

PALLIATIVE CARE FOR THE PERSON WITH DEMENTIA

GUIDANCE DOCUMENT 5

Pain Assessment and Management



Palliative Care for the Person with Dementia

Guidance Document 5: Pain Assessment and Management

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This is a guidance document provided for information and educational purposes only. It has been designed to assist caregivers of people with dementia by providing an evidence-based framework for decision-making strategies.

This guidance document is not intended as a sole source of guidance for the assessment and management of pain in people with dementia.

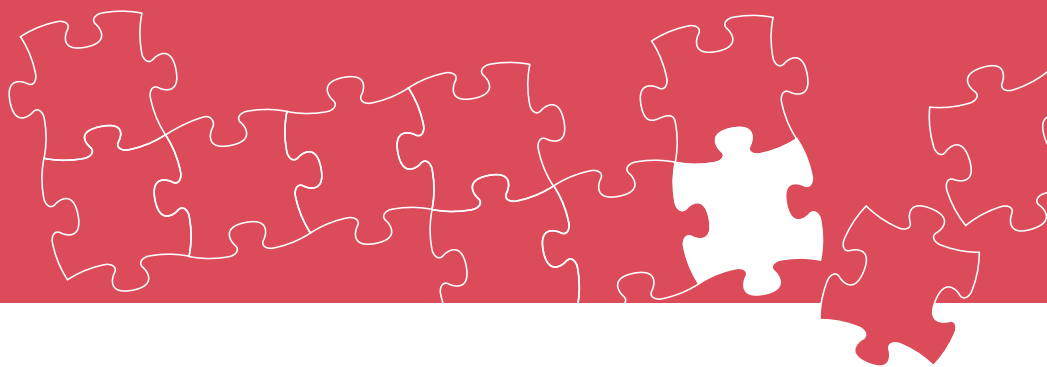
This guidance is not intended to replace clinical judgment or establish a protocol for all individuals with this condition. Guidance documents do not purport to be a legal standard of care. The guidance does not override the individual responsibility of healthcare professionals to make decisions appropriate to the circumstances of individual patients in consultation with the patient and/or family. Adherence to this guidance will not ensure successful patient outcomes in every situation.

The Irish Hospice Foundation, 2016.



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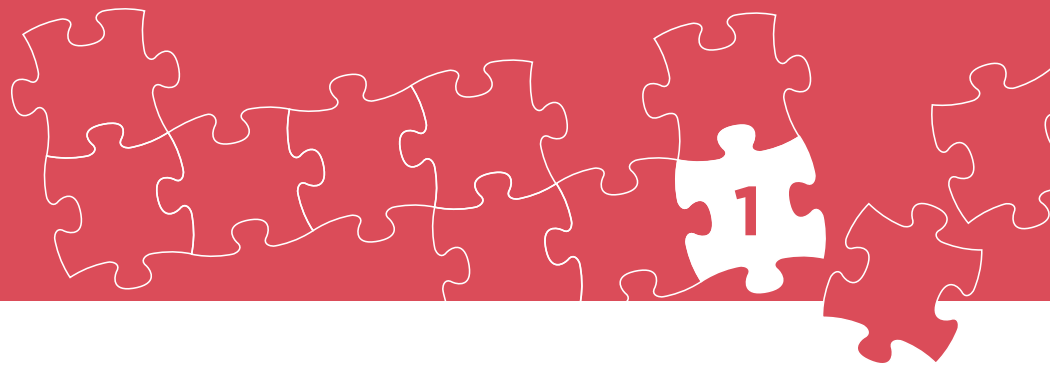
WHAT IS PALLIATIVE CARE?

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

WHO (2016) Definition of Palliative Care <http://www.who.int/cancer/palliative/definition/en/>



BACKGROUND

Dementia is an umbrella term which is used to describe a condition which may be caused by a number of illnesses in which there is progressive decline in multiple areas of function including; decline in memory, reasoning, communication skills and in the ability to carry out daily activities¹. The number of people living with dementia in Ireland today is estimated to be around 48,000 and this number is set to treble by 2045². Dementia is a chronic, life limiting condition³⁻⁵.

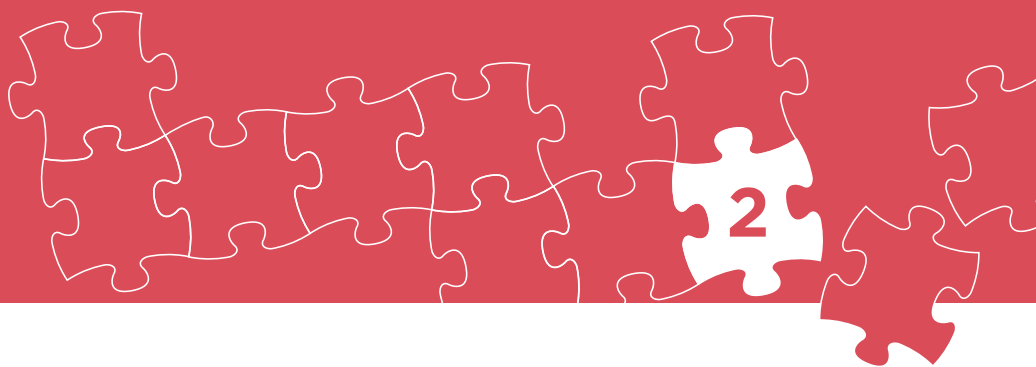
People with dementia have a unique set of care needs which include; a progressive cognitive impairment, diminishing capacity, communication difficulties, possible responsive behaviours and a prolonged illness trajectory leading to uncertainty in relation to prognosis^{1,6}. People dying with and or/from dementia are therefore a particularly vulnerable group who require staff to have knowledge, skills, competence and confidence in both dementia and palliative care⁷. Palliative dementia care involves supporting the person with dementia and their family to address and relieve the pain, distress and discomfort associated with advancing dementia and inviting them to participate in making decisions about future care needs⁸. Providing this care and comfort presents services with a significant challenge as each person's journey through dementia is unique with huge variability in the length of the final phase, difficulties in communication and a lack of awareness about the terminal nature of dementia^{5,9}. This is often compounded by staff lacking basic knowledge, awareness and skills in supporting people with dementia^{1,4}. It is recommended that palliative care principles are introduced in the person's care early on, ideally soon after diagnosis when the person can meaningfully engage in discussions about their future care^{3,8,9}.

As illustrated, there has been growing recognition of the complexities involved in providing end-of-life care for people with dementia in the literature; however, there is a notable void of guidance documents to support healthcare staff in delivering excellence in end-of-life care for people with dementia. In order to support staff in meeting the palliative care needs of people with dementia, there was a call for the development of guidance documents for the Irish context^{8,10,11,12}.

Through the Irish Hospice Foundation's Changing Minds Project, the following guidance documents have been developed.

1. Facilitating discussions about end-of-life care with the person with dementia
2. Advance healthcare directives and advance care planning
3. Loss and grief in dementia
4. Hydration and nutrition
5. Pain assessment and management
6. Ethical decision-making
7. Medication management

Irish Hospice Foundation (IHF) have taken the lead for the development of guidance documents 1 – 3 with assistance from relevant experts. University College Cork (UCC) successfully tendered for the development of the guidance documents 4-7. The steering group and project team overseeing the development of this guidance document are listed in Appendix 1.



INTRODUCTION TO THIS GUIDANCE DOCUMENT


The literature highlights pain as one of the most problematic symptoms for people with dementia – particularly at the end of life.

Central to the philosophy of palliative care is effective pain management, working within the concept of ‘total pain’ as being physical, psychological, social and spiritual.

It is estimated that approximately 86% of people with dementia in Ireland are over 70 years old¹³ and this is a population within which the detection of pain is particularly challenging, since some people may believe that pain is an inevitable aspect of aging or may not self-report for fear of admission of frailty and subsequent institutionalisation¹⁴. Coupled with a diagnosis of dementia, the situation becomes increasingly more difficult particularly due to difficulties with communication as dementia advances, and there is considerable evidence to suggest that the pain experience can be extremely challenging for people living with dementia and many variables e.g. depression, fatigue and agitation can influence responses¹⁵. People with dementia experience pain just as much as anyone else. Uncontrolled pain can seriously affect a person’s quality of life.

Central to the philosophy of palliative care is effective pain management, working within the concept of ‘total pain’ as being physical, psychological, social and spiritual¹⁶. As dementia advances, the manner by which a person communicates pain can change. Pain may be expressed in lots of different ways (e.g. nonverbally – grimacing, frowning, vocalisations, body language, being distressed/ crying/ behaviour changes like not eating, being unusually quiet, not wanting to do things they would ordinarily do through to being agitated and responsive behaviours). Healthcare staff need to be aware of this, together with their communication style and adapt it accordingly (see Guidance Document 1 for more details).

It is vital that pain is measured as accurately as possible. The consequences of untreated pain include depression, fatigue, anxiety, social withdrawal, and increased use of health services¹⁷ that can subsequently impact on quality of life and may present as responsive behaviour. Pain is associated with agitation and when pain as a cause of such behaviour goes unrecognised, it can result in a person being prescribed sedatives or neuroleptics inappropriately or receiving some level of restraint (chemical or physical). Recognition of pain is therefore important, however, deficits in the assessment and management of pain in people with dementia are well documented^{18,19,20}. For example, in an acute setting, a randomised controlled trial²¹ found that 76% of people with dementia did not receive regular post-operative pain relief following surgery for an associated hip fracture. Furthermore, they only received one third of the pain relief offered to the cognitively intact older adults in the study. Evidence suggests that responsive pain management given post operatively can reduce patient confusion in the ward setting, reduce recovery time and reduce the demand on nurses²². In the community, the prevalence of chronic pain has been estimated to vary between 20% and 50% among older adults²³ and is reported to range up to 40–80% among older adults residing in long-term care facilities²⁴. Pain in the latter group is often undiagnosed or undertreated, as a result of the person’s



inability to self-report because of dementia²⁵. A study by Thune-Boyle²⁶ highlighted how people with dementia are less likely to receive prescribed analgesics than cognitively intact people and that carers did not perceive a person with dementia to have underlying physical problems despite, in one case a person having urinary tract infection, arthritis and pressure sores²⁶. Undiagnosed and untreated pain can manifest in responsive behaviours that affect the person with dementia and people around them and can result in further cognitive impairment²⁰.

Existing guidance documents for the assessment and management of pain for people with dementia within a palliative care framework are limited and the majority of those that exist lack rigour when evaluated using the Appraisal of Guidelines for Research and Evaluation (AGREE) instrument²⁷. The aim of this guidance document is to provide caregivers of people with dementia with evidence-based information and guidance to support the assessment and management of pain.

Scope of guidance document

This guidance document will:

1. List the principles that govern good pain assessment and management.
2. Provide guidance on: (a) recognising pain in dementia; (b) pain assessment in mild through to severe dementia; (c) developing a pain management care plan and (d) when and who to refer for specialist assessment and management.

Due to the extent and type of evidence currently available, limited inferences can be made in relation to assessment and management of pain and therefore recommendations presented in this document should be considered in tandem with the circumstances of the individual person and in consultation with the person and/or family and healthcare practitioner.

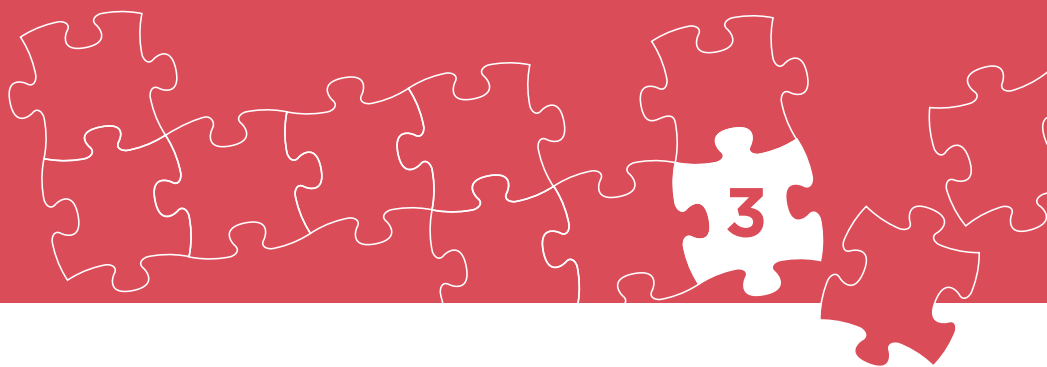
Development of guidance document

This guidance document was developed by a project team and overseen by a steering committee (please see Appendix 1 for membership of both groups) using the process below.

1. Completion of scoping review (see Appendix 2).
2. Collation of key review themes to inform the guidance and principles of pain assessment and management.
3. Preparation of Draft 1 of guidance document for comment by the project steering committee and national/international experts in the field.
4. Preparation of Draft 2 for external consultation.
5. Assimilation of feedback from external consultation to final draft.
6. Final version published.

