Palliative Care for People With Dementia

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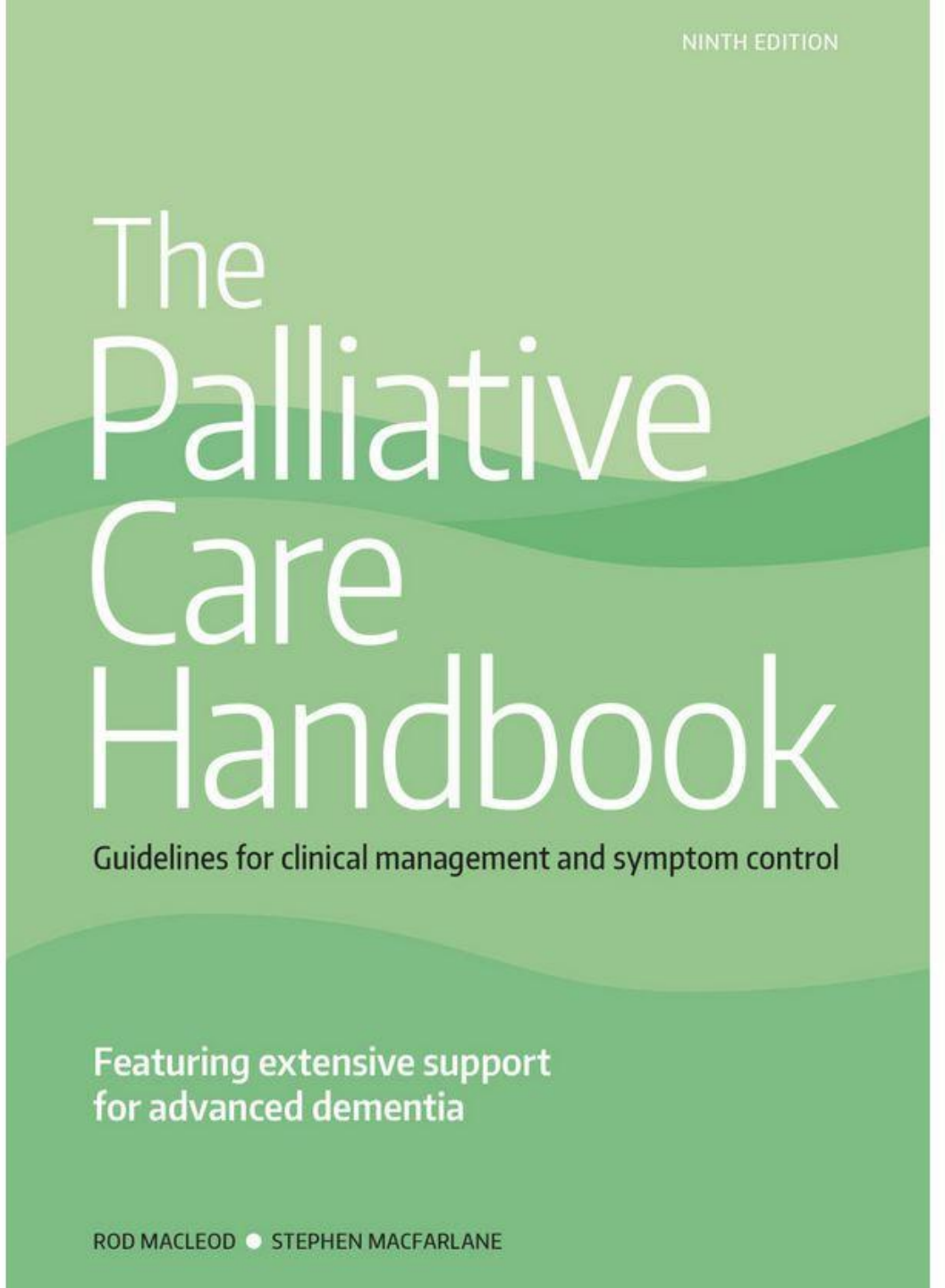

NINTH EDITION
The Palliative Care Handbook
Guidelines for clinical management and symptom control
Featuring extensive support for advanced dementia
ROD MACLEOD • STEPHEN MACFARLANE

Differentiating Terminal Delirium from non-terminal delirium and BPSD in dementia

