Hertfordshire Care Homes Dementia Support Services 18/03/2024

Fiona Shipperlee- HPFT Care home Team

Wendy Freeman - Care home educator Isabel Hospice

Learning Outcomes:

- Explain the different mental health service for older peoples, how to refer and what to expect following referral
- Understand what Mental services will need from the care home to be able to provide how to support your residents
- Be able to Complete the HCPA Dementia Checklist to support your referral to mental health services
- Describe how to assess pain in someone living with dementia
- Be able to recognise Sign of deterioration and End of life

Who does what?

Hertfordshire Partnership University NHS Foundation Trust

Early Memory Diagnosis and Support Service (EMDASS)

- Assessment and diagnosis of dementia. For those people diagnosed with dementia a period of post diagnostic support is offered.
- Resident with ongoing cognitive issues over 6 months with no diagnosis of Dementia.
- Referral via **GP ONLY** as will need dementia screening for physical health.
- Monday – Friday 9am - 5pm

as one

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Specialist Mental health Services for Older People (SMHTOP)

- Residents who have a **Primary** Mental Health Need – for example: Moderate to Severe Depression, Moderate to Severe Anxiety, Psychosis, Dementia
- Complex Behaviours associated with Dementia
- ***Exclusion*** : Conditions not attributed or associated with a mental health condition (e.g. severe anger),Primary diagnosis of alcohol or substance misuse, social care only, acquired brain injury, significant cognitive impairment due to different types of brain damage (e.g. Neurology, HIV Dementia)
- Monday – Friday 9am - 5pm

as one

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Crisis Function Team

- As above but who may also exhibit challenging behaviour and where in the case of service users without dementia there is evidence of physical frailty
- Older adults with a dementia or acute mental illness who would benefit from a short period of Crisis and Assessment support to facilitate discharge from hospital
- Specific short treatments such as medication normally requiring admission to hospital may be considered i.e. those having medicines introduced or adjusted or those requiring monitoring of a new treatment plan
- ***Exclusion*:** alcohol detoxification, Huntingdon's disease, and Korsakoff's syndrome, Social care needs only, respite care or service users where physical health needs outweigh mental health problems.
- Monday to Friday 9am to 9pm • Saturday & Sunday 11am to 7pm

Integrated care team (ICT)

- **Works in the East and North Only**
- Low level mental health needs that are secondary to physical health needs e.g. low mood due to bereavement, social isolation, adjustment to physical health.
- Attend Care Home MDT's for anticipatory advice and support
- Monday – Friday 9am - 5pm
- *South & West – is not covered by HPFT but CLCH whom cover parts of Hertfordshire also.*

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Discharge to Assess

- For residents under the discharge to assess pathway.
- Offers support for a person's mental health needs whether related to physical health, functional ability, or historical mental health needs
- Attend Weekly DTA MDT for referrals and advice and support
- Initial assessment within 5 days of accepted referral.
- Monday – Friday 9am - 5pm

as one

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What to Expect.

- **On referral to our Single Point of Access (SPA)**
  - A triage clinician will use information provided to make a decision on urgency of contact.
  - Please **ensure** the person has been **screened/treated medically treatable conditions before referral.**
  - A SPA clinician will contact the care home to discuss the referral and gather further information for triaging to the correct team.
- **Crisis Function Team**
  - The Crisis Function will contact the referrer within the same day of receipt of a referral to agree the level of urgency and a time for the assessment to occur.
  - Urgent Assessments will be completed within **24 hours** from the time the team are notified of the referral.
- **Integrated Care Team**
  - Contact within **7 days** of referral
- **Discharge to Assess**
  - Assessment within **5 days** of referral being accepted

What we need

- History of presenting complaint
- Medical History and recent physical health checks
- ABC/medication/food/fluid/bowels charts as appropriate.
- Any identified risks and how you are managing them.

