Palliative and End of Life Care in Dementia

A course for health & social care staff and family & friends of people with dementia

Workbook 2

Communication towards the end of life for the person with dementia, their families and friends

Name: ..........................................................

Workplace: ..................................................

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Acknowledgements

This series of workbooks has been written by Jenny Henderson, Development Manager, Alzheimer Scotland, specialising in palliative and end of life care for people with dementia and their families. Thanks to the following Alzheimer Scotland staff who have contributed to these publications:

- **Hazel Walker**  Learning Development Manager
- **Jenny Marlborough**  Sessional Trainer
- **Julie Miller**  Development Manager
- **Lesley Thomas**  Trainer
- **Maureen Thom**  Information Manager

Special thanks are extended to all the external contributors who agreed to allow their work to be reproduced.

Please refer to the introductory booklet for background information about the course and about dementia, the Scottish policy context and a glossary of terms relevant to this workbook.
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Learning objectives

After participating in the sessions contained in workbook 2, participants should:

- understand the terms incapacity and capacity
- understand the ethical issues that relate to end of life care
- have explored what we mean by end of life care
- have an insight into assessing and managing pain when verbal communication skills are limited or absent
- understand the role of advance statements and decisions, along with the relevant parts of the Adults with Incapacity (Scotland) Act 2000, and how this may give the person with dementia a voice
- understand and be equipped to discuss some of the ethical dilemmas that everyone who is involved in the care of people in the later stages of dementia may face
- understand the models of care planning that are available, and the need to plan care as a means of improving communication between family carers, staff and professionals of different disciplines.

Topics covered in workbook 2

<table>
<thead>
<tr>
<th>Topic</th>
<th>Length of session</th>
<th>NHS staff</th>
<th>Care home Staff</th>
<th>Relatives</th>
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</thead>
</table>
| **Session 1.**  
Living and dying | 20 minutes | Yes | Yes | Yes |
| **Session 2.**  
Capacity and incapacity | 25 minutes | Yes | Yes | Yes |
| **Session 3.**  
Making decisions, advance statements and Adults with Incapacity (Scotland) Act 2000 | 1 hour 30 minutes | Yes | Yes | Yes |
| **Session 4.**  
Communication and pain assessment | 1 hour | Yes | Yes | Yes |
| **Session 5A.**  
An end of life case study | 1 hour 30 minutes | Yes | Yes | Yes |
| **Session 5B.**  
End of life care (alternative option for staff only) | 1 hour 30 minutes | Yes | Yes | No |
| **Session 6.**  
Planning care | 30 minutes | Yes | Yes | Yes |
Introduction to the course

Personal objectives

Whether you are doing the whole course or completing this workbook as a stand-alone module, take a few minutes to think about what you would like to get out of completing it and write down your ideas. You may be unsure at the beginning of the session, but your ideas may become clearer as you go along. Please ensure you complete this.

Discussion point

It’s good to know exactly what is expected of each other and to agree some common boundaries. Think about what would help you to relax and feel comfortable in the group. Boundaries. Please take a few minutes to complete this.

‘Big ideas’

What are big ideas? Throughout the sessions, your facilitator will be keeping a note of possible projects that you and your colleagues would like to develop in your care setting. We call these ‘big ideas’. You will find an action plan at the back of this booklet to help you plan to introduce change in your care setting. You may want to jot down ideas as you think of them to help you complete your action plan later.
Session 1. Living and dying

There is an appointed time for everything, and a time for every affair under the heavens. A time to be born and a time to die.

Ecclesiastes 3:1–2

Death is such a taboo subject. It’s a big problem because all of us are so near to death. By 90 you can’t get much nearer without knowing that it is around the corner, and we need to be able to express that sometimes if we want to.1

Quote from 90-year-old woman

12 Principles of a good death2

1. To know when death is coming and to understand what can be expected
2. To be able to retain control of what happens
3. To be afforded dignity and privacy
4. To have control over pain relief and other symptoms
5. To have choice and control over where death occurs (ie at home or elsewhere)
6. To have access to information and expertise of whatever kind is necessary
7. To have access to any spiritual and emotional support required
8. To have access to hospice care in any location, not only in hospital
9. To have control over who is present and who shares the end
10. To be able to issue advance directives which ensure wishes are respected
11. To have time to say goodbye and control over other aspects of timing
12. To be able to leave when it is time to go and not have life prolonged pointlessly.

Discussion point

As a society, how do we perceive death? Write down the group’s conclusions.

2 Debate of the Age Health and Care Study Group. The future of health and care of older people: the best is yet to come. London: Age Concern, 1999
What a person with dementia and their family can expect in the later stages of the illness

The dementia journey may last for many years. In general, the way a person with dementia will die fits one of the following descriptions:

- as a result of complications arising from end-stage dementia
- from another illness, such as cancer (in which case the person may still be in the early stages of dementia)
- from a mixture of mental and physical problems. In this scenario, dementia may not be the main cause of death, but may interact with other conditions.3

End-stage dementia may last for months or years, and is the last part of a long journey that a person with dementia has to make. While everyone’s experience is different, by this stage of the illness the person is likely to have severe memory problems, and physical elements of the disease generally become more obvious. Symptoms usually include:

- very limited short- and long-term memory
- limited or no verbal skills
- only being able to see the world in terms of themselves
- inability to make judgements
- inability to solve problems
- lack of independent function
- reliance on others for personal care and continence management.

The person may enter a stage of total dependence and inactivity where they have difficulty eating and walking and may fail to recognise relatives, friends and familiar objects. In many cases they will have difficulty understanding and interpreting events, and may suffer bladder and bowel incontinence. They will often be confined to a wheelchair or bed, and this can make them particularly vulnerable to infections such as pneumonia, which can be fatal.

People with dementia differ in the speed with which their abilities deteriorate. While dementia is a life-limiting illness, death often occurs as a result of complications arising from the effects of the disease, rather than the disease itself. An example of this

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would be an inability to swallow. This can increase the risk of food and drink entering the lungs rather than the stomach, which in turn can lead to pneumonia. Many older people with dementia also have other conditions that tend to increase in incidence with age. Examples include heart disease, diabetes and cancer. These conditions can also contribute to the person’s decline and eventual death.