- PROBLEMS:
  - BPSD is common (up to90% of all those with dementia)
  - BPSD symptoms overlap with those of delirium
  - Pre-existing cognitive impairment is the biggest risk factor for delirium
  - >/= 70% of LTC residents have dementia
  - Delirium is common – up to 30% of general medical inpatients
  - Rates of delirium in LTC have not been studied

  - Delirium is usually not fatal
  - Delirium is frequently recurrent
  - No cause is identified in up to 40%

- **Clinical Dilemma: What is BPSD Vs Delirium Vs Terminal Delirium?**

Palliative Medicine

Who receives specialist palliative care in Western Australia - and who misses out

LK Rosenwax, BA McNamara

First Published June 1, 2006 | Research Article
https://doi.org/10.1191/0269216306pm1146oa

Abstract

Objectives: To describe the characteristics of Western Australian (WA) people who received, and did not receive, specialist palliative care (SPC) during their last 12 months of life. **Design:** Retrospective cohort study. **Setting and participants:** People who died between 1 July 2000 and 31 December 2002 in WA, and whose cause of death was from cancer or selected non-cancer conditions. **Main outcome measures:** Use of SPC in the last 12 months of life. **Results:** There were 27 971 deaths from all causes in WA over the study period. Two-thirds (68%) of people who died of cancer received SPC, but less than one in ten (8%) who died of selected non-cancer conditions received SPC. Those who died of cancer were significantly less likely to receive SPC if they were single or widowed, aged-/ 85 years or lived in a region other than a major city. Of those who died of selected non-cancer conditions, people other than

- Only 1.5% of people with end-stage dementia receive Palliative Care in the USA (Christakis and Escarce, 1996)
- In Europe, less than 1% of hospice patients have a neurological disease 9Davies and Higginson, 2004)
- It has been suggested that the very behaviours that might indicate a need for palliative care in dementia may serve to exclude them from appropriate admission to hospice care (Waterman et al., 2016)

Why the low rates?

- Accurate identification of the end-of-life stage in dementia is problematic?
  - Cancer literature emphasises the occurrence of behavioural symptoms in the last few days of life, but in dementia the dying process may be drawn out over weeks or months (Wilden & Wright, 2002)
- Lack of dementia-specific skills of staff who work in palliative care?
- Stigma? "We don't want the other patients disturbed"

What are the outcomes for those in LTC with advanced dementia?

- Morrison and Siu (2000)
  - Six-month mortality of those with severe dementia who were hospitalised with pneumonia or a hip fracture were 53% nd 55% respectively (13% and 12% in the cognitively intact)
  - (only 24% of thosewith dementia and a hip fracture were prescribed regular analgesia!)

- Mitchell et al. (2009) found >50% mortality at18 months
  - Predictors:
    - Pneumonia (six-month mortality 46.7%)
    - Febrile episode (six-month mortality 44.5%)
    - Eating problems (six-month mortality 38.6%)
    - Over 40% underwent a burdensome intervention in the last 3 months of life (e.g. hospital admission)

