients who are:

- inactive due to physical, mental, personal, or environmental barriers:
 - Physical health conditions e.g., asthma, heart disease, diabetes, osteoporosis, injury
 - Mental health conditions e.g., anxiety, depression, cognitive impairment
 - Age-related e.g., falls risk
 - Personal, social, or environmental e.g., isolation, lack of motivation or time
- already active but want to increase their activity levels or achieve specific performance goals.

The PhysioFITT programme aims to support patients to become, and stay, physically active. Typically, it consists of 3 or 4 sessions over 3 to 6 months, depending on how much support and advice the patient requires. PhysioFITT has no special funding. Consider funding options:

- WINZ funding through the disability allowance.

- some health insurance policies.
- ACC, if the patient has an accepted claim and PhysioFITT programme is indicated for rehabilitation.
- the patient – self-funded. Fees vary – approximately \$200 to \$300 for 3 to 4 visits.

Request via:

- ERMS > Allied Health > Physiotherapy Referral, or
- Contact the provider directly.

Clinicians listed on:

- ERMS Directory
- Physiotherapy NZ

Read the Disclaimer

Disclaimer

The inclusion of links to websites or health providers in HealthPathways, HealthPoint, and ERMS is not a recommendation or endorsement of any health provider, health professional, or their services. Use of services featured in these websites is undertaken at the user's own risk.

This may not be a complete list of providers with interest, skills or experience in this area. If you wish to be added, send your contact details using the Send Feedback button.

Some providers may take referrals only by phone and are therefore not listed in ERMS.

Note – Offer all referral options to all patients, even if they are eligible for DHB treatment. The HDC Code of Health and Disability Services Consumers' Rights Regulation 1996 Clause 2 Right 7: the right to make an informed choice and give informed consent.

- unintentional weight change or inadequate nutrition, request dietitian assessment.
- oral health concerns, request non-acute dental assessment.
- difficulties accessing services, refer to Partnership Community Workers.

Request

- If difficulties accessing services, refer to Partnership Community Workers.
- Consider the following options to help improve the patient's well-being and independence:

- Child and Parenting Community Support
- Community Māori or Pacific health providers
- Community nursing or specialised hospital-based nursing
- Community Pharmacy
- Dietitian assessment
- Employment and activity providers:
 - Catapult Employment Services Trust
 - Emerge Aotearoa – if patients need higher level of support to find and sustain employment
 - Work and Income NZ
 - Workbridge – self-referral for high-functioning patients
- Home Care and Community Support
- Home and Heating Support
- Interpreter Services
- Mental health support:
 - Mental Health Community Support
 - Children of Parents with Mental Illness and/or Addiction
- Migrant and Refugee Resources
- Non-acute Dental Assessment
- Occupational therapy:
 - Community and Home-based Intervention
 - Driving and Vehicle Assessment
 - Work Assessment and Rehabilitation
- Physical activity assessment or programmes:
 - Green Prescription
 - Physiotherapy assessment
 - PhysioFITT

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- Social work support with addressing financial or social concerns

About cognitive impairment

Dementia is increasing in incidence and prevalence in NZ because of our ageing population. The number of New Zealanders with dementia has grown from 48,182 people in 2011 (1.3% of the population) to 62,287 in 2016. It is estimated that in 2050, 170,212 people will have dementia in New Zealand (2.9% of the population). This follows the worldwide trend. ¹

Because women tend to live longer lives than men, there is a higher proportion of people with dementia who are female (56.6% versus 44.4% in 2016). ¹

General practitioners can modify disease outcomes by recognising dementia early. This can be achieved by keeping alert to changes in function and performance, and routinely enquiring about cognitive changes for patients at higher risk.

Most patients with mild-to-moderate dementia can be effectively identified and managed in primary care, with only the more complex requiring referral to secondary care.

In mild cognitive impairment, the cognitive changes exceed those of normal ageing but the functional impairment that typifies dementia is not present. People with mild cognitive impairment have a 10% chance of converting to dementia every subsequent year, whereas the general population risk is 1%.