Hertfordshire Dementia Checklist

Hertfordshire Partnership University NHS Foundation Trust

Physical Factors

Infection	• Urine, wound, ear, chest etc.
Bowels	• Change of habit, constipation
Pain	• Assess pain using pain assessment tool e.g. Abbey pain tool, Painad
Dietary concerns/Dehydration	• Loss of appetite, weight loss, hunger, check dentures
Sleep	• Environment, noise, medications, caffeine/alcohol, sleeping during the day
Falls	• Recent falls, increase in falls
Incontinence	• New incontinence or urgency.
Medication	• Check side effects of medications, concordance issue?
Communication	• Hearing, eyesight problems
Other	• Results of recent blood tests, hallucinations

Hertfordshire Dementia Checklist

Hertfordshire Partnership University NHS Foundation Trust

Environmental/Social Factors

Changes in Physical surroundings	• Recent move- to the home, within the home • Hospital admission/discharge
Staff/Residents	• New staff unfamiliar to residents • New residents or changes in existing residents presentation
Visitors	• New Visitors, frequency of visits, conflict with family members or visitors
Boredom	• Engagement in meaningful activity. Loneliness
Confinement	• Ability to access outdoor space/community spaces linked to loneliness
Bereavement	• Loss of loved one, physical ability, loss of home linked to loneliness
Environment/Overstimulation	• Too hot, too cold, too dark too bright, too loud
Time of Day	• What time does the behaviour occur?

Behavioural & Psychological Symptoms of Dementia checklist

This checklist should be used as a guide to exclude possible causes of any change in behaviour or functioning of residents with dementia. It should be completed prior to any referral to Community Mental Health Team.

Residents Name: **DOB:**

Observer:

Physical Factors	Y/N	Actions Taken/Investigations	Comments
Infection (Urine, wound, ear, chest etc.)			
Bowels (Change of habit, constipation)			
Pain (Assess pain using pain assessment tool e.g. Abbey pain tool, Painad)			
Dietary concerns (Loss of appetite, weight loss, hunger, check dentures)			
Dehydration (Thirst, check fluid chart)			
Sleep problems (Environment, noise, medications, caffeine/alcohol, sleeping during the day			
Recent Falls			
Incontinence			
Medications (Check side effects of medications, concordance issue?)			
Communication problems (Hearing, eyesight problems)			
Other (Results of recent blood tests, hallucinations)			

Environmental/Emotional Factors	Y/N	Actions Taken or Evidence	Comments
Change in Physical Surroundings (Recent move)			
Staff (Unfamiliar to resident)			
Fellow Residents (New residents, unusual behaviour)			
Visitors (New Visitors, frequency of visits, conflict with family members or visitors)			
Boredom			
Bereavement			
Confinement			
Over stimulation (TV, music, activities)			
Environment (Too hot, too cold, too dark)			
Time of the day (What time does the behaviour occur?)			

Name of staff completing the form:

Designation:

Signature:

Date/Time	Activity	Antecedent	Behavior	Consequence
Date/Time when the behavior occurred	What activity was going on when the behavior occurred	What happened right before the behavior that may have triggered the behavior	What the behavior looked like	What happened after the behavior, or as a result of the behavior

ABC Charts

Isabel Hospice
Together we care

Pain and End of Life Care in Dementia

By Wendy Freeman Care Home Educator/Facilitator

Helping people live well, for as long as possible,
and die with dignity in the place of their choice

What do you do when you're in pain?

What do you see?
What do you hear?
What was normal behaviour?

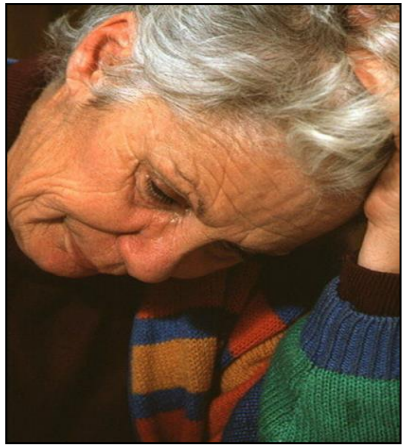
Common Causes of pain in Dementia

Musculoskeletal disease
Dental problems
Impacted earwax
Eye infections
Urinary tract infections
Constipation
Co morbidities

