Dementia Support Australia –

Improving the quality of life for people living with dementia





## Who is Dementia Support Australia?



A partnership led by













### What is Dementia Support Australia?



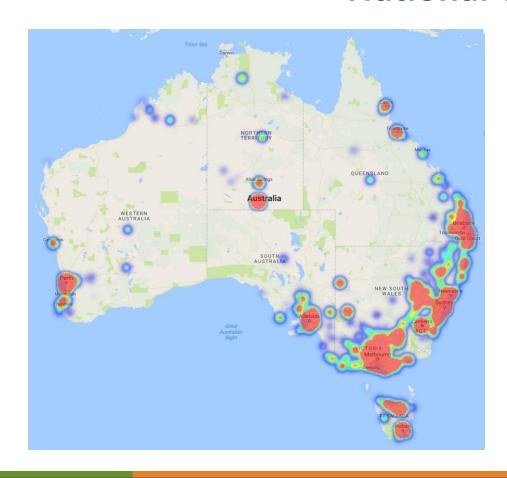
## What's the difference?





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**



#### 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.c om.au click on 'referrals'



1800 921 22**BAX:** (2 day response time to triage)



Dementia Centre

Pain: The Untold Story
Dementia and Pain



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:

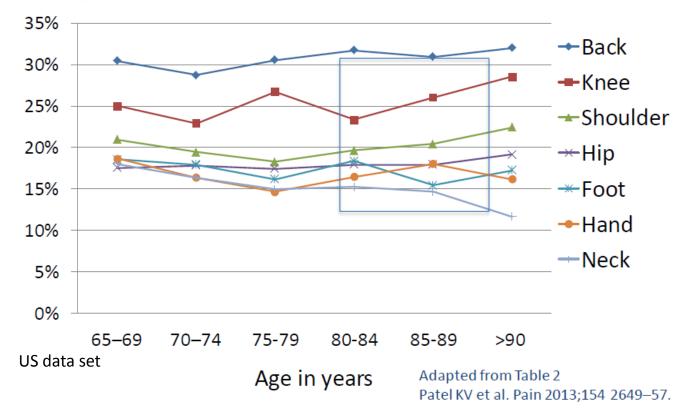
- Unrecognised- Pain and dementia do commonly co-exist
- Not adequately monitored or assessed
- Under-treated it is well documented that people with dementia receive less analgesia than people without dementia

#### 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



## 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 antidepressant adjuvants

## Components of best practice

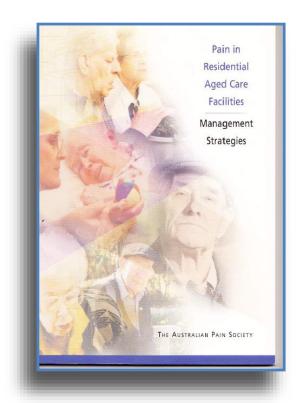
#### Non-pharmacological Management:

- 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.

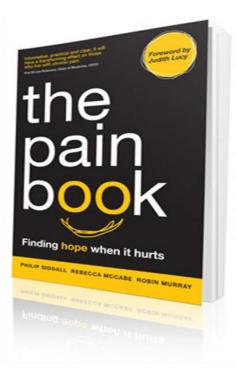
#### System and quality issues

- 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







## Contact us

## dementiacentre.com

dementiacentre@hammond.com.au

P: +61 2 8437 7355





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