Towards the end of the illness, treatment focuses on relieving symptoms. This can be challenging for those caring for someone who is increasingly unable to report or describe their pain or discomfort.\(^4\)

### Session 2. Capacity and incapacity

#### What is capacity?

Before we can consider making ethical decisions about a person with dementia, we need to understand the effect that capacity has on decision-making. Understanding what capacity – or the lack of it – means for a person with dementia is central to making ethical decisions about their care. A lack of capacity affects the person’s ability to have a say in how they would like to be treated at the end of their lives. Deciding whether someone has capacity is very difficult.

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4 Reisberg, B et al. The global deterioration scale for assessment of primary degenerative dementia. American journal of psychiatry 39 1982 1136-9
Some principles relating to capacity:

- there is always an initial presumption that the person has capacity, rather than doesn’t have capacity
- the person has the right to be supported to make his or her own decisions
- this includes the right to make unwise or eccentric decisions
- capacity is something that can vary over time.

To have capacity, the person must be able to:

- understand information presented to them
- retain it for long enough to make a judgement
- be able to make a judgement free from influence
- be ‘decision specific’.

**Who decides whether a person has capacity?**

Any decision regarding whether a person has capacity or not is underpinned by the Human Rights Act 1988 and the principles set out in the Adults with Incapacity (Scotland) Act 2000 and the Mental Health (Care and Treatment) (Scotland) Act 2003. The decision will be made by doctors and lawyers.

**Session 3. Making decisions, advance statements and Adults with Incapacity (Scotland) Act 2000**

All clinical decisions give rise to ethical concerns at some level. No treatment decision or decision not to treat is ethically neutral. Such decisions always involve values as well as facts.5

Julian C Hughes

This statement highlights how difficult it is to make ethical decisions. They are complex and involve values as well as facts.

**Discussion point**

In groups, think about a difficult ethical decision you have had to make. Describe how you arrived at your decision and what you took into account when making your decision. Write down your conclusions.

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5 Hughes, J. Palliative care in severe dementia. London: Quay Books, 2005
Further reading


Advance planning

[View PowerPoint presentation]

Key messages from the PowerPoint presentation

- there are lots of terms used to describe planning for the future; examples include living wills, advance statements, advance decisions or directives and anticipatory care planning. An advance statement is about a person’s choices and an advance directive describes the type of care that they wish to receive in the future. A living will is a less precise concept and may be used to describe either an advance statement or directive and may be completed by a lawyer
- there have been a number of Government initiatives which support the idea of planning ahead to ensure the person has a voice in future care needs
- advance statements provide a voice when the person is no longer able to speak for him or herself
- taking the wishes of the person into account is very important when making decisions about them on their behalf. Advance statements help with advance planning, which in turn helps with the decision-making process
- advance statements consist of two parts. The first part is a personal statement and covers practical arrangements, such as where the person wants to live. The second part is a statement of values. This is important in ensuring that the person’s values are respected and their care remains person-centred
- an advance decision is not an easy document to complete as it will force the person to think about the care they would wish to receive at the end of their life when they are no longer able to speak for themselves. It may be difficult to find the right time to have these discussions and the topic may have to be visited at different times and handled in a sensitive and supportive way
- discussions for completing an advance decision include resuscitation, eating and drinking, use of antibiotics, medical treatment, management of pain or antipsychotic medication and attitudes to long term care and hospital. There will be decisions to be made with regard to refusal to treat
- however having these discussions and completing such a form allows the person to have an understanding of diagnosis and prognosis. A chance to express emotional and spiritual thoughts
- consider the possibility of dying and to have these discussions with family and friends
- planning for the future helps care staff provide good palliative care because it adopts an open and honest approach which includes
- accurate diagnosis and disclosure
- education and support for the person with dementia and their families
- planning for future incapacity by nominating someone who will respect the wishes of the person and speak on their behalf when they are no longer able to do this for themselves
- sometimes welfare attorneys and guardians find making decisions on behalf of their relatives painful and difficult. It may be described as an ‘ethical burden’
- making an advance statement/decision is challenging for someone with dementia because of the length of the illness and the unpredictable course that it can take. It is also difficult to make decisions about the future when the person may not know what situations they will encounter in the future
- although advance statements/decisions are not specifically recognised in law and are not legally binding, they still have an important role to play in providing information about the person’s wishes when they are no longer able to speak for themselves.
Your notes – use this space to add your own notes

Discussion point

Spend a few minutes looking at the advance statement template below. Ask the care staff in your group whether there are implications for their patients/residents. Also talk through the implications for all of us as members of the public.
**Advance statement template**

This is my advance statement. When I wrote this, I could make decisions for myself and understand the consequences of my decisions.

My name is:  

My date of birth is:  

My address is:  

When I wrote this, I spoke to these people:  

My GP is called Dr  

My GP’s address is:  

I do/do not have a welfare attorney. His/her name is:  

My welfare attorney’s address is:  

The treatments I would like to receive are:  

If I can’t make decisions about my treatment, I would like you to consult this person:  

I would not like to receive the following treatments under the following circumstances:  

I do not want to receive any treatment to keep me alive if the following happens to me:  

Here is my signature:  

Here is the signature of my witness:  

This advance statement was witnessed on (date):  

**Advance statement review.** I reviewed this advance statement on (date):  

Here is my signature: 

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Statement of values
If you choose to, you can also include a statement of what is important to you in your advance statement. Here is a list of things you might want to include (drawn up by Alzheimer Europe).

1. Preferences. Here is a list of some preferences in my life that are important to me – for example, about what I wear, what I eat or drink, my personal habits and lifestyle, about company, music or other entertainment, hobbies or pastimes, special interests and what things I have around me. Knowing about these will help those who care for me to ensure my comfort and wellbeing.

2. My spiritual and philosophical beliefs. Here I put down the spiritual or philosophical beliefs or principles that are important to me in my life. Here I also put down what, if any, religion I belong to, and what importance religion has in my life generally.

3. What makes life worth living. Here are some of the things that give special meaning to my life, including things about my health and welfare, relationships, work, leisure, art, sport and recreations. These are the things that make me the sort of person I am.

4. Dislikes. Here is a list of some of my important personal dislikes – for example, about things I do not like doing or being involved with, or things that I dislike others around me doing, or about my environment. Knowing about these will help those who care for me avoid causing me unnecessary distress or discomfort.

5. What I fear most. Here are some of the things that might take away the pleasure from my life, or make me feel that my life had lost its meaning or quality. They include things that would make me fearful, anxious or distressed.
6. **Attitudes to making decisions.** Here I put down my thoughts about how I like to make decisions – how independent-minded I am, and/or how much I tend to depend on the advice of others.

