Dementia Support Australia –

Improving the quality of life for people living with dementia

Dementia Support Australia

A partnership led by HammondCare

Who is Dementia Support Australia?

Dementia Support Australia

A partnership led by HammondCare

Catholic Homes INCORPORATED

Wintringham SPECIALIST AGED CARE

BlueCare™

ARRCS AUSTRALIAN REGIONAL & REMOTE COMMUNITY SERVICES

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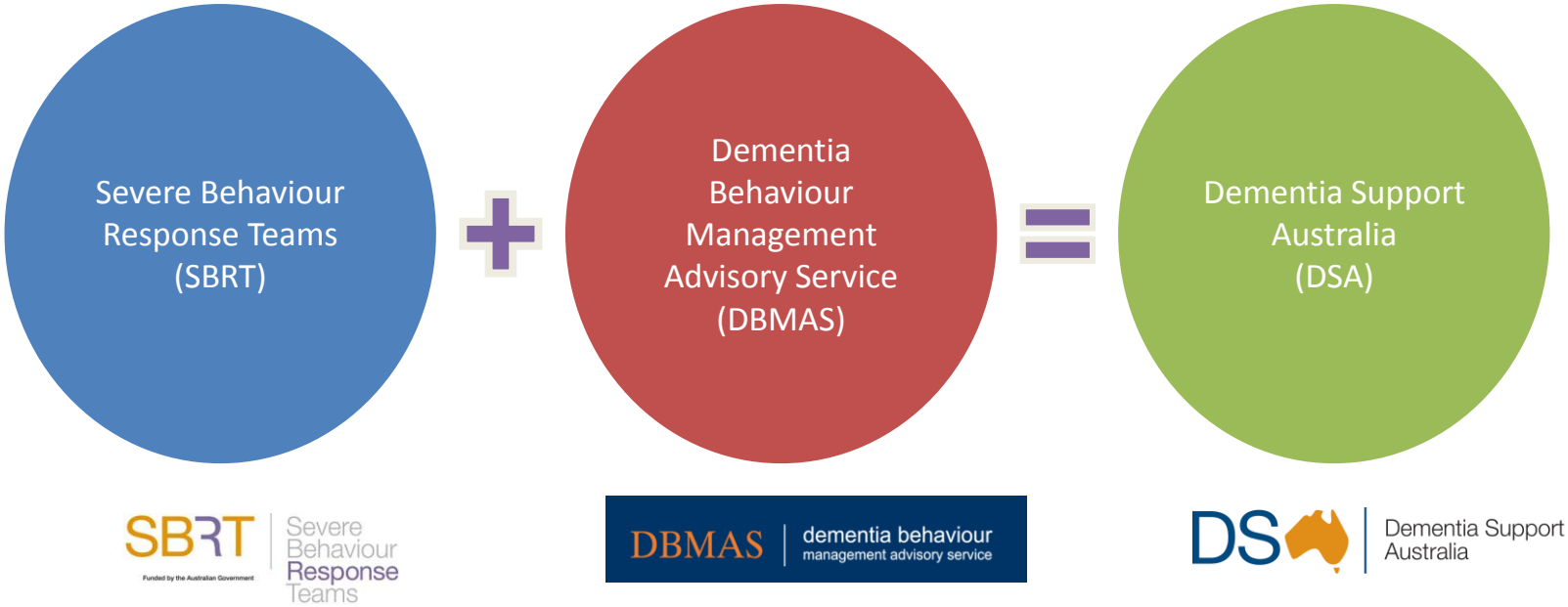
Dementia Centre