Structure of guidance document

The guidance provided in this document focuses on four key areas, based on the agreed key themes emerging from the scoping review considered most beneficial for caregivers. These areas are examined in detail in the following sections, together with the overarching assumptions, rights and values that guide ethical decision-making. Where applicable, we have signposted available resources and tools.



THEMES FROM THE LITERATURE REVIEW

Dementia palliative care reflects the qualities of both holistic, multidisciplinary focused dementia care and palliative care. Both models adhere to a set of underlying principles focusing on quality of life, whole person care, respecting autonomy and caring for both the person and their family⁴. These are the core values that underpin and inform this series of guidance documents in order to support people with dementia to live well and die with dignity. The need to support a person with dementia to plan their future care early in the trajectory of their condition has been well documented^{3,4,28,29,30}.

A scoping study (see Appendix 2) was undertaken to inform the development of this specific guidance document. The review of literature yielded a number of themes:

Literature review themes

1. The challenge of pain assessment and management for people with dementia
2. Existing guidance regarding pain assessment and management in this population
3. Pain management in long-term care settings
4. Assessment and management of pain in mild to moderate dementia
5. Assessment and management of pain in moderate to severe dementia

The key themes were presented to the project team. These themes were grouped into four overarching principles to guide optimal pain assessment and management in dementia palliative care (Figure 1) and four areas of specific guidance considered key to informing good practice around pain and dementia.

Four areas for guidance

1. **Recognising pain in dementia**
2. **Pain assessment in mild through to severe dementia**
3. **Developing a pain management plan**
4. **Referral to specialist services**





OVERARCHING PRINCIPLES TO INFORM GOOD PRACTICE

A common set of four overarching principles for optimal assessment and management of pain for people with dementia have been agreed by the project team and these will underpin the previously identified four areas for guidance;

1. Recognition and accurate assessment and regular assessment of pain is vital. People with dementia experience pain just as much as anyone else. Uncontrolled pain can seriously affect a person's quality of life. A systematic approach to assessment is required – this includes the examination of physiological, behavioural and body language changes³¹ and developing an understanding regarding how the person with dementia usually communicates their pain. There are several categories of pain:

- Nociceptive (e.g. from an injury such as post-operative pain, osteoarthritis pain, soft tissue injury from a fall)
- Neuropathic (e.g. peripheral neuropathy, carpal tunnel syndrome, post stroke central pain)
- Mixed (i.e. a combination of both neuropathic & nociceptive pain symptoms)
- Autonomic symptoms (colour and temperature changes, sweating, trophic changes)

Chronic Pain Ireland (2014)³²

Ongoing reassessment is central to a palliative approach to the care of a person with dementia.

2. A person centered approach from diagnosis to death to support the quality of life of people with dementia should be adopted³⁴. This approach should extend to the proper assessment and management of pain. A person centered approach should emphasise the following³³⁻³⁵

- the human value of people with dementia, regardless of age or cognitive impairment, and those who care for them
- the individuality of people with dementia, with their unique personality and life experiences
- the importance of the perspective of the person with dementia
- the importance of relationships and interactions with others to the person with dementia, and their potential for promoting well-being
- the needs of carers and how they may be supported.

3. Effective 'total pain' planning and management is crucial. 'Total pain' includes the physical, psychological, social and spiritual¹⁶. In addition to using the pain ladder for pharmacological treatment of physical pain, consider other sources of pain and support. For example, if a person has unresolved emotional issues, encourage the person to express their concerns or refer to a social worker, clinical psychologist, family therapist, minister/religious person or pastoral care. If the person is experiencing social pain, consider the quality and depth of relationships and how this may help or hinder pain. Consider spiritual pain and address issues such as fear of the unknown, concerns about the meaning of life referring to pastoral care as appropriate.

4. The primary caregiver can provide valuable information to aid the assessment and management of pain in people with a diagnosis of dementia. It is important to recognise that there may be more than one primary caregiver and reports from non clinical staff are important to obtain, since they may spend significant time with a person with dementia.

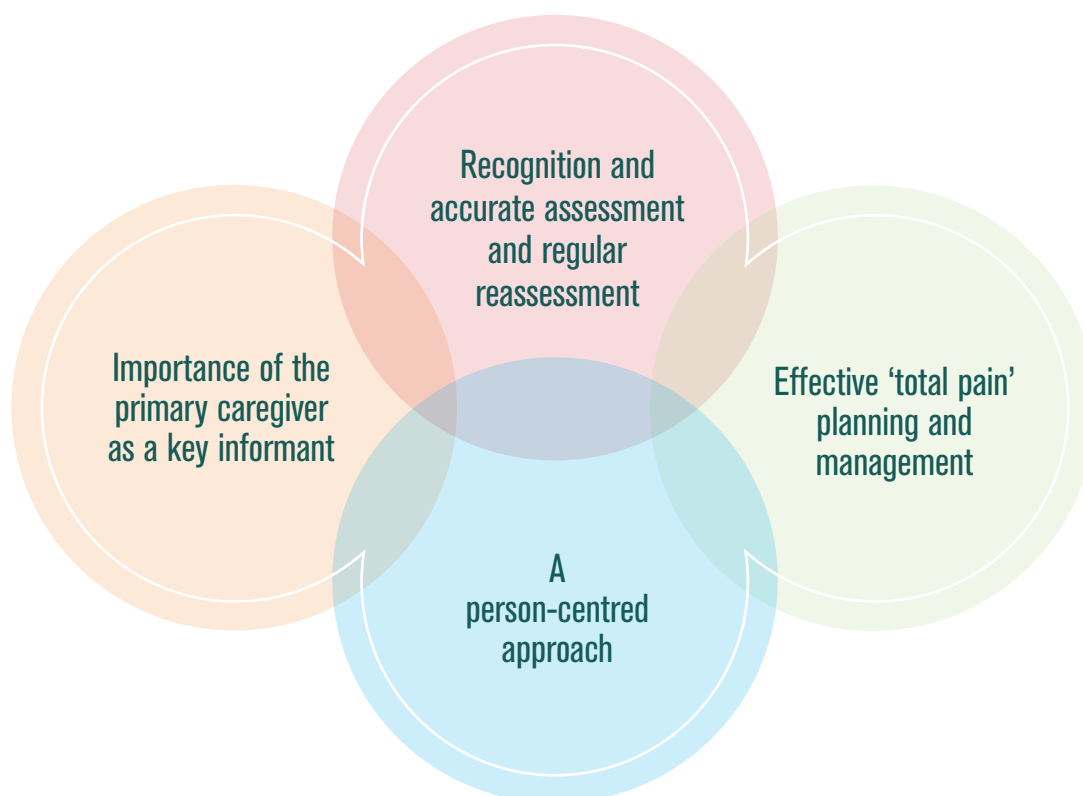
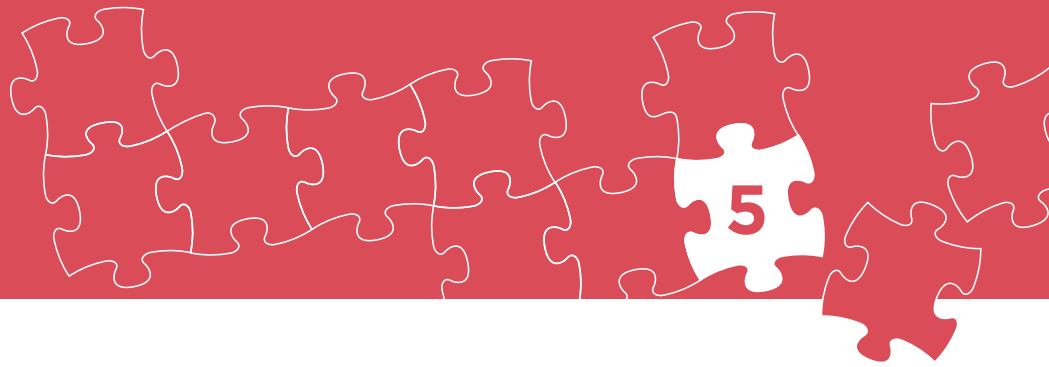


Figure 1: Four overarching principles to assessment and management of pain in dementia palliative care.



GUIDANCE AND RESOURCES

The four areas that caregivers of people with dementia would benefit from guidance with regard to pain assessment and management are introduced below and are outlined in further detail in four subsequent sections of this document. These are as follows:

1. Recognising pain in dementia

The first step in effectively managing pain in the person with dementia is recognising that pain may exist. This is often a lengthy observation process and involves knowing the person, their history and associated condition(s). Sometimes eliminating other causes or alternative explanations of behavioural change, emotional disturbance, reduced mobility, sleep disturbance, and loss of appetite can assist in determining the probability that pain is present.

2. Pain assessment in mild through to severe dementia

Pain assessment is complex and this is made even more difficult when a person has communication difficulties. Pain is what the person themselves describe it as and exists at the level of intensity at which it is perceived. This basic definition³⁶ of the existence and severity of pain is overshadowed if a person cannot describe either presence or process. There are however many tools, based on both observation of behaviour and self-report, that have been developed to assist both lay and healthcare professionals when assessing pain in the person with dementia. Decision-making regarding tool selection is dependent on the severity of dementia, and in certain instances the care context. This type of assessment combined with physical examination and accurate pain history underpins good principles of pain assessment.

3. Developing a pain management care plan

Accurate assessment of cause, type, location and intensity can significantly improve the development of an effective pain management care plan. Pain management care plans can be developed and used by lay carers in the community and escalated in level of complexity to take into account the type of medication and care context. Care plans enable: (a) good information flow between lay and healthcare professionals; (b) the observation of tracking and trending of pain behaviours; and (c) accurate presentation of the effectiveness of an analgesic trial or non-pharmacological pain management strategies. It is important that care plans are based on patient and family goals and expectations of care and are underpinned by a person-centred perspective.

4. Referral to specialist services

Sometimes, despite a comprehensive assessment and management plan, the person with dementia continues to complain of pain or display behaviours consistent with the presence of pain. It is necessary in certain circumstances to refer a person for specialist assessment and treatment (e.g. to specialist palliative care team, psychiatry, pain specialist, physiotherapy). Knowing when and where to refer, is extremely important.

5.1 Guidance Area 1:

Recognising pain in dementia

Recognising physical pain in a person with dementia can be challenging. Pain is a significant and sometimes lone indicator of physical problems, therefore caregivers need to become alert to behavioural changes that may signal pain³⁷. Considerable skill is necessary to interpret the meaning of these behaviours and to recognise expressions of pain. Reports from people who know the person well can help health professionals detect changes in behaviour that may indicate the presence of pain³⁸. Persons with cognitive impairment or dementia often have lost or impaired ability to verbally communicate pain and descriptions of pain may differ. In fact the word 'pain' may not be used³⁹. Therefore caregivers should listen for alternative words used such as *aching, hurting, soreness or burning*. The impact of dementia on communication abilities varies greatly from one person to another however it is the responsibility of health professionals to facilitate communication⁴⁰. **Please also consult the IHF guidance document number 1 on communicating with a person with dementia.**

The American Medical Directors Association (AMDA)⁴¹ recommends older patients with dementia should be evaluated for pain during periodic scheduled assessments, and whenever a change occurs in his or her condition (e.g. after a fall or other trauma or when a change occurs in the patient's behaviour, daily routines, or mental status).

If a person with dementia has unexplained changes in behaviour and/or shows signs of distress, an assessment should be conducted, preferably using an observational pain assessment tool. However, the possibility of other causes should also be considered. The AMDA (2012)⁴¹ and the American Geriatric Society (2002)⁴² both concur with the following nonspecific / behavioural signs and symptoms that may suggest the presence of pain:

Facial Expression: Frown, sad, frightened face, closed tightened eyes, any distorted expression, rapid blinking.

Vocalisation: moaning, groaning, calling out, chanting, sighing, verbally abusive, asking for help, breathing heavily.

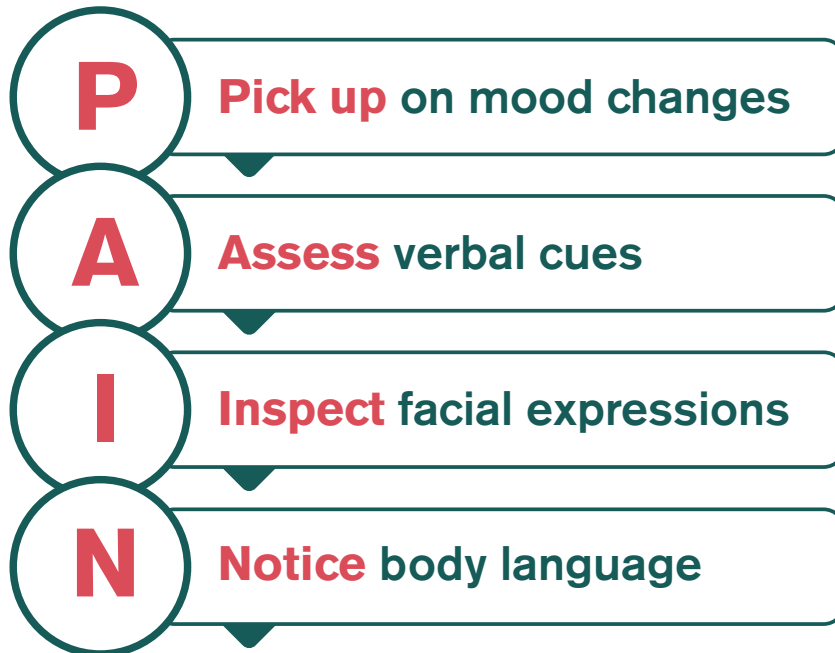
Body movements: rigidity, tense, guarding, fidgeting, pacing or rocking, restricted movement, gait or mobility changes.