Check for the
3 P's

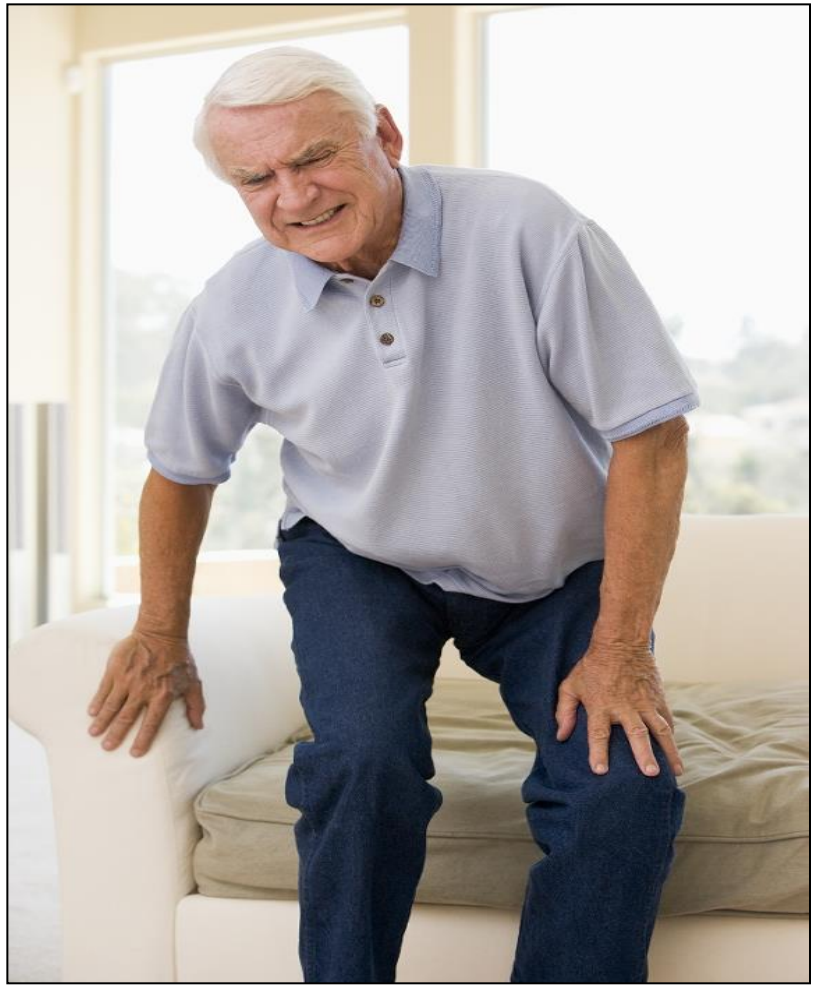
Barriers to recognising pain

- The person with dementia may not have the ability to verbally communicate what they are feeling
- The person with dementia may not be able to remember pain they experienced earlier
- The person with dementia may not be able to identify where their pain is located



- Mistaken assumptions get made:
  - The erroneous belief that behaviours resulting from the pain are “symptoms of the person’s dementia”
  - The myth that “People with dementia do not experience pain / their pain is less severe”

Observable indicators of pain:

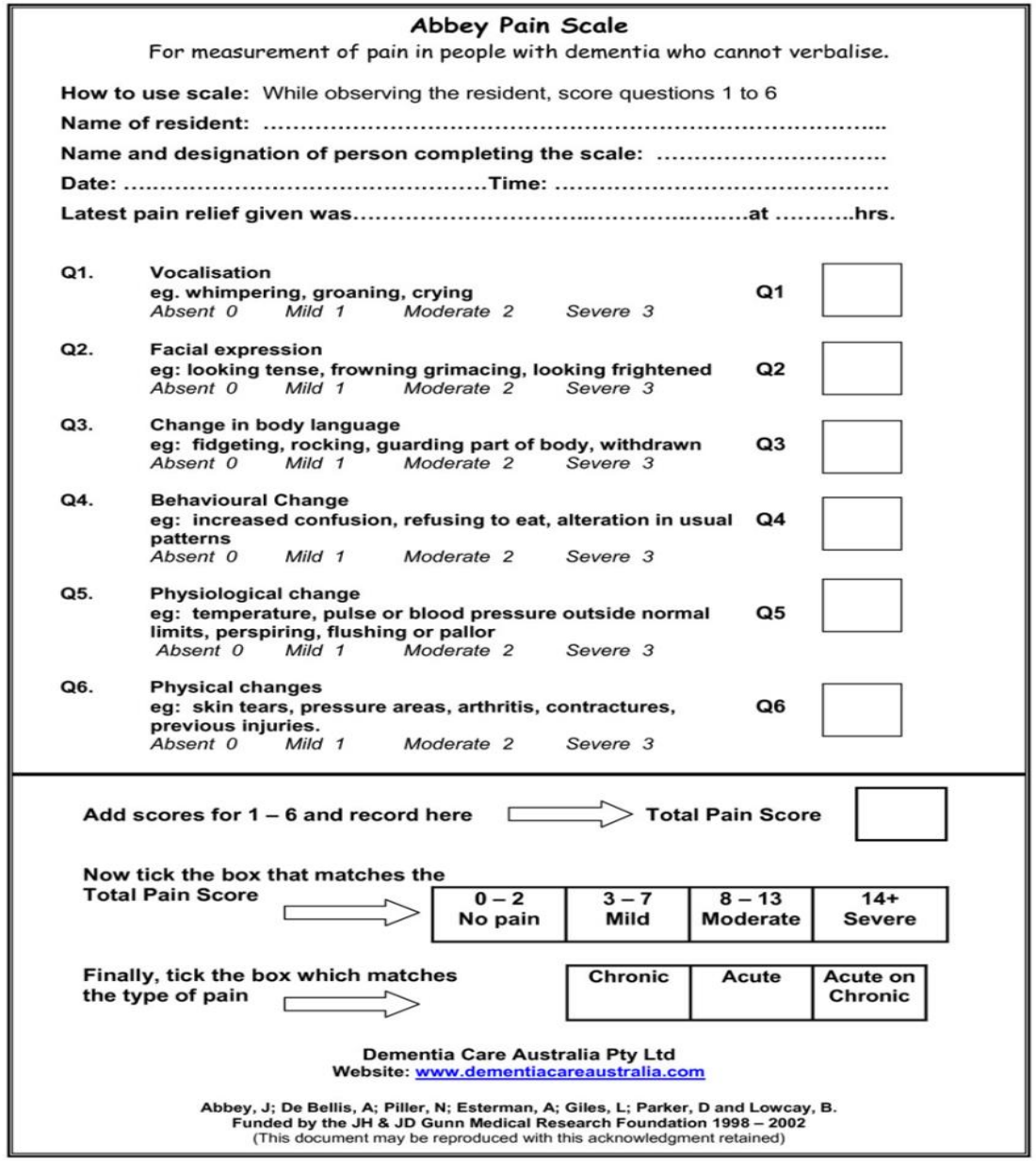


- **Autonomic changes** – e.g. hypertension, pallor, sweating, altered breathing, even hold breath.
- **Bodily indications** – e.g. altered gait, fidgeting, rocking, repetitive movements, guarding, bracing, tense muscles
- **Vocalisations** – e.g. sighing, groaning, screaming, calling out, swearing, repetitive verbalisations
- **Facial expressions** – e.g. grimacing, wincing, frowning
- Fight or flight approach to staff.
- engagement.

Observable indicators of pain continued…

- **Interpersonal reactions** – e.g. aggression, withdrawal, resisting
- **Changes in activity patterns** – e.g. pacing, trying to get out of bed, altered sleep, refusal to eat, decreased functional abilities, a new behaviour
- **Cognitive / emotional changes** – e.g. increased confusion, crying, irritability
- **Individual responses** – speak to relatives / carers about this person's normal behaviour and how they show they are in pain

Pain Assessments



Abbey Pain Scale

For measurement of pain in people with dementia who cannot verbalise.