7. **People who matter.** This is a list of the most important people in my life, and how I would like them to be involved if I am not capable of making certain decisions about my health or welfare. Here I also list particular people that I would not wish to be involved if I were not capable of making certain decisions about my health or welfare.

8. **My attitudes to professionals who are treating me and caring for me.** Here I put down any particular views I have about my relationships with doctors, nurses or others in the other caring professions, especially the degree to which I tend to rely on their judgements.

9. **Attitudes to illness and disability.** Here I put down my views about how I might cope with illness or disability, including pain and discomfort, loss of my mental powers or loss of my physical abilities.

10. **Attitudes to death and dying.** Here I put down any beliefs or principles that should influence the decisions people make on my behalf when there is a possibility of my imminent death. This includes my views about the sanctity of life, and about maintaining life artificially. Here I also put down any particular beliefs or views I hold about giving treatment to relieve pain or suffering, and about artificial methods of feeding, where giving or withholding these might either hasten or delay my death. Here are my wishes about the circumstances of my death, understanding that, for a variety of reasons, these wishes may be difficult to achieve. These include where I would like to be and whom I would like to have around me.

11. **After my death.** Here are some wishes about what should happen in the time after my death; for example, about who should be informed and my funeral.
12. **Other values.** Here I put down any other values, principles or beliefs that I have not mentioned before, but which are important to me.

Note to tell people you have made an advance statement. Here is a note to tell people that you have an advance statement. The person you name on the note could be your carer, your welfare attorney or nearest relative. You can cut it out and carry it with you all the time; for example, you could put it in your purse or wallet.

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**Medical treatment information**

My name is: ..........................................................

I have made an advance statement about the care and treatment I want. If I can’t make the decision for myself, please contact this person.

Name: ..........................................................

Phone number: ..................................................

My GP is called Dr: .............................................

My GP’s phone number is: ....................................
Making an advance decision

Planning for tomorrow
In separate staff/family member groups think about and write down your answers:
Is there a right or wrong time to discuss end-of-life care planning?

How do you approach this topic with people with dementia and their families?

What areas of care do you think you should cover?

Many people with dementia and their families will not have to face all the situations posed by these questions, although in the words of Miguel de Cervantes ‘to be prepared is half the victory’. Remember this quotation from the Dalai Lama: ‘Where ignorance is our master, there is no possibility of real peace’.

Making difficult decisions

The following extract is from an unpublished article called ‘Making difficult decisions’. It explores some of the questions that may have to be answered during the progression of a person’s dementia journey, and seeks to provide sufficient information to make informed decisions possible.

What if I am asked about resuscitation?
This is a subject that health professionals find difficult to talk about. Scotland has a fully integrated Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR) policy. This means that a form is completed communicating a decision has been made in the event of a cardiac arrest. This can be made by the person themselves and some people with dementia who have written an advance statement or advanced decision. They may already have considered this issue and may have clear views on what they would want. If they are unable to do so, a person who has obtained an intervention order or is a legally appointed welfare attorney/welfare guardian, may be asked to make the decision and sign the form. Family/carers or next of kin should not be asked to make a decision – their role is to provide information about the person’s previously expressed wishes, beliefs, values and preferences about what the person would have wished in this situation.

Things to bear in mind include:

- CPR should only be offered if it is realistically judged likely to be medically successful in achieving sustainable life for the person in the event of a cardio respiratory arrest
- healthcare staff are not obliged to carry out interventions that they judge are not indicated/may be harmful. The responsibility for deciding if resuscitation is in the person’s best interest lies with the lead clinician with responsibility for the person.
- As a relative it is very difficult to make this decision on behalf of another person, especially if you are unsure of what they would have wanted.
- CPR is not terribly successful in the best of circumstances. TV dramas have possibly given a misleading picture about the effectiveness of resuscitation
- if the person is dying naturally of his or her disease, there is really no decision to be made, as attempts to resuscitate them would generally not be in their best interests
- research evidence suggests that the chances of survival after CPR for people with dementia are very poor
- it is important to discuss with the doctor what length and quality of life could be expected if CPR was successful.

Why is the completion of the DNACPR form important?
The policy is intended to prevent inappropriate, futile and/or unwanted attempts at CPR which may cause significant distress as death with an inappropriate CPR attempt which may be undignified and traumatic.

When a person is being transferred to a different care setting it is necessary for the ambulance crew involved to have the original DNACPR or verbal confirmation that the form exists. The crew must also be informed of whether there has been discussion with the person or their family about the DNACPR prior to the journey. This ensures compliance with the Scottish Ambulance Service End of Life Care Plan.

The out of hours service should be made aware of the existence of the DNACPR form for the person who is being cared for in the community.

If there is a change of circumstance, it is essential that the form be reviewed accordingly.

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What if I have concerns about difficulties with eating and drinking?
There is nothing more distressing for staff and relatives than seeing a person struggling
to eat or drink. When someone stops eating it is often a tangible sign that they are not
going to get better. As a person with dementia, you may have clear views on the type of
treatment you would like if you stop being able to eat or drink. As a relative, this is likely
to be a very distressing situation.

Swallowing difficulties are common in people with dementia and may become
more severe as the illness advances. In straightforward situations, they can be
managed successfully by thickening liquids, positioning the person correctly and
using special cups. Speech and language therapists can also offer advice on managing
swallowing problems. Problems may arise if there is a chance of the person aspirating
food. Aspiration involves the entry of material into the lungs, and may lead to the
development of pneumonia. Swallowing difficulties also lead to the associated problems
of poor nutrition such as weight loss, susceptibility to infection and breakdown of skin
integrity.

One of the strategies that may be successful is non-oral feeding. Options include a
nasogastric (NG) tube inserted up the nose, or a percutaneous endoscopic gastrostomy
(PEG). In this procedure the tube is inserted surgically into the abdomen. However,
studies have shown that these feeding methods are contraindicated in people with
advanced dementia for a variety of reasons:

- the person with dementia may not understand what the tube is for and pull it out
  (restraint may be used to prevent this happening)
- these types of feeding have not been shown to stop weight-loss or prevent
  malnutrition
- tube feeding may still not prevent all the problems of aspiration
- inserting a PEG tube is a surgical procedure that carries a number of risks
- hospitalisation is a stressful experience for people with dementia.9

When your relative has a limited time left to live, is generally accepted that the role of
eating and drinking is limited to pleasure, rather than nutrition and hydration. In the
last few days/hours of their lives, most people only need sips of water to keep them
comfortable, and it is rare for them to feel hungry. However, adequate mouth care
becomes really important in keeping the person comfortable.