Changes in interpersonal interaction: Resisting care; decreased social interaction, socially inappropriate interaction, withdrawal.

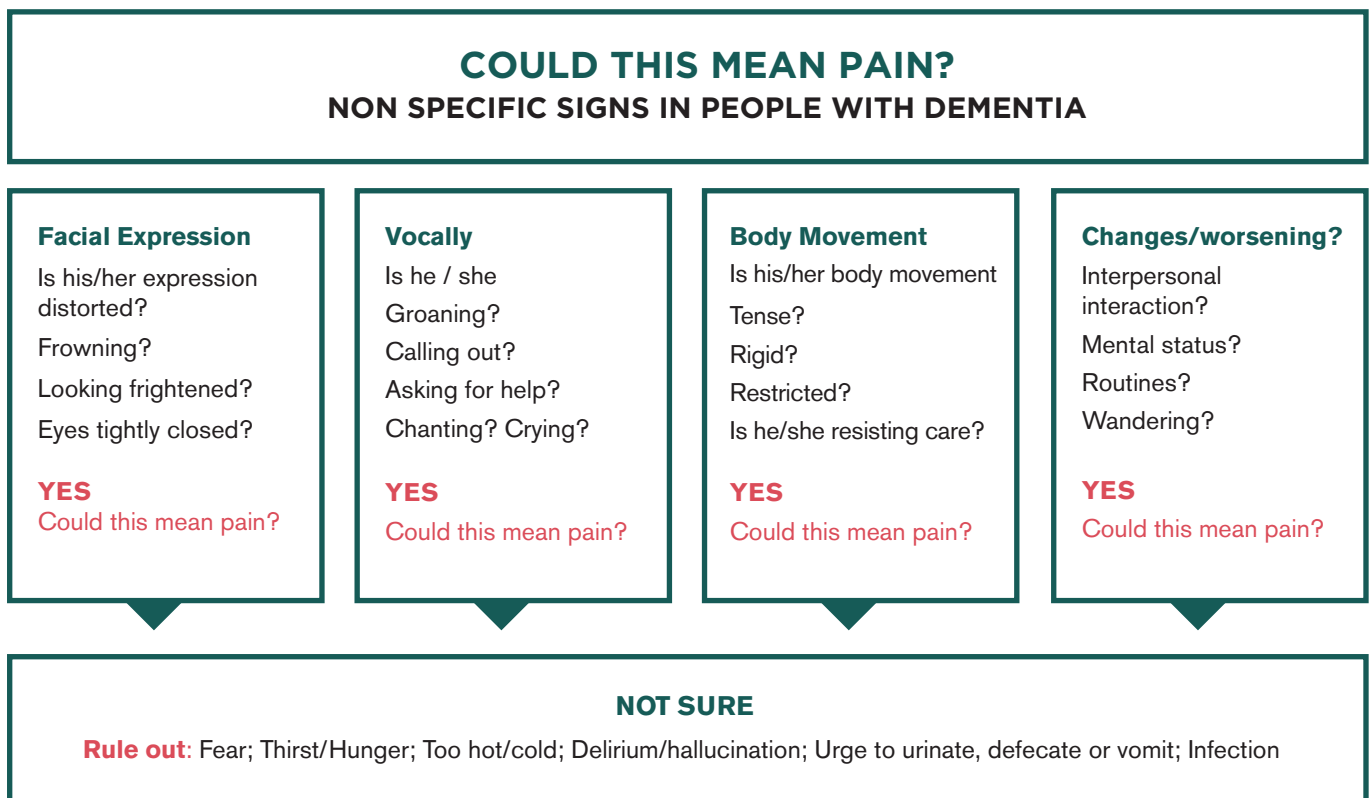
Changes in activity patterns / routines: Refusing food, appetite changes, changes in sleep patterns, increased rest periods, sudden cessation of common routines, and increased wandering.

Changes in mental status: Crying, increased confusion, irritability or distress.

A simple PAIN mnemonic⁴³ to assist caregivers to recognise and identify that pain might be present



The following decision tree is useful for recognising pain



Resources for Healthcare Professionals

1. Registered Nurses' Association of Ontario (2013). Assessment And Management Of Pain³⁹

This nursing best practice guideline is a comprehensive document, providing resources for evidence-based nursing practice and should be considered a tool or template, intended to enhance decision-making for individualised care.

See: <https://www.painbc.ca/sites/default/files/events/materials/RNAO-AssessAndManagementOfPain2014.pdf>

2. Communication Difficulties: Assessment And Interventions In Hospitalised Older Adults With Dementia

Tools to assess language deficits and facilitate communication are outlined here:

Zembruski⁴⁰ Communication Difficulties: Assessment and Interventions in Hospitalised Older Adults with Dementia. Best Practices in Nursing Care to Older Adults with Dementia. The Hartford Institute for Geriatric Nursing. www.hartfordign.org

3. Nice Guidelines [Cg42]⁴⁴

The advice in the NICE–SCIE guideline covers:

- What support and treatment people with dementia can expect to be offered, including drugs and other therapies.
- The services that are available to help people with dementia, including health and social care services (UK based).
- How families and carers may be able to support people with dementia and get support for themselves.

There is specific guidance on pain management. See

NICE guidelines [CG42] Published date: November 2006 : Dementia: Supporting people with dementia and their carers in health and social care

<https://www.nice.org.uk/guidance/cg42/chapter/1-Guidance>

Resources for People with Dementia / Family Caregivers

1. Online Resources for Caregivers

Alberta Caregiver College[®] is a virtual college dedicated to providing courses to enhance the knowledge and skills of caregivers to provide for their family member. The educational programs were developed by the Glenrose Rehabilitation Hospital, Alberta Health Services, with contributions from other partnering organizations in Alberta. The individuals who developed the programs are educators and professionals in rehabilitation and geriatrics and include dietitians, nurses, occupational therapists, physical therapists, physicians, psychologists, social workers, and speech language pathologists. Courses are free online.

See: *Support for Caregivers of Older Adults: Pain and Dementia Alberta Caregiver College⁴⁵*

2. Assessment of Pain by Caregivers

- a. Developed by a pharmaceutical company, this site provides useful assessment strategies for family caregivers of people with dementia.

See: *PartnersAgainstPain.com Assessing Pain in Loved Ones with Dementia*⁴⁶
<http://www.partnersagainstpain.com/pain-caregiver/assessment-dementia.aspx>

- b. The PAINAD scale can help caregivers identify pain in loved ones with advanced dementia

See *Health Guide May 25, 2011*⁴⁷
<http://www.healthcentral.com/alzheimers/c/42/138903/painad-caregivers/>

3. See Change: Think Pain Campaign⁴³

Short awareness video developed in association with NAPP pharmaceuticals.

<https://www.youtube.com/watch?v=zVWrem26uHg>

NAPP pain website provides tips in identifying pain in people with dementia.

<http://www.paincentrenapp.co.uk/pain-in-dementia/>

4. Leaflets for Family Caregivers

- a. Useful handouts for family caregivers have been developed by the Australian National Dementia Support Programme.

See: *Fightdementia.org.au/.../Helpsheet-DementiaQandA16 PAIN AND DEMENTIA*
https://fightdementia.org.au/sites/default/files/helpsheets/Helpsheet-DementiaQandA16-PainAndDementia_english.pdf

- b. The Foundation for Health in Aging has developed a useful leaflet regarding the assessment and treatment of pain for people with dementia, aimed at family caregivers.

See: *Pain in Dementia: Family and Caregivers Guide to Assessment and Treatment*
<http://www.geriatricpain.org/Content/Education/Patient/Documents/Pain%20in%20Dementia.pdf>

5. Real Life Experience

A family caregiver describes her experience watching her father living with pain and discusses the importance of pain assessment and management for people with dementia.

See: *Family Caregiver Alliance: Dementia and Pain Management: A Personal Story*
<https://caregiver.org/dementia-and-pain-management-personal-story>

Other Resources

In 2012 the National Council for Palliative Care developed guidance document to help carers recognise pain in people with dementia. See

http://www.ncpc.org.uk/sites/default/files/How_Would_I_know.pdf

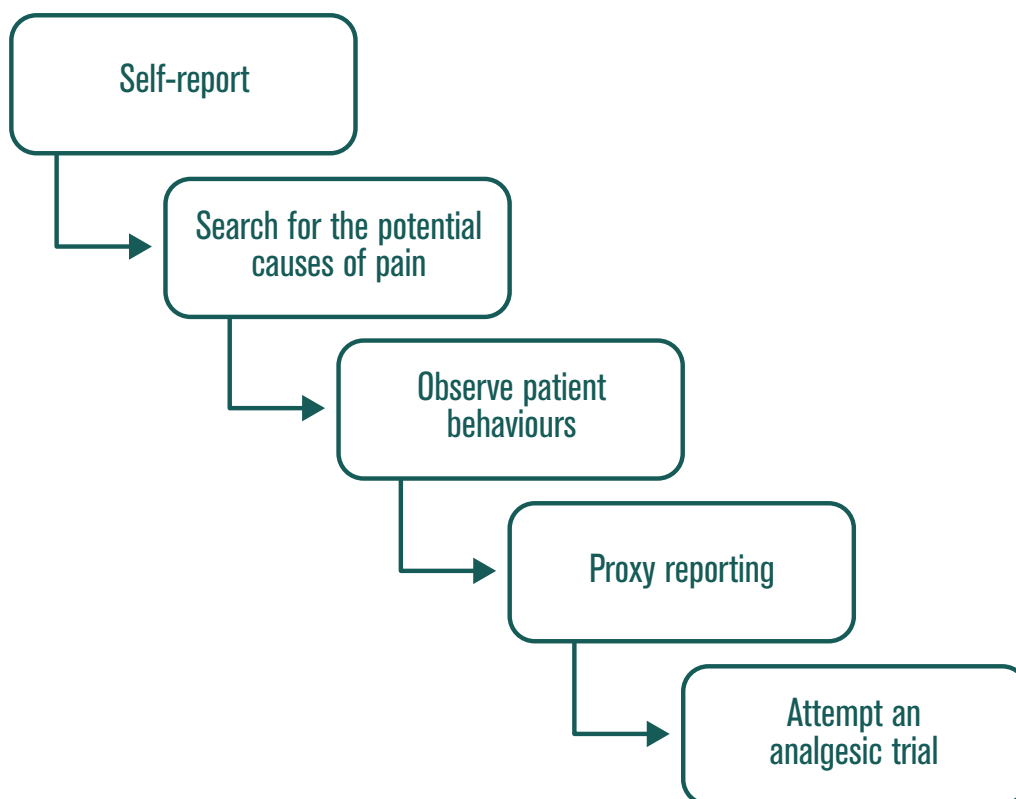
5.2 Guidance Area 2:

Pain assessment in mild through to severe dementia

Best practice suggests that the possible presence of pain should be regularly assessed by those providing direct care in order to alleviate needless suffering for people with a cognitive impairment. Assessment should consider all the causes of pain – physical, psychological, social and spiritual.

As a multi-dimensional subjective experience, there is no universal test for pain.⁴⁸ It is considered to be '*whatever the patient says it is*'⁴⁹. Whilst in principle this is an excellent guide to understanding the person's lived experience of pain and is at the heart of a person-centred perspective to care, it is important to recognise that there may come a time in the course of dementia when the person can no longer describe their pain verbally, or may not wish to, and therefore alternative strategies to verbal assessment strategies must be considered^{50,51}. A hierarchy of Pain Assessment Techniques for people unable to reliably self-report is indicated below³⁸ and described in more detail overleaf.

Hierarchy of pain assessment techniques for people with dementia (adapted from Herr et al.³⁸).



Source: Pasero, C., & McCaffery, M. (2011).
Pain assessment and pharmacologic management. St. Louis: Mosby.