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

Name of resident: .....

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

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

Latest pain relief given was.....at .....hrs.

Q1.	**Vocalisation** **eg. whimpering, groaning, crying** *Absent 0 Mild 1 Moderate 2 Severe 3*	Q1	
Q2.	**Facial expression** **eg: looking tense, frowning grimacing, looking frightened** *Absent 0 Mild 1 Moderate 2 Severe 3*	Q2	
Q3.	**Change in body language** **eg: fidgeting, rocking, guarding part of body, withdrawn** *Absent 0 Mild 1 Moderate 2 Severe 3*	Q3	
Q4.	**Behavioural Change** **eg: increased confusion, refusing to eat, alteration in usual patterns** *Absent 0 Mild 1 Moderate 2 Severe 3*	Q4	
Q5.	**Physiological change** **eg: temperature, pulse or blood pressure outside normal limits, perspiring, flushing or pallor** *Absent 0 Mild 1 Moderate 2 Severe 3*	Q5	
Q6.	**Physical changes** **eg: skin tears, pressure areas, arthritis, contractures, previous injuries.** *Absent 0 Mild 1 Moderate 2 Severe 3*	Q6	

Add scores for 1 – 6 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

Finally, tick the box which matches the type of pain ⇒

Chronic	Acute	Acute on Chronic

Dementia Care Australia Pty Ltd
Website: www.dementiacareaustralia.com

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)

Observations

+

Pain assessment tool (e.g. Abbey)

+

Medical history (known painful conditions)

+

Information from relatives and carers (individual pain indicators)

Abbey Pain Scale

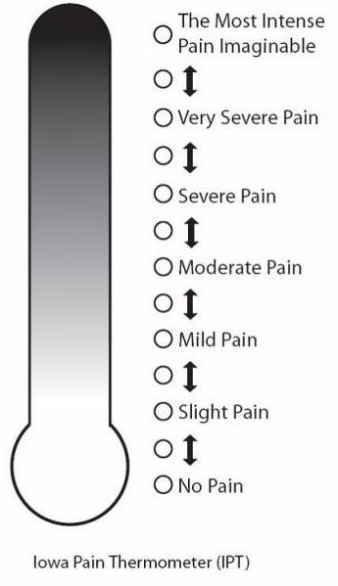
- The Abbey Pain Scale is used as a movement based, ADL tool. As an overall pain management plan.

- If the scale indicates the client is in pain, administer pain relief where appropriate.

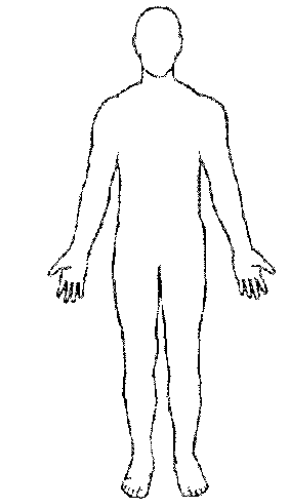
- 1 hour after administration of medications conduct a second assessment. If the clients score has not reduced, consider further intervention.

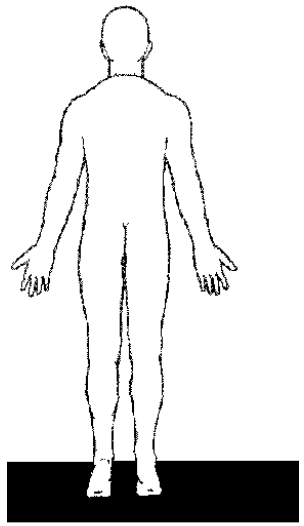
- Assess the client until the score is 7 or fewer. After this assess every 4 hrs for the next 24 hrs. If pain recurs, continue relief through interventions.

- Where pain persists undertake a comprehensive assessment of all facets of the clients care and monitor closely over 24 hrs. If there is no improvement speak with doctors.