What if you feel strongly about not being given antibiotics?
One carer commented: ‘I had specifically asked that he was not given antibiotics and
was very angry when I discovered the doctor had prescribed antibiotics. I did not want
his life prolonged.’ A person with dementia may wish to comment in their advance
statement about when they would like to be treated with antibiotics and under what
circumstances. As a relative, you may have made a decision that any treatment to
prolong their life would be wrong and may be disappointed to find that the doctor has
decided to give antibiotics.

9 Summersall, J and Wight, S. When it’s difficult to swallow: the role of the
speech therapist. Nursing & Residential Care 6(11) 2004 550–553
Things to think about include:

- as with any therapy, it is important to assess whether antibiotics would be helpful on a case-by-case basis. For instance, it is possible that they may relieve distress without necessarily prolonging life. Clinical experience suggests that treating a chest infection with an antibiotic is the simplest and quickest way to relieve distress.
- whether antibiotics prolong life is not a clear-cut issue, and there has been some research that the closer the person is to death, the less effective antibiotics will be in prolonging life.\(^{10}\)
- on the other hand, there are also a number of non life-threatening conditions which antibiotics can be used to treat successfully, such as sinusitis or a dental abscess. Whilst this type of infection seldom causes death, it could impact on the remaining quality of life.
- ‘never say never’.

**Adults with Incapacity (Scotland) Act 2000**

[View PowerPoint presentation]

Some adults aged 16 or over may not have the capacity to make important decisions about their finances or welfare. This may be as a result of a mental health problem, learning disability or dementia. The Adults with Incapacity (Scotland) Act 2000 sets out a legal framework which provides a variety of ways for other people to make decisions on their behalf, subject to a range of safeguards.

For more information on the Adults with Incapacity (Scotland) Act 2000 see:

- www.scotland.gov.uk/Topics/Justice/law/awi
- www.publicguardian-scotland.gov.uk

Your notes – use this space to add your own notes

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\(^{10}\) Hallenbeck, J. Palliative care perspectives. Oxford University Press, 2003
The legal framework

The Adults with Incapacity (Scotland) Act 2000 was based on several fundamental principles. These principles are a set of rules which must be followed by anyone making a decision on behalf of someone with dementia.

The principles are:

**Principle 1 – benefit**
- any action or decision taken must benefit the person and only be taken when that benefit cannot reasonably be achieved without it.

**Principle 2 – least restrictive option**
- any action or decision taken should be the minimum necessary to achieve the purpose. It should be the option that restricts the person’s freedom as little as possible.

**Principle 3 – take account of the wishes of the person**
- in deciding if an action or decision is to be made, and what that should be, account must be taken of the present and past wishes and feelings of the person, as far as this may be ascertained. Some adults will be able to express their wishes and feelings clearly, even although they would not be capable of taking the action or decision which you are considering. For example, he/she may continue to have opinions about a particular item of household expenditure without being able to carry out the transaction personally.
- the person must be offered help to communicate his or her views. This might mean using memory aids, pictures, non-verbal communication, advice from a speech and language therapist or support from an independent advocate. A Guide to Communication and Assessing Capacity is available at: www.scotland.gov.uk/Topics/Justice/law/awi/010408awiwebpubs/awiotherpubs

**Principle 4 – consultation with relevant others**
- take account of the views of others with an interest in the person’s welfare. The Act lists those who should be consulted whenever practicable and reasonable. It includes the person’s primary carer, nearest relative, named person, attorney or guardian (if there is one).

**Principle 5 – encourage the person to use existing skills and develop new skills**
- the person should be encouraged to exercise whatever skills he/she has concerning property, financial affairs or personal welfare as the case may be, and to develop new such skills.
In small groups think about the principles of the Act. Discuss examples from the principles, where the principles have been adhered to and provide examples from experience. Consider also other legislation which safeguards a person with dementia where capacity might be an issue, such as the Adult Support & Protection (Scotland) Act 2007 and the Mental Health (Care & Treatment) (Scotland) Act 2003. Both of these are based on a set of key principles.

Your notes – use this space to add your own notes
Medical treatment – Section 47 certificates, also known as Part 5 certificates

The Adults with Incapacity Act brought new rules for treatment when someone is not able to consent. If a doctor believes that a treatment will benefit a patient with dementia who is incapable of consenting, the doctor should sign a certificate of incapacity under Section 47 of the Act which gives him or her authority to treat the person. Before doing so, the doctor should consult with the carer and anyone else closely involved with the person, to get their views on the person’s ability to give consent.

Section 47 certificates provide an important safeguard for people with dementia who no longer have capacity. Unfortunately, a recent joint report by the Care Commission and the Mental Welfare Commission for Scotland found that these forms were ‘often impersonal, too bland or poorly completed and were not accompanied by a treatment plan’.¹¹

Printed on the following page is a copy of a section 47 certificate. For further help refer to the Mental Welfare Commission for Scotland’s document Consent to treatment: a guide for mental health practitioners¹² or the Adults with Incapacity (Scotland) Act 2000 Code of practice for persons authorised under intervention orders and guardians.¹³

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Certificate of Incapacity for the purposes of Section 47(1) of the Adults with Incapacity (Scotland) Act 2000

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Further reading

Mental Welfare Commission for Scotland. Right to treat: delivering physical healthcare to people who lack capacity and refuse or resist treatment, 2011.
Mental Welfare Commission. Dementia: decisions for dignity, Our visits to people with dementia in general hospitals, September to December 2010.
Scottish Government. Making decisions – your rights. (DVD). Telephone 0131 244 3581 to order a DVD or go to www.scotland.gov.uk/Publications/2006/10/26103435/0

Session 4. Communication and pain assessment

Pain impacts on dementia and dementia impacts on pain\textsuperscript{14} 

Dr W McClean

Exercise

Spend a few minutes with your neighbour describing a pain that has troubled you over the last few weeks or months. Then write down how it made you feel and behave.