The observation of people with dementia is central to the framework of assessment and the established indicators of pain have been outlined in Section 5.1. However, in a person with dementia, these indicators may have other causes, including the illness itself. Therefore, as with the assessment and management of all people presenting with pain, a systematic approach to assessment and care planning is required – this includes the examination of physiological, behavioural and body language changes³¹ and developing an understanding regarding how the person with dementia usually communicates their pain. The **OLD CARTS** mnemonic can be applied to assess pain further by lay carers and healthcare professionals – this is described in Case Study 1.

Guidance – Pain assessment in mild to severe dementia

- **Staff should gather a comprehensive pain history from the person with dementia, family and other healthcare professionals who have treated the person in the past.**
- **Self-report from the person with dementia should be sought regardless of level of dementia.**
- **Observation for pain behaviours and surrogate reporting should complement any attempts of self-report.**
- **Use pain assessment tools that are selected based on the person's needs and communication level, not on what is easily accessible.**



Case Studies

Two case studies are presented. The first demonstrates how the 'OLD CARTS' mnemonic can be used by lay carers to develop a pain picture in a person with suspected pain. The second case study applies the American Society for Pain Management Nursing Hierarchy of Assessment Techniques to a case of a person with dementia in long-term care and demonstrates how healthcare professionals could apply this systematic approach.





CASE STUDY 1 | **TIMMY**

Timmy was diagnosed with mild dementia 12 months ago. He lives with his son and daughter in-law. He needs assistance with some activities of daily living. Lately his son has noticed that his father does not appear rested in the morning and suspects that his sleep is disturbed. His daughter in-law has also noticed that he is not walking around the garden as much and when he does she can see him rubbing his knee periodically. The family suspect Timmy is in pain.

The **OLD CARTS** mnemonic can be applied to assess pain further. Documenting the answers to the following questions, together with observation over a period of time will help to build a very good picture and assist when creating a management plan for Timmy.

- O** Onset: Timmy when did your pain start?
- L** Location: Where is your pain, is it in your knee?
- D** Duration: Is it there all the time or only when you walk?
- C** Characteristics: When the pain is there, can you describe what it feels like? Is it sharp, dull, aching....

- A** Aggravating factors: What makes the pain worse?
- R** Relieving factors: What makes the pain better?
- T** Treatment: What medications or non-medication treatments (hot/cold packs etc) ease the pain?
- S:** Severity: How severe is the pain?

Source of OLD CARTS mnemonic: Seidel HM, Ball JW, Dains JE, Benedict GW. Mosby's Guide to Physical Examination (6th Ed). Mosby: St Louis, 2003.



CASE STUDY 2 | DEIRDRE

Deirdre is a resident of Woodlands nursing home. She was diagnosed with dementia a number of years ago. Her husband of 40 years visits regularly. She needs assistance with all aspects of daily living. Care staff have reported that when they are repositioning Deirdre or assisting her to mobilise she becomes aggressive and can sometimes moan. Sometimes she calls out and it is often difficult to reassure her. There has also been a recent change in her appetite. Deirdre can respond consistently to certain questions.

Applying the **Hierarchy of Pain Assessment Techniques systematically** can help staff to establish if Deirdre has physical pain, what may be causing it and determine if her recent behaviour is resulting from a worsening in her illness, or in fact represents pain behaviours.

1. A **self-report** is requested from Deirdre using plain, simple language. Example; Do you have pain? Other descriptors might be used such as *discomfort* or *soreness*. This question may need to be repeated up to 3 times.
2. It is important to search for a **cause**. Does Deirdre have a history of falls, fracture, or arthritis. Is she constipated? Is there any history of shingles, diabetes, cancer?
3. **Observe** the person's behaviours. It is clear that Deirdre is displaying pain behaviours – calling out, aggression, moaning on movement, loss of appetite. The use of a **behavioural pain assessment tool** is recommended. This will enable accurate recording over time and assist in determining if pain treatments are effective.
4. Elicit **surrogate reporting**. Ask Deirdre's husband if he thinks she is in pain. If he thinks she is, try to develop an understanding of the cues he has noticed, document these and incorporate into future assessment.
5. **Attempt an analgesic trial**. Develop a pain care plan for Deirdre that includes the introduction of analgesics. Start low and go slow. Conduct (at a minimum) daily pain assessments to determine if there is a change in behaviours and/or pain report. Consider complementing this trial with non-pharmacological methods, for example, massage.

Pain Assessment Tools

Mild Dementia: Assessment of Pain

Self-Reporting

The gold standard for pain assessment is self-reporting¹⁸. Where a person living with mild dementia is able to respond verbally, then the detection and assessment of current pain is similar to any other person presenting with pain. It is important to ask the person about their pain³¹. People with cognitive impairment have been shown to rate pain reliably and validly⁵², however due to memory difficulties, they may find presenting a history of pain challenging.

Before assessing any person with dementia for pain it is important to⁵¹:

- Avoid overly stimulating the person
- Eliminate distractions
- Ensure good lighting

Standardised assessment tools, comprising of specific, focused questions are recommended for use with people with mild dementia. To measure pain intensity and pain affect, numerous self-report pain rating scales are available, i.e. Visual Analogue Scales (VASs; horizontal or vertical), the Verbal Descriptor Scale (VDS)⁵³, the Numeric Rating Scale (0)⁵⁴, the Faces Pain Scale (FPS)⁵⁵, the Color Pain Assessment Scale⁵⁶ and the Pain Thermometer⁵⁷. Other self-report pain scales include the Functional Pain Scale⁵⁸, the Present Pain Intensity⁵⁹ and the Global Pain Assessment⁶⁰.

The ability to indicate pain by self-report rating scales obviously depends on the cognitive functioning of the person with dementia, and some types of dementia may affect language more or less than others (eg. one person may have very poor understanding of speech, but still be able to choose the appropriate “pain face”, another may find a verbal scale easiest). Whilst pain intensity and visual analogue scales may be useful, some may find it difficult to distinguish between the levels, depending on their degree of cognitive impairment. Some of the most common ones are described in Appendix 3.

The literature supports the use of NRS and VDs for assessment of pain in older adults even with mild to moderate cognitive impairment, however, generally in Western culture, scales using faces may depict mood amongst the older population, so may not give a true reading. The VAS has been considered too conceptually challenging for older people to complete. Poor completion rates have been noted when complex instruments are utilised⁶¹. Therefore, when asking a person with dementia to self-report the following tips should be applied:

- Ask questions simply
- Pain is such an abstract concept, older adults may not be able to understand if you ask “Do you have pain?” and this can be confounded if there is cognitive impairment. When asking a person with dementia about pain, it is important to ask the question in difference formats – for example “Are you sore?” and “Does it hurt?”
- Use large print cards to enable the person to select their answer
- Consider using images to assist people to make their selection
- Where a tool has been used effectively to assess a patient, it should be reused subsequently to maintain consistency.

Moderate to Severe Dementia: Assessment Pain

As a person’s dementia increases in severity, they may need more time to answer questions and it may not be possible, due to the person’s memory problems, to assess pain history reliably. Evidence suggests that it can be difficult for carers and staff to gauge the point of loss of ability to self-report⁶². However, there is evidence that self-reporting of pain at a more advanced stage of dementia may still be possible⁶³, so it is important to continue to ask the person about their pain.

A combination of the use of *observational scales* and *self-report* measures may prove useful to detect the presence of pain in people with moderate dementia.

Several assessment tools have been developed for people with cognitive impairment or who are unable to communicate their pain symptoms. Examples include the Pain Assessment for the Dementing Elderly (PADE)⁶⁴, DOLOPLUS 2⁶⁵, the Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC)⁶⁶, the Abbey pain scale¹⁵, the Nursing Assistant-Administered Pain Assessment instrument for use in dementia (NOPPAIN)⁶⁷, and the Checklist of Nonverbal Pain Indicators (CNPI)⁶⁸.

TIP:

Consider other sources of physical pain like positioning, pressure areas, poor dentition, pain related to instrumentation (catheter), painful skin rashes, abdominal pain, and infections etc.

Observational Scale	Method	Scoring System
Abbey Pain Scale (6 indicators)	Vocalisation Facial expression Change in language Change in behaviour Physiological response Physical response	Rate each indicator (1-6) and sum total.
Dementia Scale – dementia of Alzheimer’s type (9 indicators)	Noisy breathing Negative vocalisation Content facial expression Sad facial expression Frightened Frown Relaxed body language Tense body language Fidgeting	Identify presence or absence of indicators Observe duration, frequency and intensity.
Checklist of non-verbal pain indicators	Non verbalisation Facial grimacing Wincing Bracing Rubbing Restlessness Vocal	Score 1 if present on rest, 1 if present on movement. 0 if absent.
Non communicative patients with pain assessment instrument	Nursing tool for activities involved in daily care	Works on presence or absence of pain assessing intensity in accordance to varying behaviour.
Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC)	Caregivers tool for pain assessment based on changes in: <ul style="list-style-type: none"> • Facial expression • Activity and body movement • Social activity • Personality or mood 	Checklist to document pain behaviours.
DOLOPLUS-2	Assessment of multidimensional pain using: Somatic indicators Psychometric indicators Psychosocial indicators.	Score 0-3 on each subject.
PAINAD	Observation of the person for 3-5 minutes during activity/with movement (such as bathing, turning, transferring)	Select the score (0, 1, 2) that reflects the current state of the behavior. Add the score for each item to achieve a total score. Total scores range from 0 to 10 (based on a scale of 0 to 2 for five items), with a higher score suggesting more severe pain (0 = “no pain” to 10 = “severe pain”). After each use, compare the total score to the previous score received. An increased score suggests an increase in pain, while a lower score suggests pain is decreased.

Table 1: Assessment tools for people with moderate – severe dementia.

Deciding on which tool to use can be difficult for healthcare professionals. The following basic decision aid can be applied:

Pain Tools	Level of Cognitive Impairment			
	None	Mild	Moderate	Severe
Visual Analogue Scales Thermometer, Colour	✓	✓	✓	✗
Numerical Rating Scales 1-10 Rating	✓	✓	✗	✗
Faces Scale	✓	✓	✗	✗
Behaviour Observation	✗	✗	✓	✓

Table 2: Decision Aid to Select a Pain Assessment Tool Based on Level of Cognitive Impairment. Source: Mary-Lou van der Horst (2008)⁶⁹

Resources for Healthcare Professionals

1. Checklist of Nonverbal Pain Indicators³⁸

The CNPI is a simple and short assessment tool with potential to facilitate nursing staff's alertness regarding pain behaviours in Nursing Home patients and it can be managed by various categories of nursing personnel.

2. Pain Assessment In Advanced Dementia Scale (Painad)⁴⁸

The American Medical Directors Association has endorsed the Pain Assessment in Advanced Dementia Scale (PAINAD) (Warden, Hurley, & Volicer, 2003).

3. Registered Nurses' Association of Ontario (RNAO) Self Directed Study Programme

Assessment and Management of Pain in the Elderly is a self-directed learning package incorporating the recommendations from the RNAO Best Practice guideline, *Assessment and Management of Pain*. The purpose of this learning package is to help nurses to gain the knowledge and skill required to effectively manage the unique challenges inherent in the assessment and management of pain in a long-term care setting. The information in the package covers general concepts related to acute and chronic pain.

See: http://rnao.ca/sites/rnao-ca/files/Assessment_and_Management_of_Pain_in_the_Elderly_-_Learning_Package_for_LTC.pdf

4. Patient Comfort Assessment Guide

Partners Against Pain have developed a number of resources including the patient comfort assessment guide.

See: <http://www.partnersagainstpain.com/printouts/Patient-Comfort-Assessment-Guide.pdf>

5. The Honor Society of Nursing Resource

The Honor Society of Nursing has developed a resource for healthcare professionals providing core principles of pain assessment and recommendations for effective pain management. It includes tools for assessing, documenting and monitoring pain in older adult, together with resources to train staff to screen and assess. Best practice tools for assessing pain behaviour in nonverbal adults are also provided.

See: <http://www.geriatricpain.org/Content/Assessment/Pages/default.aspx>

6. The British Geriatrics and Pain Society Guidelines

The British Geriatrics Society and the British Pain Society in conjunction with the Clinical Standards Department of the Royal College of Physicians have developed a guideline to provide professionals with a set of practical skills to assess pain as the first step towards its effective management.

See Algorithm for assessment of pain in older people <https://www.guidelines.co.uk/rps-bgs-bps/pain-in-older-people>

7. The US Alzheimer's Association Residential Care Guidelines

The US Alzheimer's Association Campaign for Quality Residential Care has developed Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes. This document contains specific recommendations regarding the assessment and management of pain.

See: https://www.alz.org/national/documents/brochure_DCPRphases1n2.pdf

8. A conceptual model of pain assessment

A conceptual model of the pain assessment process in persons with dementia is presented and methods for validating the model within this population are discussed

See: Snow, L et al (2004) *A conceptual model of pain assessment for noncommunicative persons with dementia* *Gerontologist*, 44(6), pp.807-817.