General indictors of the need for a palliative approach

the gold standards framework®

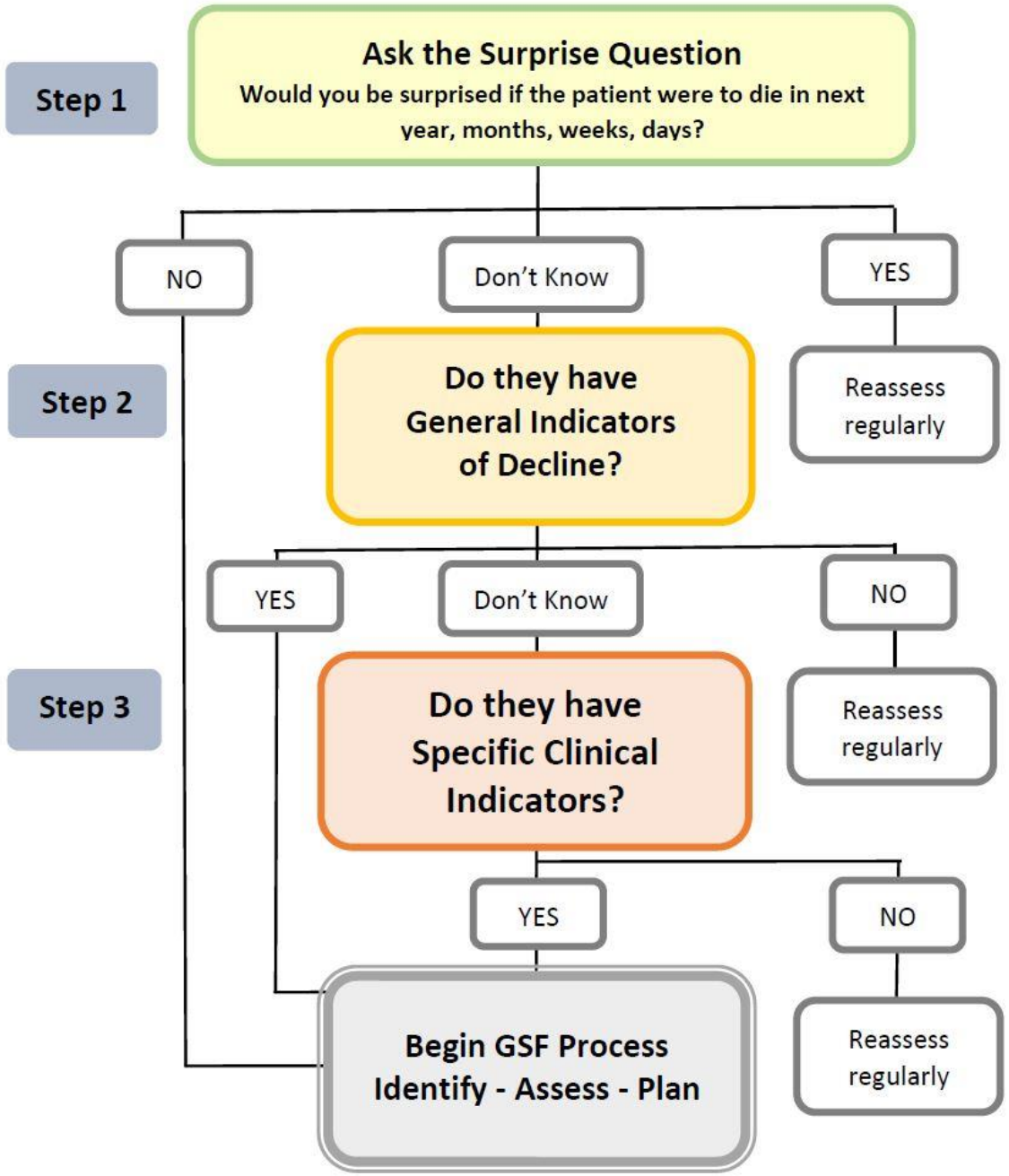
The Gold Standards Framework
Proactive Identification Guidance (PIG)

RCGP Royal College of General Practitioners

The National GSF Centre's guidance for clinicians to support earlier identification of patients nearing the end of life, leading to improved proactive person-centred care.

GSF PIG 6th Edition Dec 2016 K Thomas, Julie Armstrong Wilson and GSF Team, National Gold Standards Framework Centre in End of Life Care
http://www.goldstandardsframework.org.uk for more details see GSF PIG

Proactive Identification Guidance – GSF PIG Flow-chart



Indicators of the need for end-of-life care in the setting of dementia?

Choices, Attitudes, and Strategies for Care of Advanced Dementia at the End-of-Life (CASCADE) study

(Mitchell, 2006)

- 323 NH residents with advanced dementia
- At 18 months, 55 % mortality, median survival was 1.3 years.
- Over 18 months, 41% had pneumonia, 51% had a febrile episode, and 86% developed an eating problem.
- ●Adjusted six-month mortality rates after the development of pneumonia, a febrile episode, and eating problems were 47, 45, and 39 percent, respectively.
- ●Other major acute illnesses (eg, hip fracture, myocardial infarction) were rare in the last three months of life.

Advanced Dementia Prognostic Tool (ADEPT) (Mitchell, 2010)

- 12-item additive score including information on age, gender, level of functional dependence, nutritional status, presence or absence of various symptoms and medical conditions, such as CCF and SOB.

- In a prospective validation study of 606 nursing home residents with advanced dementia, ADEPT had a specificity of 89 percent and a sensitivity of only 27 percent for predicting death within six months.