Discussion point

Think about your answer to the exercise above, then talk about:

\begin{itemize}
  \item whether the feelings you have described might be interpreted as ‘challenging behaviour’ when expressed by someone with dementia
  \item if so, how the person might be treated
  \item whether sedation would be considered as the first-line response to the behaviour, rather than a pain assessment and analgesia.
\end{itemize}

Pain and dementia

[View PowerPoint presentation]

\textsuperscript{14} McClean, W and Cunningham, C. Pain in Older People with Dementia: A Practice Guide. Stirling: Dementia Services Development Centre, 2007
Key messages from the PowerPoint presentation
Research tells us that:

- older people living in the community have significant prevalence of pain
- in acute wards people with dementia do not receive analgesia as readily as younger patients with fewer cognitive impairments
- in long-term care there is a high prevalence of pain in those who can respond verbally
- those with dementia receive less pain management than those with normal cognition
- the awareness, attitudes and knowledge of the attendant staff are important factors in how pain is treated.

Emotions and behaviour associated with uncontrolled pain may include fear, frustration, anxiety, depression, sleeplessness, helplessness and restlessness. These behaviours are often treated with sedation rather than analgesia.

Assessing pain is a skilled and complex task, and carrying out an effective pain assessment becomes more difficult during the later stages of dementia. The process involves:

- taking an accurate pain history
- listening to family and friends
- understanding the concept of probability
- good observation
- good listening skills
- time
- knowing the person
- intuition
- using the most appropriate assessment for the person.

To manage pain effectively you need to combine a range of background information with a variety of practical approaches:

- a knowledge of how the person usually expresses their pain
- a knowledge of treatments the person has previously found helpful
- an avoidance of ‘as required’ analgesia use
- use of both pharmacological and non-pharmacological treatments
- anticipation of any side-effects that may occur when using medication
- following the guidelines set out in the WHO analgesic ladder.

Your notes – use this space to add your own notes

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........................................................................................................................................
On your own, place the following 15 words in order of strength or severity. Then compare your list with your neighbours’.

<table>
<thead>
<tr>
<th>Words describing pain</th>
<th>Most severe</th>
</tr>
</thead>
<tbody>
<tr>
<td>paining</td>
<td></td>
</tr>
<tr>
<td>aching</td>
<td></td>
</tr>
<tr>
<td>hurting</td>
<td></td>
</tr>
<tr>
<td>sore</td>
<td></td>
</tr>
<tr>
<td>stinging</td>
<td></td>
</tr>
<tr>
<td>tender</td>
<td></td>
</tr>
<tr>
<td>excruciating</td>
<td></td>
</tr>
<tr>
<td>agonising</td>
<td></td>
</tr>
<tr>
<td>uncomfortable</td>
<td></td>
</tr>
<tr>
<td>burning</td>
<td></td>
</tr>
<tr>
<td>smarting</td>
<td></td>
</tr>
<tr>
<td>niggling</td>
<td></td>
</tr>
<tr>
<td>sensitive</td>
<td></td>
</tr>
<tr>
<td>cramping</td>
<td></td>
</tr>
<tr>
<td>shooting</td>
<td></td>
</tr>
</tbody>
</table>

Least severe

Adapted from McClean, W and Cunningham, C. Pain in Older People with Dementia: A Practice Guide. Stirling: Dementia Services Development Centre, 2007.

Examples of pain/distress assessment tools
A visual analogue scale
This is not the usual style of an analogue scale. Normally, these are horizontal rather than vertical. However, it is thought that people with dementia can cope better with this orientation, along with the yellow and black colour scheme. The person is asked to rate their pain on the scale, where 1 is the smallest or mildest pain, and 10 is the biggest or worst. In practice, finding out whether an individual can use this type of pain scale will be a matter of trial and error.

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

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

<table>
<thead>
<tr>
<th>Question</th>
<th>Description</th>
<th>Absent 0</th>
<th>Mild 1</th>
<th>Moderate 2</th>
<th>Severe 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q1</td>
<td>Vocalisation e.g. whimpering, groaning, crying</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q2</td>
<td>Facial expression e.g. looking tense, frowning, grimacing, looking frightened</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q3</td>
<td>Change in body language e.g. fidgeting, rocking, guarding part of body, withdrawn</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q4</td>
<td>Behavioural change e.g. increased confusion, refusing to eat, alteration in usual patterns</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q5</td>
<td>Physiological changes e.g. temperature, pulse or blood pressure outside normal limits, perspiring, flushing or pallor (you can still use the tool if you are unable to make these recordings)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q6</td>
<td>Physical changes e.g. skin tears, pressure areas, arthritis, contractures, previous injuries</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Add scores for 1–6 and record here: **total pain score**

Now tick the box that matches the total pain score

<table>
<thead>
<tr>
<th>Score Range</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0–2</td>
<td>No pain</td>
</tr>
<tr>
<td>3–7</td>
<td>Mild</td>
</tr>
<tr>
<td>8–13</td>
<td>Moderate</td>
</tr>
<tr>
<td>14+</td>
<td>Severe</td>
</tr>
</tbody>
</table>
Abbey Pain Scale

Disability Distress Assessment Tool (DisDAT)

Individual's name: ................................................................. .................................................................
Date of birth:  Gender:  NHS No:
Your name: ............................................................................................................................
Date completed: ..........................................................................................................................
Names of others who helped complete this form: ........................................................................

The Distress Passport

Summary of signs and behaviours when content and when distressed

Appearance when CONTENT
Face: .................................................................
Tongue/jaw: .............................................................
Skin: .................................................................
Vocal signs when CONTENT
Sounds: .................................................................
Speech: .................................................................
Habits and mannerisms when CONTENT
Habits: .................................................................
Mannerisms: .............................................................
Comfortable distance: .................................................................
Posture and observations when CONTENT
Posture: .................................................................
Observations: .................................................................

Appearance when DISTRESSED
Face: .................................................................
Tongue/jaw: .............................................................
Skin: .................................................................
Vocal signs when DISTRESSED
Sounds: .................................................................
Speech: .................................................................
Habits and mannerisms when DISTRESSED
Habits: .................................................................
Mannerisms: .............................................................
Comfortable distance: .................................................................
Posture and observations when DISTRESSED
Posture: .................................................................
Observations: .................................................................

Known triggers of distress
(write here any actions or situations that usually cause or worsen distress)

.............................................................................................................................................................
.............................................................................................................................................................
.............................................................................................................................................................
**Disability Distress Assessment Tool**

Please take some time to think about and observe the individual under your care, especially their appearance and behaviours when they are both content and distressed. Use these pages to document these. We have listed words in each section to help you to describe the signs and behaviours. You can circle the word or words that best describe the signs and behaviours when they are content and when they are distressed. Your descriptions will provide you with a clearer picture of their ‘language’ of distress.