<http://www.scie-socialcareonline.org.uk/a-conceptual-model-of-pain-assessment-for-noncommunicative-persons-with-dementia/r/a1CG0000000GUZJMA4>

9. Disability Distress Assessment Tool (DisDAT)

The DisDAT is intended to help identify distress cues in people who, because of cognitive impairment or physical illness have severely limited communication. It has been designed to document a person's usual content cues, thus enabling distress cues to be identified more clearly. This can help pinpoint pain. The tool can be used by professional and lay caregivers.

See: <http://www.stoswaldsuk.org/how-we-help/we-educate/resources/disdat.aspx>

Resources for People with Dementia / Family Caregivers

1. Observation Factsheet

Pain in Dementia fact sheet developed by the North West Dementia Services provides useful information for family caregivers regarding what information to gather and report when observing for the signs of pain and assessing the effectiveness of treatment.

http://www.pssru.ac.uk/pdf/MCpdfs/Pain_factsheet.pdf

2. Alzheimer's Association-Greater Illinois Chapter Guide for Families

Encouraging Comfort Care: A Guide for Families of People with Dementia Living in Care Facilities was produced by the Alzheimer's Association-Greater Illinois Chapter, as part of a grant project "Palliative Care for Advanced Dementia". The guide is intended for families and other decision-makers of people with dementia who are living in nursing homes and other residential care facilities. providing them with information to promote their relatives comfort, prevent or minimise discomfort.

See:

http://www.alzheimers-illinois.org/pti/downloads/Encouraging%20Comfort%20Care_SINGLE.pdf

3. See change: Think Pain Audit Report

<http://www.paincentrenapp.co.uk/wp-content/uploads/2014/02/FINAL-Independent-Care-Home-Audit-Report.pdf>

3. Partners against pain

Partners Against Pain.com is a pharmaceutical company website and includes information on Assessing Pain in Loved Ones with Dementia. The site provides useful assessment strategies for family caregivers of people with dementia.

See: <http://www.partnersagainstpain.com/pain-caregiver/assessment-dementia.aspx>

4. Australian National Dementia Support Programme

Useful handouts for family caregivers have been developed by the Australian National Dementia Support Programme regarding pain and dementia. The Q&A Style format makes the document easy to read.

See: https://fightdementia.org.au/sites/default/files/helpsheets/Helpsheet-DementiaQandA16-PainAndDementia_english.pdf

5.3 Guidance Area 3:

Developing a pain management care plan

Formal care planning is based on assessment, planning, implementation and evaluation. Effective care plans are evidence-based and should ensure that optimum care is provided and that goals are met in accordance with the person's wishes, in collaboration with family and carers. Care plans should be person-centred⁷⁰ reflecting the individual needs of the person, maximising their choice and ensuring their involvement in care decisions. The person with dementia's right to be involved in decisions regarding their care should be acknowledged in all care plans. Please also refer to Guidance Documents 1,2 and 6 in this series.

People with dementia, experiencing pain require comprehensive, individualised care plans that incorporate personal goals, specify treatments, and address strategies to minimise the pain and its consequences on functioning, sleep, mood, and behaviour⁷¹. The goal for pain management and the best possible outcome is the relief and control of pain.

Care planning is an ongoing inter-disciplinary process that is initiated at the time of admission to a service (community, residential or acute). Care plans demonstrate input from the multidisciplinary team, including:

- Nursing staff
- Person with dementia / Family
- General Practitioners / Medical Team
- Occupational Therapist / Physiotherapist
- Other practitioners (e.g. Palliative care team, social work, pastoral care)

Interventions should be based on identified factors from the pain assessment process, with measurable goals that address the person with dementia's preferences, expectations and needs. The effectiveness of the interventions should be evaluated periodically, and the care plan revised as necessary to reflect changes in the pain assessment.

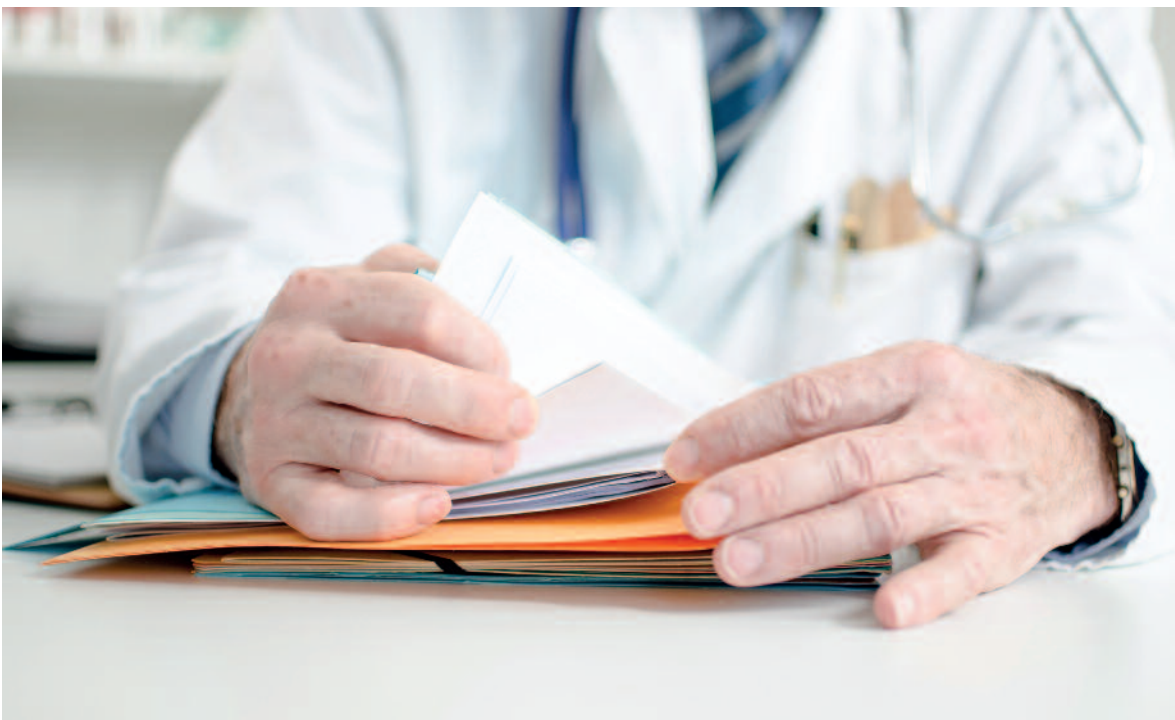
Pain Management Care Plan Guidance

1. Assess: Assess the person with dementia for signs and symptoms of pain. If possible obtain a self-report of pain. If not, ask family and carers to describe their understanding of the person's pain i.e. how it affects their interactions, mobilisation, and behaviour. Obtain a report of whether any activities cause increase in intensity of duration of pain. Ask the person with dementia or family/carers to identify what relieves or exacerbates the pain.

2. Plan: Develop a plan to provide methods of pain relief for the person with dementia. These methods should include both pharmacological and non-pharmacological methods. The plan should address the person or family/carer's identified goals for pain relief.

3. Implement: Implement a pain management plan that incorporates the identified goals. Minimise adverse side effects associated with pharmacological interventions. Educate the person with dementia and family/carer about the pain management strategies chosen. Address any misconceptions and concerns.

4. Evaluate: Reassess the person's response to the prescribed analgesia or the non-pharmacological method of pain relief. Monitor presence and location of pain, intensity and severity of pain and effectiveness of chosen method of pain relief. Gather both self-reports from the person with dementia and observations of family/carers. Report findings or request medical review if no relief obtained.



Resources for Healthcare Professionals

1. Example of a Pain Management Care Plan

Identified Care Need:

Pain (Controlled with analgesia/Uncontrolled)
Specifics (i.e. add suspected or identified reason here):

Goal of Care:

To promote pain relief and comfort
To maximise functional ability
To promote and establish a good quality of life for the person with dementia

Intervention required to achieve goal:

No.	Intervention	Signature
	Conduct individual assessment, using both reported pain and observation of pain.	
	Discuss with the patient and get their understanding of the quality of their pain, in their own words, if able. If patient unable to verbalise pain, discuss with family or carers and get their understanding of pain.	
	Identify any triggers that increase pain.	
	If possible obtain information on the intensity (severity on scale of 1-10) and duration (constant, intermittent).	
	Determine what if anything relieves or exacerbates pain.	
	Develop a plan that incorporates both pharmacological and not pharmacological methods of pain relief.	
	Ensure the patient receives prescribed analgesia at least 30 minutes prior to taking part in any activity that triggers pain.	
	Evaluate the effectiveness of prescribed analgesia and non pharmacological methods of pain relief using both reported evidence of pain relief and observations of family and carers if unable to obtain report from patient.	
	If pain uncontrolled with analgesia request medical review.	

Other examples of care plans are available here:

https://www.northcott.com.au/sites/default/files/Pain%20Management%20Care%20Plan_0.pdf

2. Checklist for developing a pain management care plan

Depending on the local quality system your organisation adheres to, checklists for developing care plans may be available. Information on the requirements in residential and acute services regarding care planning published by HIQA is available from the following links:

HIQA (2015) Guidance on Dementia Care for Designated Centres for Older People⁷²
http://www.hiqa.ie/system/files/Dementia_Care-Guidance.pdf

HIQA (2012) National Standards for Safer Better Healthcare⁷³
<http://www.hiqa.ie/standards/health/safer-better-healthcare>

HIQA (2008) National Standards for Residential Care Settings for Older People in Ireland 2009⁷⁴
<http://www.hiqa.ie/standards/social-care>

A checklist, should be aligned to the Standards and may look something like this produced by the BPG International Affairs & Best Practice Guidelines-RNAO
<http://ltctoolkit.rnao.ca>

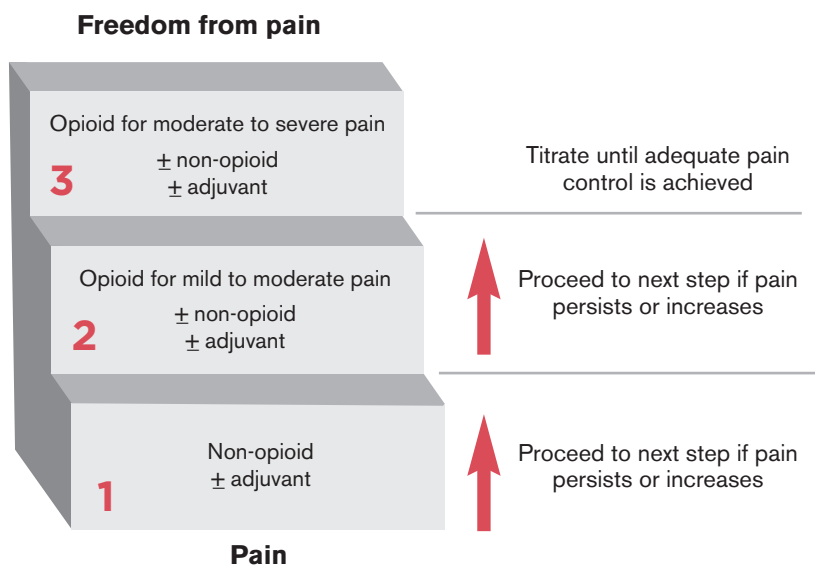


3. Management of Pain

Management of pain should consider all the causes of pain – physical, psychological, social and spiritual. The first steps in the management of physical pain should always be to:

1. Identify the cause of the pain where possible and remedy the cause.
2. Explore the potential role to use non-drug approaches of all kinds, before proceeding to even simple analgesia (Step One of the WHO ladder).
3. Where use of opioids is necessary, the lowest effective dose should be used, increasing the dose slowly and only if necessary to get the desired effect i.e. **Start Low and Go Slow**.
4. Consider referral to the multidisciplinary team.

WHO's Pain Relief Ladder



Where a person is unable to communicate verbally and pain is suspected, it may be appropriate to conduct an analgesic trial to validate the presence of pain using the WHO analgesic ladder and associated principles of titration⁷⁵. Herr et al⁷⁵. suggests starting with paracetamol four times a day (each time 500-1,000 mg) for mild to moderate pain. In the absence of the expected treatment effect, escalation through each step of the WHO ladder may be appropriate. In case of moderate to severe pain, Herr et al⁷⁵. advise beginning the treatment with a low dose of an opioid (codeine, morphine, and oxycodone). Opioids frequently cause constipation and therefore a laxative should be co-prescribed. **Meticulous assessment and re-assessment at each step is necessary. Be sure to monitor the effect of analgesics on the person's ability, since some may cause confusion.**

NSAIDs may be useful for musculoskeletal pain but can cause GI problems and retention of fluid and possible renal impairment. A proton pump inhibitor should be co-prescribed to reduce the risk of severe GI adverse effects⁷⁶.

It is important to identify the cause of pain so that treatment can be tailored to the problem and non-pharmacological treatments explored.