Iowa Pain Thermometer (IPT)


Front


Back

Verbal pain assessment

- Use words that the patient can understand or how they describe Pain ie discomfort. Aches, hurt,
- Capture the moment – the patient might not remember pain they had 5 minutes ago
- Ask the person to point on their own body or on a body map
- Use verbal / numerical / visual rating scale

Pain Management

- Appropriate, regular analgesia (including PRN and anticipatory analgesia) administered through the most suitable method. Assume pain and treat.
- Reduce isolation and anxiety by providing reassurance, communication, empathy and kindness.
- Carry out procedures in a way that avoids or minimises triggering pain.
- If advised by a physiotherapist, help with gentle exercises and/or massage.
- If appropriate, provide an air mattress, air cushions and/or heat pads (for limited duration).
- Provide distraction by helping the person become occupied but don’t ignore needs.
- Assist the person into a position of maximum comfort.

Distressing Symptoms End of Life

Last 18 months of life

- Agitation 54%
- Dyspnea 46%
- Aspiration 41%
- Pain 39%
- Pressure Ulcer 39%

Last week of life

- Pain 52%
- Agitation 35%
- Shortness of breath 35%

Mitchell, S.L. et al. The clinical course of advanced dementia. NEJM 2009; 361(16), 1529-1538.
Hendricks SA et al. Dying With Dementia: Symptoms, Treatment, and Quality of Life in the Last Week of LifeJ Pain Symptom Manage 2014;47:710-720

Isabel Hospice
Together we care

Table 4

Clinical Features in Late-Stage Dementia[11,26]

Alzheimer Disease	Frontotemporal Dementia	Lewy Body Dementia	Vascular Dementia
Memory, visual-spatial and language disturbances Indifference Delusions Agitation Behavioral changes	Personality changes Executive dysfunction Disinhibition Impulsivity Progressive loss of speech	Visual hallucinations Delusions Falls Syncope Parkinsonism Fluctuating memory Sensitivity to antipsychotic medications	Abrupt onset Stepwise deterioration Prominent aphasia Motor dysfunction Mood or behavior changes Severe depression symptoms

End-stage Dementia

Prognosis < 6 mos:

- Severe dementia with need for total assistance in ADLs (dressing, bathing, continence), unable to walk, only able to speak a few words
- Comorbid conditions – aspiration pneumonia, urosepsis, decubiti, sepsis
- *Unable to maintain caloric intake with weight loss of 10% or more in 6 months (and no feeding tubes)

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What are the average life expectancy figures for the most common types of dementia?

The average life expectancy figures for the most common types of dementia are as follows:

- Alzheimer's disease – around eight to 10 years. Life expectancy is less if the person is diagnosed in their 80s or 90s. A few people with Alzheimer's live for longer, sometimes for 15 or even 20 years.
- Vascular dementia – around five years. This is lower than the average for Alzheimer's mostly because someone with vascular dementia is more likely to die from a stroke or heart attack than from the dementia itself.
- Dementia with Lewy bodies– about six years. This is slightly less than the average for Alzheimer's disease. The physical symptoms of DLB increase a person's risk of falls and infections.
- Frontotemporal dementia – about six to eight years. If a person has FTD mixed with motor neurone disease – a movement disorder, their dementia tends to progress much quicker. Life expectancy for people who have both conditions is on average about two to three years after diagnosis.

What are the signs that someone with dementia is dying?

It is difficult to know when a person with dementia is coming to the end of their life. However, there are some symptoms that may indicate the person is at the end of their life including:

- limited speech (single words or phrases)
- needing help with everyday activities
- eating less and swallowing difficulties
- incontinence and becoming bed bound.
- Pain/Ache/Discomfort

When these are combined with frailty, recurrent infections and/or pressure ulcers, the person is likely to be nearing the end of their life. If the person has another life limiting condition (eg cancer), their condition is likely to worsen in a more predictable way.