<table>
<thead>
<tr>
<th>Communication level*</th>
<th>When content</th>
<th>When distressed</th>
</tr>
</thead>
<tbody>
<tr>
<td>This individual is unable to show likes or dislikes</td>
<td>Level 0</td>
<td></td>
</tr>
<tr>
<td>This individual is able to show that they like or don’t like something</td>
<td>Level 1</td>
<td></td>
</tr>
<tr>
<td>This individual is able to show that they want more, or have had enough of something</td>
<td>Level 2</td>
<td></td>
</tr>
<tr>
<td>This individual is able to show anticipation for their like or dislike of something</td>
<td>Level 3</td>
<td></td>
</tr>
<tr>
<td>This individual is able to communicate detail, qualify, specify and/or indicate opinions</td>
<td>Level 4</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Appearance</th>
<th>When content</th>
<th>When distressed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ring the words that best describe the facial appearance</td>
<td>Passive, Laugh, Smile, Frown, Grimace, Startled, Frightened, Other: .................................................</td>
<td>Passive, Laugh, Smile, Frown, Grimace, Startled, Frightened, Other: .................................................</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Jaw movement</th>
<th>When content</th>
<th>When distressed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ring the words that best describe the jaw movement</td>
<td>Relaxed, Drooping, Grinding, Biting, Rigid, Other:</td>
<td>Relaxed, Drooping, Grinding, Biting, Rigid, Other:</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Appearance of eyes</th>
<th>When content</th>
<th>When distressed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ring the words that best describe the appearance</td>
<td>Good eye contact, Little eye contact, Avoiding eye contact, Closed eyes, Staring, Sleepy eyes, ‘Smiling’, Winking, Vacant, Tears, Dilated pupils, Other: ..........................</td>
<td>Good eye contact, Little eye contact, Avoiding eye contact, Closed eyes, Staring, Sleepy eyes, ‘Smiling’, Winking, Vacant, Tears, Dilated pupils, Other: ..........................</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Skin appearance</th>
<th>When content</th>
<th>When distressed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ring the words that best describe the appearance</td>
<td>Normal, Pale, Flushed, Sweaty, Clammy, Other: ......................</td>
<td>Normal, Pale, Flushed, Sweaty, Clammy, Other: ......................</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Vocal sounds (NB the sounds that a person makes are not always linked to their feelings)</th>
<th>When content</th>
<th>When distressed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ring the words that best describe the sounds. Write down commonly used sounds (write them as they sound; ‘tizz’, ‘eeiow’, ‘tetetetete’)</td>
<td>Volume: high, medium, low Pitch: high, medium, low Duration: short, intermittent, long Description of sound/vocalisation: Cry out, Wail, Scream, Laugh, Groan/moan, Shout, Gurgle, Other: ......................</td>
<td>Volume: high, medium, low Pitch: high, medium, low Duration: short, intermittent, long Description of sound/vocalisation: Cry out, Wail, Scream, Laugh, Groan/moan, Shout, Gurgle, Other: ......................</td>
</tr>
<tr>
<td>Speech</td>
<td>When content</td>
<td>When distressed</td>
</tr>
<tr>
<td>--------</td>
<td>--------------</td>
<td>-----------------</td>
</tr>
<tr>
<td>Ring the words which best describe the speech. Write down commonly used words and phrases. If no words are spoken, write NONE: Clear, Stutters, Slurred, Unclear, Muttering, Fast, Slow, Loud, Soft, Whisper, Other (eg swearing):</td>
<td>Clear, Stutters, Slurred, Unclear, Muttering, Fast, Slow, Loud, Soft, Whisper, Other (eg swearing):</td>
<td>Clear, Stutters, Slurred, Unclear, Muttering, Fast, Slow, Loud, Soft, Whisper, Other (eg swearing):</td>
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</table>

<table>
<thead>
<tr>
<th>Habits and mannerisms</th>
<th>When content</th>
<th>When distressed</th>
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</thead>
<tbody>
<tr>
<td>Write down the habits or mannerisms, eg ‘Rocks when sitting’</td>
<td>Close with strangers</td>
<td>Close with strangers</td>
</tr>
<tr>
<td>Write down any special comforters, possessions or toys this person prefers</td>
<td>Close only if known</td>
<td>Close only if known</td>
</tr>
<tr>
<td>Ring the statements which best describe how comfortable this person is with other people being physically close by</td>
<td>No one allowed close</td>
<td>No one allowed close</td>
</tr>
<tr>
<td></td>
<td>Withdraws if touched</td>
<td>Withdraws if touched</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Body posture</th>
<th>When content</th>
<th>When distressed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ring the words that best describe how this person sits and stands</td>
<td>Normal, Rigid, Floppy, Jerky, Slumped, Restless, Tense, Still, Able to adjust position, Leans to side, Poor head control, Way of walking: normal/abnormal</td>
<td>Normal, Rigid, Floppy, Jerky, Slumped, Restless, Tense, Still, Able to adjust position, Leans to side, Poor head control, Way of walking: normal/abnormal</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Body observations</th>
<th>When content</th>
<th>When distressed</th>
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</thead>
</table>

*Adapted from the Kidderminster Curriculum for Children and Adults with Profound Multiple Learning Difficulty (Jones, 1994, National Portage Association)*
Information and instructions

DisDAT is:

- **intended** to help identify distress cues in individuals who have severely limited communication
- **designed** to describe an individual’s usual content cues, thus enabling distress cues to be identified more clearly
- **NOT a scoring tool.** It documents what many carers have done instinctively for many years, thus providing a record against which subtle changes can be compared
- **only the first step.** Once distress has been identified, the usual clinical decisions have to be made by professionals
- **meant to help you and the individual in your care.** It gives you more confidence in the observation skills you already have, which in turn will give you more confidence when meeting other carers.

When to use DisDAT

**When the team believes the individual is NOT distressed,** the use of DisDAT is optional, but it can be used as a:

- baseline assessment document
- transfer document for other teams.

**When the team believes the individual IS distressed,** if DisDAT has already been completed it can be used to compare the present signs and behaviours with previous observations documented on DisDAT. It then serves as a baseline to monitor change.

If DisDAT has not been completed:

- when the person is well-known DisDAT can be used to document previous content signs and behaviours and compare these with the current observations
- when the person is new to a carer, or the distress is new, DisDAT can be used to document the present signs and behaviours to act as a baseline to monitor change.