Non-Pharmacological Management of Pain

- Acupuncture, Transcutaneous Electrical Nerve Stimulation (TENS) and massage can reduce pain and anxiety.
- Psychological approaches including guided imagery, biofeedback training, relaxation and Cognitive Behaviour Therapy are also considered useful to reduce pain.
- These can be used with or without pharmacological therapies.



Oral routes of medication administration should be considered first before proceeding to more invasive options such as injections.

If chronic pain is suspected, where appropriate and following full medical assessment and review of the persons medications, it is recommended that analgesia should be prescribed as a 'regular' medication. PRN 'as required' may not be appropriate for a person with communication issues.

Ongoing reassessment of pain is a central feature of a palliative approach to caring for a person with dementia.



Think beyond the physical

Unresolved emotional issues: encourage the person to express their concerns or refer to a social worker, clinical psychologist, family therapist, minister/religious person or pastoral care.

Social pain: consider the quality and depth of relationships and how this may help or hinder pain.

Spiritual pain: address issues such as fear of the unknown, concerns about the meaning of life refer to pastoral care as appropriate

5.4 Guidance Area 4:

Referral to specialist services

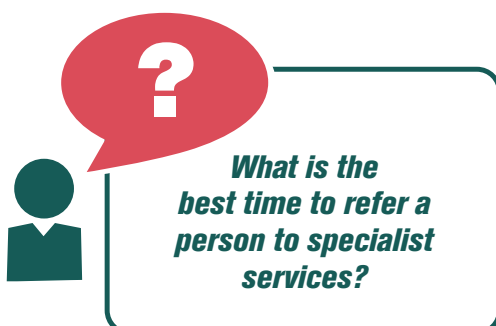
The management of pain in individuals with dementia is complex. Pain is recognised as one of the most problematic symptoms for people with dementia – particularly at the end of life^{70,6}. Effective pain management requires a thorough initial assessment to inform the implementation of pharmacological and non-pharmacological interventions⁷⁵. Subsequently, the effectiveness of the intervention should be assessed and the treatment plan modified to ensure adequate pain management is maintained. However, if pain remains difficult to manage, advice should be sought from specialist services such as the specialist palliative care team. The HSE's Palliative Care Clinical Programme has developed a Needs Assessment Guidance to guide healthcare staff when considering making a referral to a Specialist Palliative Care service⁷⁷.

Guidance – Referral to Specialist Services

- Staff should undertake regular continuous assessment of pain and document their findings.
- Staff should be aware of the specialist services available in their area and the referral processes for these services.
- **Staff should involve the specialist services at the earliest opportunity and especially if there is any concern regarding inadequately managed pain.**
- Staff should understand the importance of liaising closely with specialist services to ensure continued effective pain management.



There are many reasons why a person with dementia might experience pain. The table overleaf outlines the most common causes of pain, the key specialist services available for referral, the role of the clinician and the most appropriate time for referral.

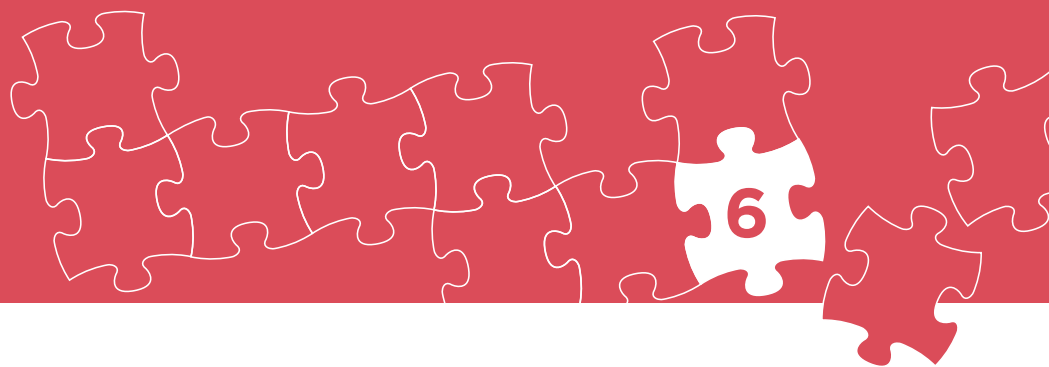


Overview of Services and Referral Pathways

Cause of Pain	Points of Care Contact Clinician:	Initial Referral for Review	Role of Clinician(s)	Relevant Specialist Services
Other morbidities (e.g. arthritis, angina, peripheral vascular disease, cancer etc.)	Residential Care Nurses HCAs Home Helps PHNs	General Practitioner (GP) Public Health Nurse (PHN)	To assess pain, prescribe interventions and make appropriate referrals to specialist services, as necessary. To assess pain, liaise with the GP and make appropriate referrals to specialist services, as necessary.	Specialist for specific morbidity as identified by GP (e.g. Rheumatologist, Cardiologist etc.) Consultant in Pain Medicine Dietician Physiotherapist Occupational Therapist Specialist Palliative Care Team
Pressure sores	Residential Care Nurses HCAs Home Helps PHNs	GP PHN	To assess pain, prescribe interventions and make appropriate referrals to specialist services. To assess pain, perform wound care, liaise with the GP and make appropriate referrals to specialist services.	Consultant in Pain Medicine Wound Care Clinic Dietician Physiotherapist Occupational Therapist
Injuries	Residential Care Nurses HCAs Home Helps PHNs	GP Emergency Department Staff	To assess pain, prescribe interventions and make appropriate referrals to specialist services. To assess pain, implement interventions to treat pain and to treat the underlying cause of pain (e.g. fracture, burn etc.)	Consultant in Pain Medicine Orthopedic Surgeon or relevant specialist Physiotherapist Occupational Therapist Dietician
Contractures	Residential Care Nurses HCAs Home Helps PHNs	GP PHN	To assess pain, prescribe interventions and make appropriate referrals to specialist services, as necessary. To assess pain, liaise with the GP and make appropriate referrals to specialist services.	Consultant in Pain Medicine Physiotherapist Occupational Therapist

Other Resources

1. The Office of the Nursing and Midwifery Services Director (ONMSD) working collaboratively with HSELand.ie developed an e-learning programme for pain management. The programme provides practitioners with a sound introduction to the relevant theories of pain, paying particular attention to the Biopsychosocial Model of pain. Significantly, the programme also provides clear and practical guidance on the assessment of pain across the care groups; including: Children, Adults, Older Persons and Persons with Intellectual Disabilities. Further information is available on the Health Service Executive website (<http://hse.ie/eng/about/Who/ONMSD/eductraining/e-learningprog/>).
2. Developing a pain management programme; useful section on the multi-disciplinary team and their role in pain management in the long term care.
<http://www.acclaimhealth.ca/wp-content/uploads/2013/11/Pain-Management-Program-Guidelines-for-Developing.pdf>



ADDITIONAL RESOURCES

6.1 Understanding the progression of dementia

When considering the assessment and management of pain for a person with dementia, it is important to understand the progression of the condition and consider its effect on the person’s ability to report their pain and adhere to medication regimes.

Whilst many classification systems exist to grade the severity of the dementia such as the Global Deterioration Scale for Assessment of Primary Degenerative Dementia (GDS) (also known as the Reisberg Scale)⁷⁸ and the FAST - Functional Assessment Staging⁷⁹ the Clinical Dementia Rating (CDR) Scale^{80,81} is considered to be the most widely used staging system in dementia research. Here, the person with suspected dementia is evaluated by a health professional in six areas: memory, orientation, judgment and problem solving, community affairs, home and hobbies, and personal care and one of five possible stages (0-3) of dementia is assigned (see below).

CDR-0	No dementia
CDR-0.5	Mild Memory problems are slight but consistent; some difficulties with time and problem solving; daily life slightly impaired
CDR-1	Mild Memory loss moderate, especially for recent events, and interferes with daily activities. Moderate difficulty with solving problems; cannot function independently at community affairs; difficulty with daily activities and hobbies, especially complex ones
CDR-2	Moderate More profound memory loss, only retaining highly learned material; disoriented with respect to time and place; lacking good judgment and difficulty handling problems; little or no independent function at home; can only do simple chores and has few interests.
CDR-3	Severe Severe memory loss; not oriented with respect to time or place; no judgment or problem solving abilities; cannot participate in community affairs outside the home; requires help with all tasks of daily living and requires help with most personal care. Often incontinent.

The Clinical Dementia Rating Scale^{80,81}

Progression of Dementia

Three important influences on the life-span of dementia are the type of dementia, the stage of dementia, and whether the course of deterioration is rapid or slow^{82,83}.

Life expectancy of the person with dementia

Although dementia is a progressive, life limiting and an incurable condition, it is not possible to clearly predict a person's life expectancy and this uncertainty can be very challenging for the person with dementia and their relatives/friends.

Although, specific life expectancy cannot be provided, there are some indicators below that healthcare staff can provide on the probable life expectancy of the person:

- 4.5 years post diagnosis is the average survival time for a person living with dementia⁸³. However, some people can live for 20 years post diagnosis and this is also dependent on the type of dementia and the existence of other co-morbidities.
- Half of the people with late stage dementia will die within 1.3 years⁸².



FACT SHEET **5A** 5B 5C 5D

Pain Assessment and Management in Dementia Palliative Care



Why is this important?



The pain experience can be extremely challenging for people living with dementia and many variables such as depression, fatigue and agitation can influence response.

The principles of pain assessment and management in Dementia Palliative Care include:

- Regular, accurate assessment and reassessment.
- Importance of the primary caregiver as a key informant.
- A person-centred approach.
- Effective management of total pain.

Pain can be:

- Physical – Acute (i.e. chest pain, fracture) or chronic (i.e. arthritis)
- Psychological – Grief, uncertainty around diagnosis or symptoms etc.
- Social – loss of independence, changing family and friend relationships
- Spiritual – fear of the unknown

Central to the philosophy of palliative care is effective pain management, working within the concept of ‘total pain’ as being physical, psychological, social and spiritual.

Recognise, Assess and Reassess for Pain



- Staff should gather a comprehensive pain history from the person with dementia, their family and other healthcare professionals who have treated the person with dementia in the past.
- Self-report from the person with dementia should be sought regardless of level of dementia.

- Observe for pain behaviours.
- Surrogate reporting should complement any attempts of self-report.
- Use pain assessment tools that are selected based on the person’s needs and communication level, not on what is easily accessible.



*This Factsheet is a visual aid to accompany the IHF dementia palliative care guidance document: ‘Pain assessment and management’.
This is available to download from www.hospicefoundation.ie*

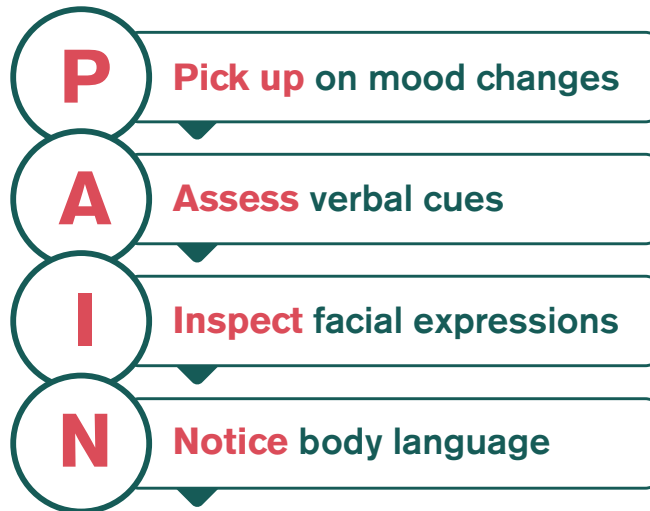


FACT SHEET 5A **5B** 5C 5D

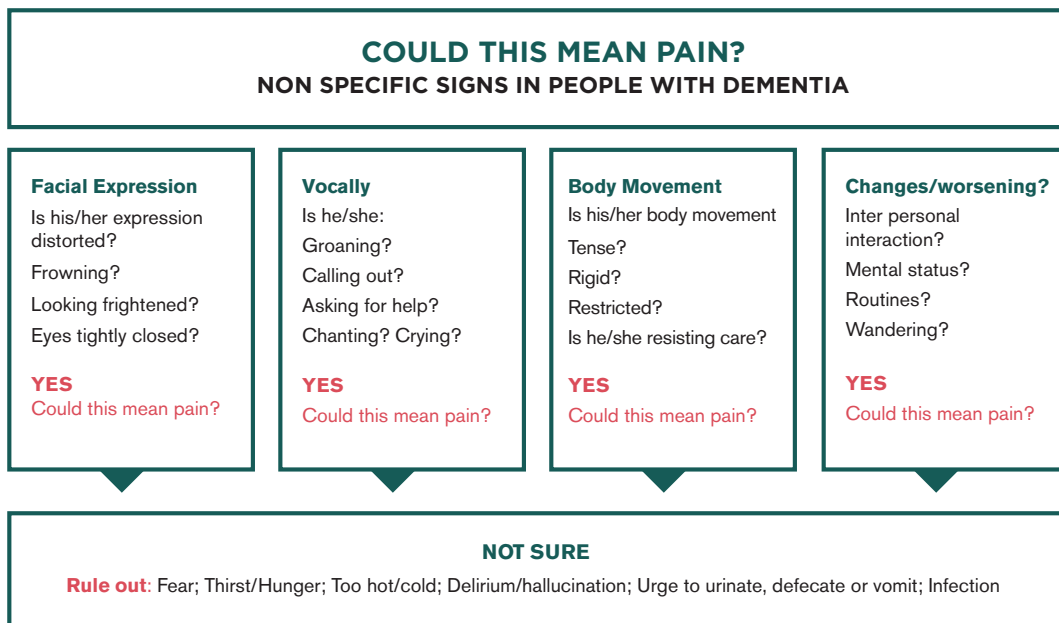
Recognise, Assess and Reassess for Pain



A simple PAIN mnemonic⁴³ to assist caregivers to recognise and identify that pain might be present