Symptoms in Last Week of Life with End Stage Dementia

Hendriks et al.
J Pain Symptom Management 2014; 47(4): 710-
JAMDA 2015; 16: 475-

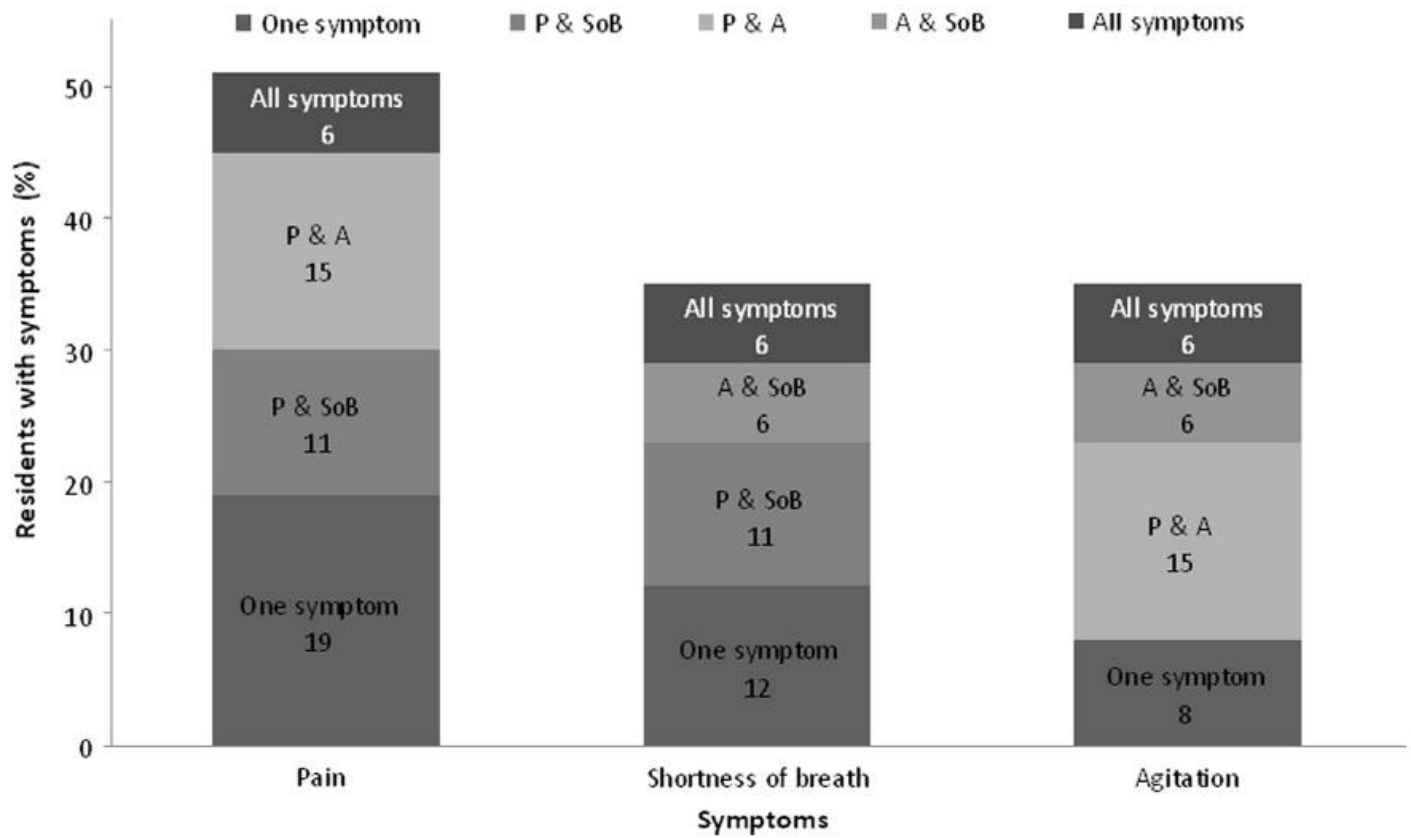


Fig. 1. Nursing home residents with symptoms of P, SoB, and A in the last week of life. P = pain; SoB = shortness of breath; A = agitation.