How to use DisDAT

- observe the individual when content and when distressed. Document this on the accompanying pages. Anyone who cares for them can do this
- observe the context in which distress is occurring
- use the accompanying clinical decision distress checklist to assess the possible cause
- treat or manage the likeliest cause of the distress
- the monitoring sheet is a separate sheet, which may help if you want to see how the distress changes over time
- the goal is a reduction in the number or severity of distress signs and behaviours.

Remember

- most information comes from several carers together
- the assessment form need not be completed all at once and may take a period of time
- reassessment is essential as the needs may change due to improvement or deterioration
- distress can be emotional, physical or psychological. What is a minor issue for one person can be major for another
- if signs are recognised early then suitable interventions can be put in place to avoid a crisis.
Clinical decision distress checklist.
Use this to help decide the cause of the distress.

Is the new sign or behaviour?

Repeated rapidly?
- consider pleuritic pain (in time with breathing)
- consider colic (comes and goes every few minutes)
- consider repetitive movement due to boredom or fear.

Associated with breathing?
- consider infection, COPD, pleural effusion, tumour.

Worsened or precipitated by movement?
- consider movement-related pains.

Related to eating?
- consider food refusal through illness, fear or depression
- consider food refusal because of swallowing problems
- consider upper GI problems (oral hygiene, peptic ulcer, dyspepsia) or abdominal problems.

Related to a specific situation?
- consider frightening or painful situations.

Associated with vomiting?
- consider causes of nausea and vomiting.

Associated with elimination (urine or faecal)?
- consider urinary problems (infection, retention)
- consider GI problems (diarrhoea, constipation).

Present in a normally comfortable position or situation?
- consider anxiety, depression, pains at rest (eg colic, neuralgia), infection, nausea.

If you require any help or further information regarding DisDAT see www.disdat.co.uk for contact details.

Further reading


Understanding pain in dementia

Compiled by Dr Lindsay Martin, Palliative Care Consultant, Dumfries & Galloway NHS Trust.

Many cognitively impaired patients communicate poorly, if at all, and are unable to describe pain or discomfort accurately. These patients may express problems behaviourally – sometimes using combative or agitated behaviours. Pain relief can sometimes improve cognitive performance and behaviour. More than 60% of older adults have co-morbidities – such as arthritis, cancer and neuropathy – that elevate the likelihood of pain.

Taking a history
In taking a pain history when the person is cognitively impaired it is essential to ask the views of relatives or care staff who know the person best. It is important to assess the following:

- the past history, which may indicate falls or co-morbidities that may cause pain
- the site of the pain (this may indicate an underlying local cause or a referred origin)
- changes in behaviour that may be caused by the pain
- the nature of the pain (the duration and speed of onset; whether the pain is intermittent or constant)
- the impact of the pain on the patient’s activities.

It is important to understand that the physical aspects of a patient’s pain cannot be treated in isolation from the psychological, emotional, and social aspects.

Assessment – select the appropriate tool for each individual
Many patients who are cognitively impaired can rate pain as reliably as others, provided that the appropriate pain assessment tool is selected. Research indicates that 83% of patients with mild to moderate cognitive impairment can complete pain assessment scales for the pain they are experiencing at that moment.

When the person with dementia is no longer able to express their pain verbally
Once cognitive impairment becomes severe, verbal skills diminish. The burden of pain assessment and intervention shifts to those who can observe the patient. Clinicians and caregivers must rely on the patient’s non-verbal behaviours, vocalisations and changes in functional status as pain indicators.

Analgesic ladder
The World Health Organization (WHO) has produced an analgesic ladder to be used as a guide for prescribing analgesics. If a patient does not experience pain relief on one step of the analgesic ladder, they should progress to the next step. When a patient’s behaviour, expression or verbalisations change for no obvious reason, pain is a possibility.

The best pain assessment by proxy is that provided by caregivers or family members who know the patient. Only they can identify changes from a patient’s baseline behaviours that may signify pain.

In its guidelines for treating pain in the cognitively impaired person, the Hospice Foundation recommends that clinicians use the following guide: if the clinician would expect a cognitively intact person to experience pain in the cognitively impaired patient’s circumstances, he or she should assume that the patient is experiencing pain.

Prescription
Analgesia should be provided in the same way that it is provided for cognitively intact individuals. The WHO analgesic ladder should be the basis for the choice of treatment, with consideration given to medication side-effects and patient co-morbidities. Remember to consider side-effects of co-analgesics, eg renal and gastrointestinal problems with non-steroidal anti inflammatory drugs (NSAIDs) such as aspirin, ibuprofen and naproxen.

Oral analgesic drugs are usually the first-line option for treating pain. The choice of analgesic should be based on the severity of the pain, rather than the stage of the patient’s disease. Analgesics should be taken regularly and the dose gradually increased, as necessary.

Step one. The first step of the analgesic ladder is to use a non-opioid analgesic, for example paracetamol. Adjuvant drugs to enhance analgesic efficacy, treat concurrent symptoms that exacerbate pain and provide independent analgesic activity for specific types of pain may be used at any step (eg NSAIDs).
**Step two.** If the pain is persisting or worsening despite step one, then a mild opioid such as codeine should be added (not substituted). Examples are combination preparations including Co-proxamol and Co-codamol.

**Step three.** When higher doses of opioid are necessary, the third step is used. At this step an opioid for moderate to severe pain is used, eg morphine. The dose of the stronger opioid can then be titrated upwards, according to the patient’s pain, as there is no ceiling dose for morphine.

Medications for persistent pain should be prescribed on a regular basis and the patient should always have extra medication available to take in between doses if they experience breakthrough pain.

**Increasing or uncontrolled pain**
At all steps, consider use of adjuvant analgesic\(^\text{15}\)

**Regular reassessment**
If the mild to moderately impaired individual used a pain scale successfully before treatment, the same scale should be used periodically afterwards. If the patient experiences some relief but does not return to baseline, the dose or frequency of medication can be increased. If the pain persists, other causes should be considered, including side-effects of the medication used. The treatment may become an assessment tool, with a positive outcome substantiating that pain had been present.

Treatment with analgesics will of necessity be empiric (derived from trial and observation) in the cognitively impaired patient. Caregivers should make specific notes of those behaviours they think are manifestations of pain, including the frequency and duration of behaviours or verbalisations. Once they administer analgesics, they should monitor to ensure that the manifestations are improving, keeping in mind that mild sedation and cognitive changes are side-effects of opioids.