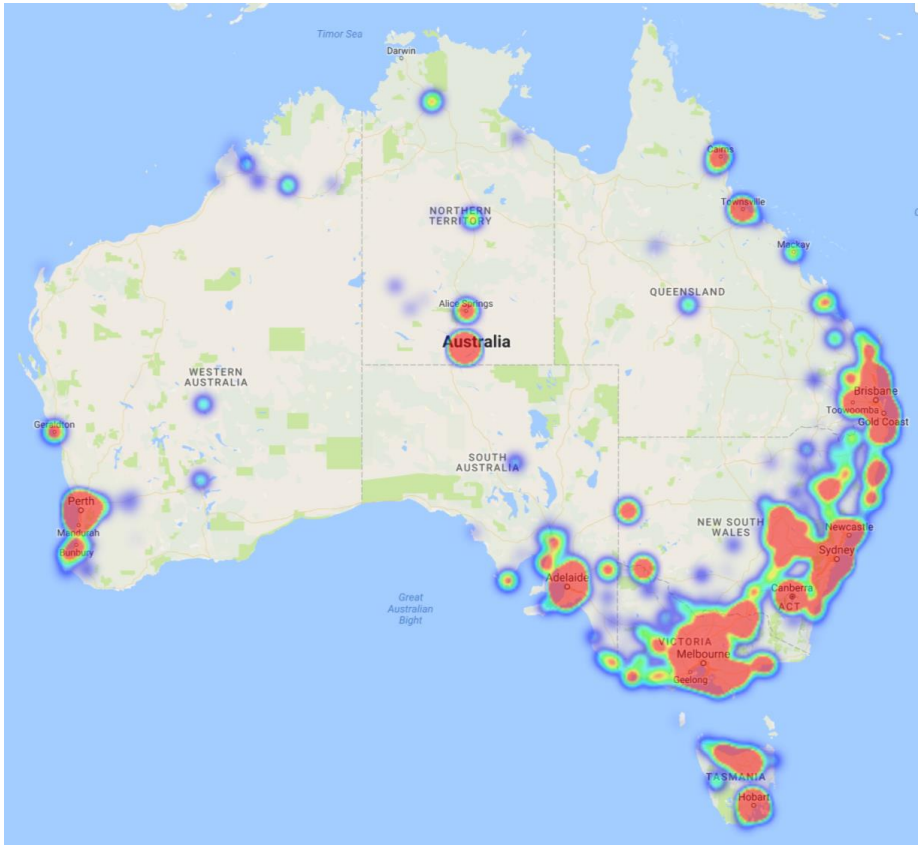
What is Dementia Support Australia?



What's the difference?

DBMAS dementia behaviour management advisory service	SBRT Severe Behaviour Response Teams
Mid-severe dementia behaviours	Severe-extreme dementia behaviours
For clients in residential care, hospital or community care settings	For clients in residential care only
Triage immediate or within 4 business hours	No need to re-triage in DSA
Onsite within 1 week of referral acceptance	Onsite within 48 hours of transfer
Shorter-term case management	Longer-term case management

National Team



Dementia Centre

What we do

- Advise on behaviour for people living with dementia
- Onsite visit or over the phone
- Individual focus
- Holistic Assessment, Review of person, observation of person, review of documentation
- Meet with/working alongside staff
- Meet with other stakeholders - family/GP's/others
- Trialing of initial strategies with staff/modelling
- Brainstorming with staff
- Written strategies /report
- Brokerage
- Follow-up / support

Clinical Associates in the DSA service

SBRT

- Prompt access to senior specialist medical staff is invaluable to the assessment and management process.
- Multiple Associate staff on a 7/365 roster.

DBMAS

- On the ground specialist medical staff for case review and advice.
- Our Associates provide a detailed knowledge of psychopharmacology and of the interplay between general medical conditions and behavioural disturbance.

Most common contributing factors to behaviour on referral

Three most common factors in 50% of all referrals are:

- Pain- up to 70%
- Environment - up to 70%
- Limited carer knowledge- up to 40%

How to refer to Dementia Support Australia

1800 699 799

Anywhere in Australia 24/7

Online form:
www.dementia.com.au
click on 'referrals'

FAX:
1800 921 228
(2 day response time to triage)

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Pain: The Untold Story
Dementia and Pain

HammondCare

An independent Christian charity

Pain- Over-arching Issues

- Two decades of research has shown problems with recognition, assessment and treatment of pain in people living with dementia.

- Research suggests that people with dementia feel pain in the same way as people without dementia– but may have more trouble explaining it or making sense of it.

- Estimates vary but it is reported that pain affects between 60% to 80% (Achterberg et al 2013) of people living with dementia in residential care.

- There is a real risk that people with dementia are still "suffering" excessively from pain.

Pain and dementia – What we do know….

People living with dementia are at greater risk of having their pain:

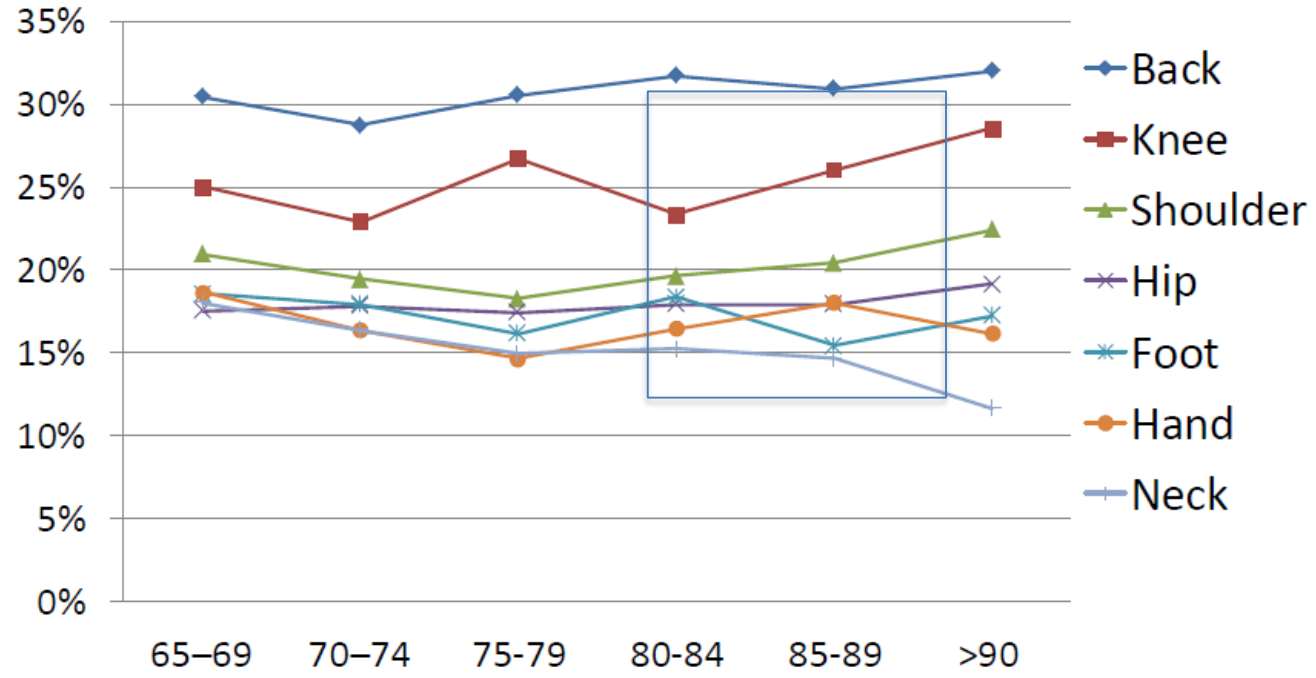
- **Unrecognised**- Pain and dementia do commonly co-exist
- **Not adequately monitored or assessed**
- **Under-treated** – it is well documented that people with dementia receive less analgesia than people without dementia

Most common causes of pain:

  - Musculoskeletal conditions; previous or current injuries; chronic pain associated with other co-morbid conditions

Pain in specific site by aged group (N=7061)

Bothersome pain in the last month



US data set

Adapted from Table 2
Patel KV et al. Pain 2013;154 2649–57.

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Recent study by Dementia Centre

Survey of staff knowledge

- Questions relating to pain 70-90% answered correct.

File Audit - 208 files (52% diagnosis of dementia and 78% had pain in last month)

- Only 19% had a formal pain assessment
  (eg: ABBEY, PAINAD, VERBAL PAIN INVENTORY) if they had pain
- People who had pain and received analgesic medication 64%
- People who had pain and received non-pharmacological intervention 62%
- Use of formal assessment tools for evaluation of pain 0%- 20%
- Descriptive entries for evaluation 73- 87%

Focus group – Findings

43 participants (92% care staff) Some key issues:

- Fragmented communication between staff.
- Difficulty getting GPs to respond to concerns about pain.
- Care staff engagement in the 'pain pathway' largely restricted to the identification and reporting of pain.
- Limited feedback to care staff.
- Care staff reported difficulties in "being heard" by colleagues.
- Multi-disciplinary engagement was difficult.

Implications of untreated pain

- Reduction in functional ability, decrease in mobility, muscle weakness, falls
- Reduction in overall quality of life
- BPSDs – aggression and mood disorders (increased depression)
- Unpublished data from Dementia Support Australia suggests that pain is a factor causing BPSD's in approx. 70% of referrals.

Treatment of pain

- Research from the late 90's and onwards reported that people with cognitive impairment received less analgesia

  (Scherder & Bouma 1997; Horgas & Tai 1998; Bernabei 1998; Morrison & Sui 2000; Feldt et al. 1998; Pickering et al 2006)

- Recently in an Australian RACF study– people with dementia were 29-32% less likely to receive opioids or optimised paracetamol compared to those without dementia (Veal et al. 2014)

What do we need to do?

- Regular assessment of pain is vital for optimal management

BUT

- Research shows inadequate assessment

AND

- Difficulty of staff being able to identify

  Pain vs BPSDs

Treatment of pain – more recent research is hopeful

More recent overseas studies indicate an improving trend:

- Higher percentage of PWD getting paracetamol compared to people without Dementia in Swedish study(Hassum et al 2011)
- Increase in analgesic (paracetamol and strong opioids) prescription between 2000-2011 in Norway showing a possible shift from under-prescription (Sandvik et al. 2016)

Recent Australian study in South Australia showed prescription of analgesia was similar for people with and without dementia (Tan et al. 2016)

Components of best practice

Identification:

- Self report
- Non-communicative residents – assess and observe
- Pain should be considered if there is a change in behaviour & every three months.