Dutch End of Life in Dementia study
28 RACFs in Netherlands, n=372
Agitation most common symptom overall (57-71%) but decreased to 35% in last week of life

??SPECIFICITY

Related Behaviors

BEHAVIORS

Agitation
Extreme emotional disturbance; perturbation
- Anger
- Despair
- Combativeness
- Irritability
- Striking out
- Grimacing

Anxiety
State of uneasiness and apprehension
- Nervousness
- Tearfulness
- Tension
- Fear
- Anguish
- Furrowed brow
- No eye contact
- Wild-eyed look

Distress
Anxiety or mental suffering
Behaviors listed under both agitation and anxiety included here

RESTLESSNESS

Not able to rest, relax or be still

- Repetitive movement
- Constant moving or motion
- Inability to be still
- Movement
- Unable to rest
- Constantly changing positions
- Movement of limbs
- Increased movement
- Non-purposeful motor activity
- Hyperactivity
- Tossing and turning
- Busyness
- Thrashing/flailing
- Can not get comfortable
- Head rolling
- Trying to get out of bed
- Fidgeting/squirming
- Unsettled
- Shifting from side to side
- Jerking
- Pulling/picking at clothes and sheets
- Removing clothes and sheets
- Climbing out of bed
- Grabbing people
- Rocking

SLEEP ISSUES

- Inability to sleep
- Wakefulness/insomnia
- Impaired sleep
- Sleep disturbance

VERBALIZATIONS

- Singing/humming
- Confused speech
- Incoherent speech patterns
- Unintelligible babble
- Calling out
- Moaning/groaning
- Crying
- Rhythmic vocalizations

MENTAL STATE

Management

Treat any underlying issues, such as:
- Pain
- Full bladder
- Spiritual distress
- Emotional distress

Patient/Caregiver Support
- Create a calm and safe environment
- Attempt to re-orient the patient as possible
- Educate the family on what is occurring as this can be a fearful time
- Encourage family assistance, as appropriate

Medications
- Ativan
- Haldol
- Thorazine
- Versed

Statistics

According to the National Hospice and Palliative Care Organization and Hospice Pharmacia, 42% of dying patients experience terminal restlessness in the final 48 hours of life.

The agitation is a terminal event, occurring only in the very last hours of life. It is NOT to be confused with the anguish and distress of many patients who are not yet dying and who need company and counseling and NOT sedatives.

It is important to eliminate other causes

❑ Does the patient have an infection?

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Terminal Agitation

(Hospice of Cincinnati)

Note, again, the lack of specifity of these symptoms in the setting of dementia with BPSD

Mini-Suffering State Examination (Aminoff et al., 2004)

	Items of MSSE	YES – 1
1	Not calm	
2	Screams	
3	Pain	
4	Decubitus ulcers	
5	Malnutrition	
6	Eating disorders	
7	Invasive action	
8	Unstable medical condition	
9	Suffering according to medical opinion	
10	Suffering according to family opinion	
	MSSE score /10	

Low suffering 0-3
Intermediate suffering 4-6
High suffering 7-10

Survival and its correlation with MSSE score

- Aminoff and Adunsky (2006)

- 134 consecutively admitted patients who survived < 6 months

- Mean survival times:
  - LOW MSSE: Mean score 2.24 +/- 0.99) = 57.76 (SD 9.73) days
  - INTERMEDIATE MSSE: Mean score 4.92 +/- 0.83 = 44.70 (SD 5.99) days
  - HIGH MSSE: Mean score 8.06 +/- 1.00 = 27.54 (SD 4.16)
  - *P* = 0.0018 (Kaplan-Meier Analysis Log Rank)

“Relief of Suffering” Units

(Aminoff 2008)

- Located within existing health services
- Cater for the needs of those with end-stage dementia whose care is currently spread across a variety of medical, surgical, orthopaedic and geriatric settings
- ? High MSSE score as an admission criterion
- Acknowledges death is not invariable upon admission
- Those who improve could be discharged back to long-term care.

REACH out in Dementia Toolkit

- Recognise End of Life & Care Holistically
- Identify evidence based signs and symptoms of end stage dementia
- Reviewed/demontrated usefulness in RACFs
- Eight signs and symptoms: (presence of one or more can indicate need to change to a palliative approach)
  - Dependent in all ADLs, double incontinence
  - Severe communication impairment
  - Eating or feeding difficulties
  - Loss of ability to walk followed by loss of ability to stand
  - Contractures
  - Persistent confusion, agitation, withdrawal, lethargy, apathy
  - Recurrent infections
  - No recognition of family/friends/everyday objects

Potter et al. Aust J Ageing 2013; 32(4): 241-

Finally….

- Don’t forget people with dementia often die of/with another pathology and that those co-existent illnesses often worsen the symptoms of agitation/distress

- Most people with dementia will die **with** it, rather than **from** it