Decision tree for recognising pain



This Factsheet is a visual aid to accompany the IHF dementia palliative care guidance document: 'Pain assessment and management'. This is available to download from www.hospicefoundation.ie

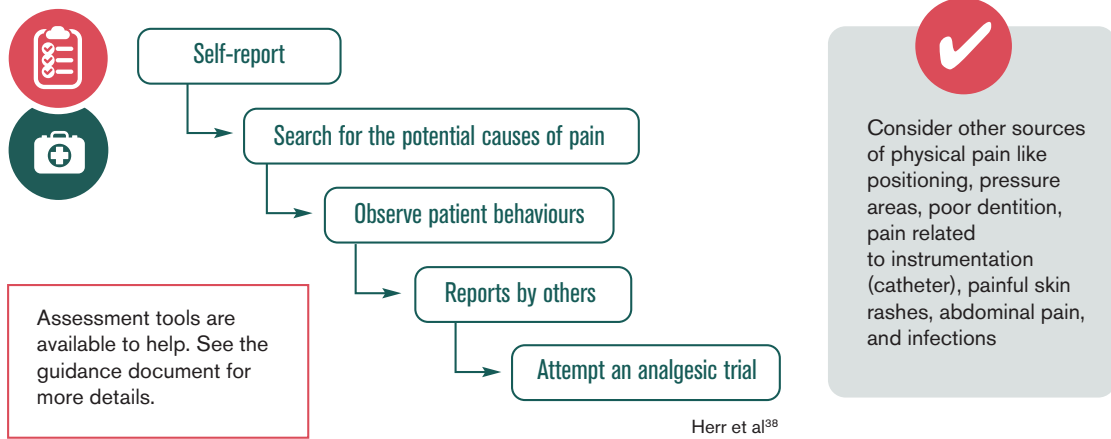


FACT SHEET 5A 5B **5C** 5D

Pain Assessment and Management in Dementia Palliative Care



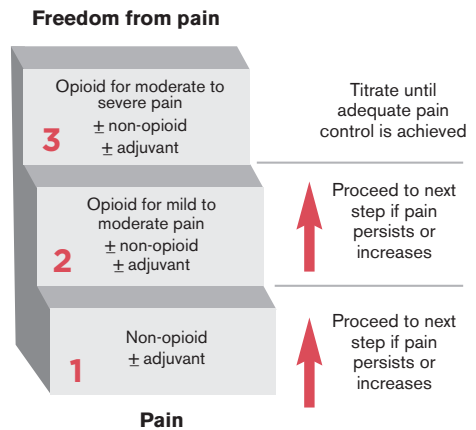
Regularly assess for the possibility of presence of pain.



Management of Pain

The first steps in the management of pain should always be to:

- Identify the cause of the pain where possible and remedy the cause.
- Explore the potential role and use of non-drug approaches of all kinds, before proceeding to even simple analgesia (Step One of the WHO ladder).
- Determine whether the use of opioids is necessary. The lowest effective dose should be used, increasing the dose slowly and only if necessary to get the desired effect. i.e. Start Low and Go Slow.
- Consider referral to the multidisciplinary team



Consider Non Pharmacological Therapies for Pain

Acupuncture, transcutaneous electrical nerve stimulation (TENS) and massage can reduce pain and anxiety.



This Factsheet is a visual aid to accompany the IHF dementia palliative care guidance document: 'Pain assessment and management'. This is available to download from www.hospicefoundation.ie



FACT SHEET 5A 5B 5C **5D**

Pain Assessment and Management in Dementia Palliative Care



Care Planning

People with dementia, experiencing pain require comprehensive, individualised care plans that incorporate personal goals, specify treatments, and address strategies to minimise the pain and its consequences on functioning, sleep, mood, and behaviour.

The goal for pain management and the best possible outcome is the relief and control of pain.

- 1. Assess:** Assess the person with dementia for signs and symptoms of pain. If possible obtain a self-report of pain. If not, ask family and carers to describe their understanding of the person's pain i.e. how it affects their interactions, mobilisation, and behaviour. Obtain a report of whether any activities cause increase in intensity of duration of pain. Ask the person or family/carers to identify what relieves or exacerbates the pain.
- 2. Plan:** Develop a plan to provide methods of pain relief for the person with dementia. These methods should include both pharmacological and non-pharmacological methods of pain relief. The plan should address the person or family/carer's identified goals for pain relief.
- 3. Implement:** Implement a pain management plan that incorporates the identified goals. Minimise adverse side effects associated with pharmacological interventions. Educate the person with dementia and family/carer about the pain management strategies chosen. Address any misconceptions and concerns.
- 4. Evaluate:** Reassess the person's response to the prescribed analgesia or the non-pharmacological method of pain relief. Monitor presence and location of pain, intensity and severity of pain and effectiveness of chosen method of pain relief. Gather both self-reports from the person with dementia and observations of family.

Think beyond the physical.

Unresolved emotional issues: encourage the person to express their concerns or refer to a social worker, clinical psychologist, family therapist, minister/religious person or pastoral care.

Social pain: consider the quality and depth of relationships and how this may help or hinder pain.

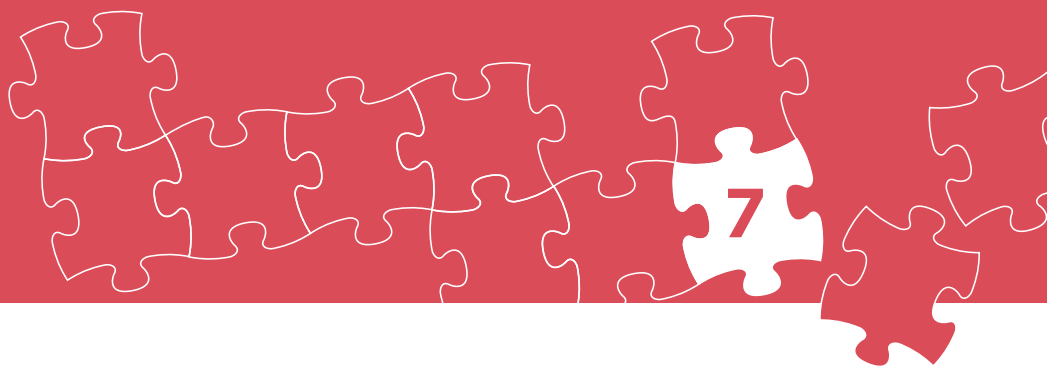
Spiritual pain: address issues such as fear of the unknown, concerns about the meaning of life refer to pastoral care as appropriate

IF YOU ARE CONCERNED ABOUT EFFECTIVE PAIN CONTROL FOR A PERSON WITH DEMENTIA – REFER TO SPECIALIST PALLIATIVE CARE OR TO A PAIN SPECIALIST.



This Factsheet is a visual aid to accompany the IHF dementia palliative care guidance document: 'Pain assessment and management'. This is available to download from www.hospicefoundation.ie





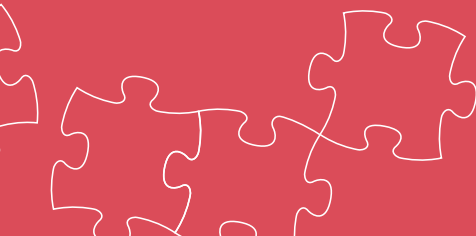
CONCLUSION

This document seeks to provide caregivers of people with dementia, regardless of care setting, with guidance to support optimal assessment and management of pain.

The literature highlights pain as one of the most problematic symptoms for people with dementia – particularly at the end of life. Existing guidance documents for the assessment and management of pain for people with dementia within a palliative care framework are limited and the majority of those that exist lack rigour when evaluated using AGREE²⁷. The Gold Standard for pain assessment is self-reporting, however this becomes difficult as the person's verbal abilities are reduced due to the progress of dementia. Hierarchies of observational assessment of pain in people with dementia have been recommended, however it is important to rule out causes other than pain. A combination of the use of observational scales and self-report measures may prove useful to detect the presence of pain in people with mild-moderate dementia. Further development and research into the validation of pain tools specifically designed for adults with dementia is required⁸⁴.

Where a person is non-verbal and pain is suspected, it may be appropriate to conduct an analgesic trial to validate the presence of pain using the WHO analgesic ladder and associated principles of titration. Guidelines for pain treatment in people with dementia in general do not particularly relate pain medication to the *type* of pain. This requires review as, for example, central neuropathic pain does not respond to paracetamol⁶³. Regular, ongoing reassessment of pain is a central component of a palliative approach to caring for a person with dementia.

Where guidance documents such as this are developed, it is important for them to be accompanied by education programmes for staff and family caregivers⁸⁵ and audit tools to monitor implementation.



APPENDIX 1

STEERING AND PROJECT GROUP MEMBERSHIP

Guidance Documents 4-7 Project Lead: **Dr. Alice Coffey**

Guidance Documents Project Researcher: **Dr. Kathleen McLoughlin**

Principal Investigator for Pain Document: **Dr. Nicola Cornally**

Authors: **Dr. Nicola Cornally, Dr. Kathy McLoughlin, Dr. Alice Coffey, Dr. Elizabeth Weathers, Dr. Catherine Buckley, Mary Mannix, Professor David William Molloy, Dr. Suzanne Timmons.**

A draft document was reviewed by the following **subject experts**:

Professor Patricia Schofield, Anglia Ruskin University in Cambridge and Chelmsford. UK.

Professor Patricia Bruckenthal, Chair – Department of Graduate Studies/Advanced Practice Nursing Clinical Associate Professor. Stony Brook University School of Nursing Stony Brook, New York. USA.

Dr Feargal Twomey, Palliative Medicine Consultant, HSE and Milford Care Centre, Limerick, Ireland.

Steering Committee

The outputs from the Project Group were overseen by a Steering Committee convened by The Irish Hospice Foundation comprising of:

1. **Prof. Geraldine McCarthy** (Chair). Emeritus Professor, University College Cork and Chair South/South West Hospitals Group.
2. **Dr. Ailis Quinlan**, former member of National Clinical Effectiveness Committee (NCEC).
3. **Ms. Marie Lynch**, Head of Healthcare Programmes, Irish Hospice Foundation.
4. **Prof. Cillian Twomey**, Geriatrician (Retired).
5. **Ms. Kay O’Sullivan**, Lay Representative, Marymount Hospice, Volunteer Support.
6. **Ms. Mary Mannix**, Clinical Nurse Specialist Dementia Care, Mercy University Hospital, Cork.
7. **Professor Philip Larkin**, Director of the Palliative Care Research Programme, School of Nursing and Midwifery, University Collge Dublin.
8. **Dr. Bernadette Brady**, Consultant in Palliative Medicine, Marymount Hospital & Hospice, Cork.

APPENDIX 2

METHODOLOGY

The process for developing this guidance document is outlined as follows:

1. The IHF project advisory group issued a tender for the development of a suite of four guidance documents. A project team, led by Dr. Alice Coffey, UCC, successfully tendered to develop Guidance Documents 4-7. (See Appendix 1 for membership of the team). This Guidance Document (No. 5) was developed by a team led by Dr. Nicola Cornally. A Steering Committee was established by the IHF to establish an Expert Advisory Group to oversee the development of this guidance document (See Appendix 1 for membership of the group). Drafts of the guidance document were reviewed by international / national subject experts (See Appendix 1 for details).
2. A literature review was conducted using scoping review methodology.^{86,87}

DATABASES SEARCHED

EBSCO Database

Medline

CINAHL Plus with Full Text

Academic Search Complete

Psychology and Behavioural Sciences Collection

SocINDEX

PsycINFO

PsycARTICLES

EMBASE

The Cochrane Library

SEARCH STRATEGY

The following key word strategy was agreed by the project team and used in EBSCO, adapted variations were developed for the other databases:

S1: palliative OR dying OR “end of life” OR “end-of-life” OR hospice OR terminal* OR “end-stage” OR “end stage” OR chronic OR “advanced illness” OR “advanced life limiting illness” OR “advanced life-limiting illness” OR “advanced life limited illness” OR “advanced life-limited illness” OR “late stage”

S2: Dementia OR Alzheimer* OR demented

S3: Guideline* OR guidance OR algorithm* OR “decision aid” OR pathway* OR policy OR policies OR protocol* OR standard* OR checklist* OR Decision N3 (aid OR aids OR support OR tool OR tools OR system OR systems OR making) OR Standard N3 (care OR clinical OR treatment) OR care N3 model OR framework OR flowchart

S4: pain OR discomfort OR pharmacological

S5: S1 AND S2 AND S3 AND S4

References from relevant papers were scanned to identify additional papers as necessary.