Assessment:

- Identify type of pain
- Systematic multi-disciplinary assessment of severity and impact.
- Structured procedures to identify causes and impact on ADL's QOL, mood and sleep
- ADLs, QOL, mood and sleep.
- Assessment to suit person
- At rest and at movement periods should be included in the assessment process when observational pain measures are used.

Components of best practice

Multidisciplinary Pain Management

- Both pharmacological and non-pharmacological approaches should be routinely used within a multi-disciplinary approach.
- Referral to specialist or multi-disciplinary pain clinic for pain that persists after interventions.

Pharmacological management:

- Should be based on a diagnosis of the pain.
- Drugs should be appropriate to type of pain and severity.
- Persistent pain should have round-the-clock administration.
- Paracetamol (1mg/6hly) for musculoskeletal pain.
- Anti-inflammatories should be used with caution (low dose, short duration).
- Neuropathic pain should be evaluated and with anti-epileptic and anti-depressant adjuvants

Components of best practice

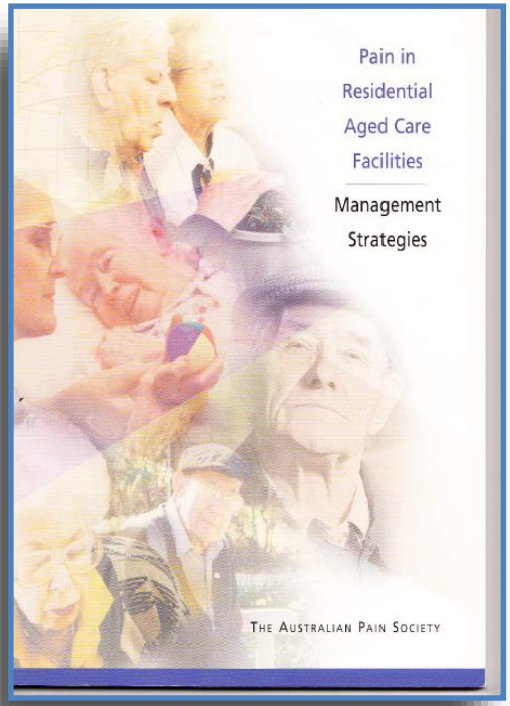
Non-pharmacological Management:

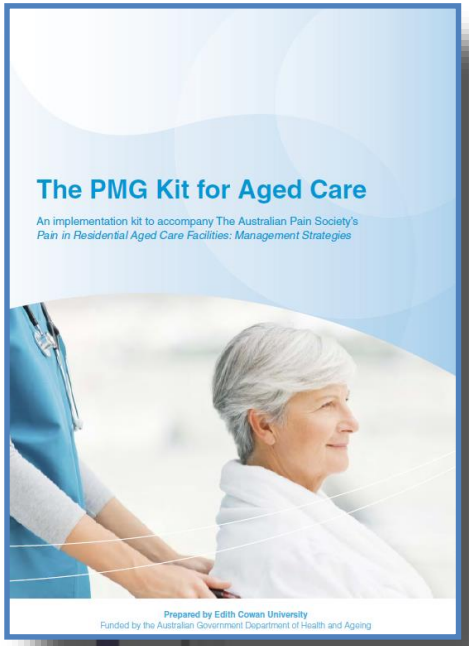
- Cognitive-behavioural therapies show strong evidence for management of persistent pain in older people -should be available to all aged care residents.
- Physical therapies (strengthening, aerobic and stretching activities) should be part of care for older people with chronic pain and be tailored to the needs of the older person.
- Physical modalities such as application of heat may be helpful but benefits for chronic pain are dubious.
- TENS can be considered to effective management of persistent pain in people who can provide feedback.

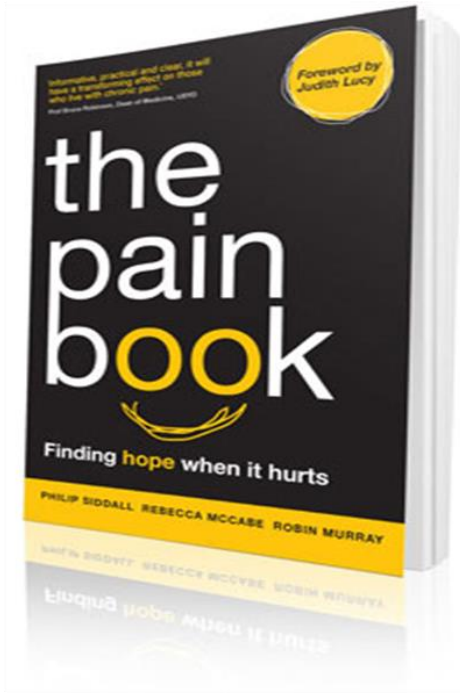
System and quality issues

- Regular quality assurance activities.
- Integrated multi-disciplinary pain management systems should be in place at the service.

Australian Pain Society: http://www.apsoc.org.au







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