Main symptoms at end of life for someone with dementia

(McCarthy and Addington Hall 1997)

- Pain (64%)
- Confusion (83%)
- Loss of appetite (57%) and/or swallowing difficulties
- Low mood (61%)
- Incontinence- (72%) pressure area risks
- Delirium
- Terminal agitation
- Excess secretions especially if has pneumonia
- Constipation

St Christopher's

Harris HospisCare
with St Christopher's

Signs that a person with dementia might be approaching the end of their life include:

- significantly reduced appetite, loss of interest in food and drink, or refusing it completely
- weight loss
- swallowing difficulties (for example, coughing/throat-clearing during or after eating or drinking, spending a long time chewing food, or storing food in their mouth)
- frequent infections
- reduced mobility, perhaps requiring care in a bed or chair
- frequent falls
- reduced communication
- becoming more withdrawn, or more agitated and/or restless
- sleeping more, seeming drowsy and less aware
- difficulties controlling their bladder and/or bowel (incontinence)
- needing help with most daily activities
-

When a person gets to within a few days or hours of dying, further changes are common. These include:

- deteriorating more quickly
- loss of consciousness
- inability to swallow
- becoming agitated or restless
- irregular breathing
- cold hands and feet.

These are part of the dying process, and it's important to be aware of them so that you can help family and friends understand what is happening.

When a person with dementia is at the end of life it's important to support the person to be as comfortable as possible until they die

Focus on communication

People with dementia are at risk of receiving poor care because they are not able to say what they want. For example, a person with dementia may be in pain but unable to verbalise it – they may cry out or become restless instead. This is an attempt to communicate a need but can often be dismissed because they have dementia. People with dementia often communicate their needs and feelings through non-verbal means – body language, gestures and facial expressions. The following tips may help:

- It's important to continue to communicate with the person, even if you think they don't understand. The person will still have feelings.
- Try to maintain eye contact with the person.
- Think about your non-verbal communication and tone of voice.

- Touch and human contact are important. Sitting with the person, talking to them, brushing their hair and holding hands may help.
- A calm and familiar environment is usually best for a person with dementia at the end of their life. Stimulating the senses, for example with music and aromas the person likes, can also help. The focus should be on making sure the person is as comfortable as possible.
- Take your time and take cues from the person.
- Use what you know about the person to engage them. This could include hobbies and interests from their past. It can help to make use of a range of resources such as photos, objects and memorabilia.

The most important thing is to engage with the person – talk to them, make use of the senses (touch, music, smells) and use what you know about them

Contact Details

Hertfordshire Partnership University NHS Foundation Trust

Mental Health Services

Single Point of access

0800 6444 101

24 hours a day 7 days a week

SMHTOP/CRISIS

EAST 01707 364 003

NORTH 01438 792190

NORTHWEST 01442 275628

SOUTHWEST 01923 837148

INTEGRATED CARE

01707 364003

hpft.integratedcareteam@nhs.net

Monday to Friday 9am-5pm

Discharge to Assess

01707 364070

Hpft.carehometeam@nhs.net

as one

Our Values

Welcoming Kind Positive Respectful Professional

Contact Details

Hospice and Palliative care

Wendy Freeman Care Home
Specialist Educator: 07843218316

Isabel Hospice 24 hr Advice Line:

01707 382575

Isabel Hospice Palliative Care Team:

01707 382500 Mon-Fri 9-5pm

- Garden House Hospice: 01462 679540
- Lister Hospital SPC Team:
- 01438 284035
- North Herts Community SPC Team:
- 01462 427034

- WEST HERTS:
- Hospice of St Francis: 01442 869550
- Michael Sobell House: 02038262377
- Peace Hospice Care:
- 01923 330330
- Rennie Grove Hospice:
- 01442 890222

- Watford Hospital SPCT:
- 01923 217930
- West Herts Community SPC Team:
- 01442 454689

Thank you,

for listening.

HCPA Training 24/25

Dementia person-centred care CHAMPION Revalidation
Dementia person-centred care CHAMPION
Positive Behaviour Support for Dementia CHAMPION
Dementia: Communication support
Dementia: Creating a culture of person-centred care for managers
Dementia: Person-centred care
Dementia: Planning risk-positive care

See all upcoming training here

Support Service Directory Here