INCLUSION CRITERIA

English language

Peer reviewed publication

Focus on adult populations (patients /family caregivers) with dementia

Studies published between 2005-2015

EXCLUSION CRITERIA

Written in a language other than English

Conference abstracts, thought pieces, reflective articles, dissertations, book chapters and book reviews.

Focus on populations under 18 years of age

Studies with a purely biochemical focus

Animal/lab based studies

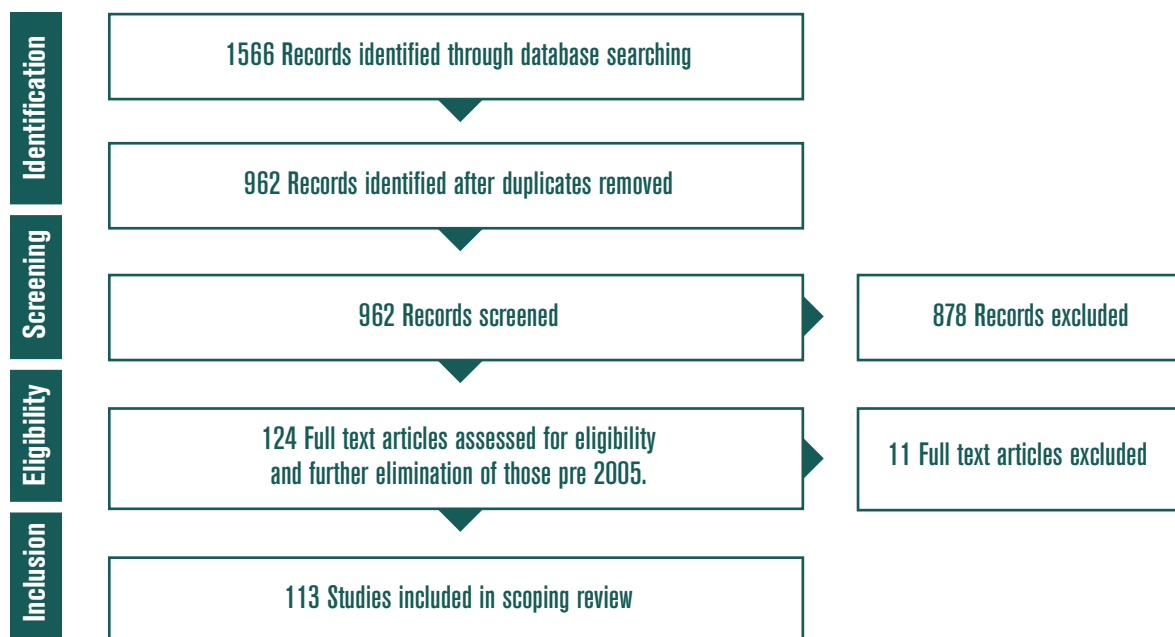
Papers generic to older people

Mixed Populations e.g. Parkinson's and Dementia where data/ themes relating to dementia could not be separated from other diseases

Not in English.

Records retrieved were divided into three groups “Yes”, “Maybe” and “Reject”. A second and third screening of the “Yes” and “Maybe” folders was conducted to produce a final list for full-text review. Only papers satisfying the criteria above were included for data extraction. Where there was a disagreement regarding inclusion of a record, a third reviewer was consulted.

OUTCOME OF LITERATURE SEARCH



LITERATURE WAS REVIEWED TO CONSIDER:

The volume and level of evidence available.
 Theoretical models or principles proposed.
 Instruments and procedures to assess manage and review patients with regard to assessment and management of pain in dementia palliative care.
 Evidence specific to a variety of care settings.
 Recommendations for practice.
 Gaps in current knowledge, relevant research in progress and key emerging issues.

Based on the review of full text papers, data was extracted onto a table, organised under the following headings, to aid thematic analysis:

- (1) Title of Paper
- (2) Authors
- (3) Year of Publication
- (4) County of Origin
- (5) Level of Evidence
- (6) Aim
- (7) Setting (Primary Care / Residential Care Setting / Hospital / Hospice/Other (specify))
- (8) Population – Patients - to include age profile; comorbidities; classification of stage of dementia (against the CDR scale) / Family caregivers / Healthcare Providers
- (9) Focus on: Assessment / Treatment / Review / Other
- (10) Reference to other pre-existing guidance
- (11) Key findings / arguments
- (12) Key recommendations for practice

CLEARING HOUSES AND PROFESSIONAL BODIES

Searches of the following major clearing houses to identify pre-existing guidance documents, relevant to the domains above were also conducted:

Australian Government NHMRC
 NHS Quality Improvement Scotland
 Department of Health Australian Government
 WHO
 US: Institute of Medicine
 Institute for Healthcare Improvement
 United States National Guideline Clearinghouse
 The Guidelines International Network
 New Zealand Guidelines Group, NLH
 National Library of Guidelines (UK) Includes NICE
 Scottish Intercollegiate Guidelines Network
 Health technology Assessment
 NICE

Where specific guidance documents were sourced, these were critically assessed using the AGREE tool.

3. Collation of key themes to inform the guidance and principles of medication management and assessment by the Project Team.

LITERATURE REVIEW THEMES

1. The challenge of pain assessment and management for people with dementia
2. Existing guidance regarding pain assessment and management in this population
3. Pain management in long term settings
4. Assessment and management of pain in mild-moderate dementia
5. Assessment and management of pain in moderate-severe dementia

4. Hand search of international and national policy and best practice guidelines - ongoing throughout the process in order to inform and populate the resources.

Limitations

Evidence on effectiveness and cost effectiveness was not explored due to time and resource constraints. It is challenging to include representatives from all relevant professional associations and people with dementia in the initial phases of development. The targeted external consultation included as many groups as possible in order to get feedback from all relevant stakeholders in this area.



APPENDIX 3

BEHAVIOURAL PAIN ASSESSMENT TOOLS

Abbey Pain Scale

For measurement of pain in patients who cannot verbalise

How to use scale: While observing the patient, score questions 1 to 6.

Name of patient:.....

Name and designation of person completing the scale:.....

Date: **Time:**.....

Latest pain relief given was athrs.

Q1. Vocalisation

eg whimpering, groaning, crying

Absent 0 Mild 1 Moderate 2 Severe 3

Q2. Facial expression

eg looking tense, frowning, grimacing, looking frightened

Absent 0 Mild 1 Moderate 2 Severe 3

Q3. Change in body language

eg fidgeting, rocking, guarding part of body, withdrawn

Absent 0 Mild 1 Moderate 2 Severe 3

Q4. Behavioural change

eg increased confusion, refusing to eat, alteration in usual patterns

Absent 0 Mild 1 Moderate 2 Severe 3

Q5. Physiological change

eg temperature, pulse or blood pressure outside normal limits, perspiring, flushing or pallor

Absent 0 Mild 1 Moderate 2 Severe 3

Q6. Physical changes

eg skin tears, pressure areas, arthritis, contractures, previous injuries

Absent 0 Mild 1 Moderate 2 Severe 3

Add scores for Q1 to Q6 and record here Total pain score

Now tick the box that matches the total pain score

0-2 no pain	3-7 mild	8-13 moderate	14+ severe
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Finally, tick the box which matches the type of pain

chronic	acute	acute on chronic
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Abbey, J; De Bellis, A; Piller, N; Esterman, A; Giles, L; Parker, D and Lowcay, B.
 Funded by the JH & JD Gunn Medical Research Foundation 1998 – 2002
 (This document may be reproduced with this acknowledgment retained)

Pain Assessment IN Advanced Dementia PAINAD

	0	1	2	Score
Breathing Independent of vocalization	Normal	Occasional labored breathing. Short period of hyperventilation	Noisy labored breathing. Long period of hyperventilation. Cheyne-stokes respirations	
Negative Vocalization	None	Occasional moan or groan. Low level speech with a negative or disapproving quality	Repeated troubled calling out. Loud moaning or groaning. Crying	
Facial expression	Smiling, or inexpressive	Sad. Frightened. Frown	Facial grimacing	
Body Language	Relaxed	Tense. Distressed pacing. Fidgeting	Rigid. Fists clenched, Knees pulled up. Pulling or pushing away. Striking out	
Consolability	No need to console	Distracted or reassured by voice or touch	Unable to console, distract or reassure	
				TOTAL

Warden V, Hurley AC, Volicer L. Development and psychometric evaluation of the Pain Assessment in Advanced Dementia (PAINAD) scale. *J Am Med Dir Assoc.* 2003;4(1):9-15.

Pain Tool Kit 10.

Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC)

Date: _____ Time Assessed: _____

Name of patient/resident: _____

PURPOSE: This checklist is used to assess pain in patients/residents who have dementia and are unable to communicate verbally.

Indicate with a checkmark, which of the items on the PACSLAC occurred during the period of interest. Scoring the sub-scales is derived by counting the checkmarks in each column. To generate a total pain sum all sub-scale totals.

Facial Expression	Present
Grimacing	
Sad look	
Tighter Face	
Dirty Look	
Change in Eyes (Squinting, dull, bright, increased eye movements)	
Frowning	
Pain Expression	
Grim Face	
Clenching Teeth	
Wincing	
Open Mouth	
Creasing Forehead	
Screwing Up Nose	

Activity/Body Movement	Present
Fidgeting	
Pulling Away	
Flinching	
Restless	
Pacing	
Wandering	
Trying to Leave	
Refusing to Move	
Thrashing	
Decreased Activity	
Refusing Medications	
Moving Slow	
Impulsive Behaviours (Repeat Movements)	
Uncooperative/Resistance to care	
Guarding Sore Area	
Touching/Holding Sore Area	
Limping	
Clenching Fist	
Going into Fetal Position	
Stiff/Rigid	

Social/Personality/Mood	Present
Physical Aggression (e.g. pushing people and/or objects, scratching others, hitting others, striking, kicking).	
Verbal Aggression	
Not Wanting to be Touched	
Not Allowing People Near	
Angry/Mad	
Throwing Things	
Increased Confusion	
Anxious	
Upset	
Agitated	
Cranky/Irritable	
Frustrated	

Other (Physiological changes/Eating Sleeping Changes/Vocal Behaviors)	Present
Pale Face	
Flushed, Red Face	
Teary Eyed	
Sweating	
Shaking/Trembling	
Cold Clammy	
Changes in Sleep Routine (Please circle 1 or 2) 1) Decreased Sleep ----- 2) Increased Sleep During the Day	
Changes in Appetite (Please circle 1 or 2) 1) Decreased Appetite ----- 2) Increased Appetite	
Screaming/Yelling	
Calling Out (i.e. for help)	
Crying	
A Specific Sound of Vocalization For pain "ow," "ouch"	
Moaning and groaning	
Mumbling	
Grunting	
Total Checklist Score	

Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC)

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The PACSLAC may only be used by a licensed, certified or registered qualified health professional or under the supervision and direction of a licensed, certified or registered health professional.

****You DO NOT have permission to modify the PACSLAC in any way without our approval****

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Any modification of the content of the PACSLAC without our expressed written permission is strictly prohibited.

It would be best to adopt an individualized approach using the PACSLAC regularly (under similar conditions) with each patient and then examining significant changes or fluctuations in the patient's pattern of scores. Also note that the research on the validation and evaluation of the PACSLAC is not complete. As such, if you choose to use it, you must do so with caution. Many underlying pain problems are easier to identify during periods of movement than during rest.

The PACSLAC has been validated with older adults suffering from dementia and may not be suitable for other populations.

We recommend assessment of all patients within 24 hours of admission and a minimum of once a week thereafter. If following an appropriate examination of the patient it is determined that pain is present, we recommend that treatment plans be put in place and implemented within 24 hours at the latest with re-assessment following twenty four hours.

We recommend that any side effects of treatment be evaluated and addressed as soon as possible.

Patients with suspected pain will require more frequent assessments.

There is no definitive acceptable baseline because of the variability among patients. We recommend observation of the pattern of scores and fluctuations over time.

PACSLAC info should always be viewed in the context of medical history, physical exam results etc. The following source (in Physiotherapy Canada) provides more information on the use of the PACSLAC.

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