Pain assessment among cognitively impaired patients requires vigilant observation. When changes are detected, those that are associated with disease pathology need to be distinguished from those that are symptomatic of pain.\(^\text{16}\)

**Further reading**

---

### Accurate assessment and reassessment of pain

<table>
<thead>
<tr>
<th>STEP ONE</th>
<th>Non-opioid eg paracetamol 1g QDS (four times a day)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>If MAXIMUM REGULAR dose ineffective MOVE UP</strong></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>STEP TWO</th>
<th>Weak opioid eg Co-codamol 30/500 2 tabs QDS (four times a day)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>If MAXIMUM REGULAR dose ineffective MOVE UP NOT SIDEWAYS</strong></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>STEP THREE</th>
</tr>
</thead>
<tbody>
<tr>
<td>- strong opioid eg Sevredol tablets</td>
</tr>
<tr>
<td>- initially 5–10mg 4-hourly and as required</td>
</tr>
<tr>
<td>- titrate dose until pain controlled, increasing by 30–50% from previous dose</td>
</tr>
<tr>
<td>- when pain controlled, convert to modified release preparation, eg Zomorph</td>
</tr>
<tr>
<td>- prescribe breakthrough analgesia prn (equivalent to 1/6 total daily dose)</td>
</tr>
<tr>
<td>- if breakthrough medication required twice or more in 24 hours consider increasing modified release preparation by 30–50% from previous dose or adding adjuvant.</td>
</tr>
</tbody>
</table>

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\(^\text{15}\) NHS Dumfries & Galloway. Palliative care guidelines. Dumfries: NHS Dumfries & Galloway, 2007

Session 5A. An end-of-life case study

Form two groups, one made up of care staff and the other of relatives. In your group, identify the issues raised in the following case study from the perspective of Molly, the care staff and Liz. Then come together as a single group again and share your responses.

Case study
Molly has Alzheimer’s disease and has been in long-term care for five years. She also has Type 2 diabetes and arthritis. Her husband Tom died 10 years ago. She was a schoolteacher with lots of interests including country dancing and reading. She has one daughter (Liz) who visits on a regular basis.

When Molly first moved into care she was very active and walked about a lot, but over the past year she has had a number of falls and is now unable to walk at all. She has lost nearly all her verbal skills but still smiles when she sees Liz. The only time she is vocal and shouts out is when she is receiving personal care. She is doubly incontinent and needs help with all aspects of personal care. Over the past few months she has had recurrent urinary tract/chest infections, and on several occasions Liz has been called as the staff felt that Molly was close to death. On each occasion she rallied.

Over the last few weeks the situation has become critical again: she is now refusing food and it is extremely difficult to get her to drink.

What are the issues for the staff? Think as widely as possible including the emotional and support aspects.


What are the issues for Molly?


What are the issues for Liz?
Session 5B. End-of-life care
(alternative option for staff only)

Palliative care has been described as ‘a safe place to suffer’\(^{17}\) and for care to be effective it is critical that physical symptoms are properly managed.

Exercise part 1

Working in small groups, list end of life symptoms that are commonly experienced by people with dementia.

Exercise part 2

Working in small groups, describe a person with late-stage dementia who you have looked after, and whose confusion has presented you with a challenge. This may have occurred as they were approaching the end of their life, or perhaps within an acute hospital setting where they were being treated for a physical illness. Talk about why it was difficult.

Discussion point

Talk about the difference between dementia and delirium.

---

17 Stedeford, A. A safe place to suffer. Palliative Medicine 1 1987 73-4
Dementia and delirium

There is a difference between dementia and delirium, and a person’s mental confusion may be partly due to delirium, as well as dementia. It is vital to distinguish between delirium (acute confusional state), which can be treated, and the chronic confusional state of dementia. You should never assume that symptoms which might be due to delirium are in fact due to dementia.

Causes of delirium:

- infection
- biochemical factors
- dehydration
- uraemia
- hypercalcaemia
- hormonal causes (thyroid, pituitary or adrenal abnormalities)
- cardiac problems
- terminal illness
- recent trauma, such as a fracture or major surgery
- constipation
- side-effects of medication, such as analgesia or steroids
- suddenly stopping drugs
- being in an unfamiliar place
- pain.

Delirium is often caused by more than one factor, and sometimes the cause cannot be identified. However, in order to treat the delirium it is essential to treat the cause. Delirium can be difficult to differentiate from dementia. On admission, it is important to identify all older people who may have dementia or delirium. The distinguishing features of delirium are:

- rapid onset
- levels of confusion that fluctuate during the day
- potential increase or decrease in alertness.

In addition, the person’s thinking will be increasingly disorganised, and they are likely to exhibit inattention and memory/psychomotor impairment.

Discussion point

How can the effects of delirium be minimised?

Discussion point

Talk about the role of medication when treating delirium.
Sometimes it is difficult to recognise when someone is very close to death. The long illness trajectory experienced by many people with dementia can make it hard for professionals to diagnose the onset of active dying. Despite this, it is important to try and recognise when someone is entering the last few days or hours of their life so that a care pathway can be established for them. This will help with the planning of care and ensure that relatives are fully aware of the situation. Working together in small groups, discuss signs and symptoms that may suggest the person with dementia is dying.

Talk about what support is available to you when you are working with patients who are close to dying. If no/little support is currently available, how could this be addressed?

Further reading

Session 6. Planning care

[View PowerPoint presentation]

Key messages from the PowerPoint presentation

The *Living and dying well*\(^{18}\) action plan stresses the importance of good care planning. Effective communication is central to good care planning. People with dementia need easy access to appropriate services, and integrated care pathways (ICPs) are one way of achieving this. They aim to ensure that the right people:

- do the right things
- in the right order
- at the right time
- in the right place
- with the right outcome
- all paying close attention to the patient experience.

A national dementia ICP has been developed, and there are already other ICPs in place to manage the care of people who are dying.

The Prognostic Indicator Tool, developed by the Gold Standards Framework\(^{19}\) enables care to be planned more effectively and encourages better communication between all those involved in providing care.

Your notes – use this space to add your own notes


\[^{19}\text{www.goldstandardsframework.nhs.uk/content/gp_contract/PG%20Paper%20Final%20revised%20v5%20Sept08.pdf}\]
## Record of completed sessions

<table>
<thead>
<tr>
<th>Topic</th>
<th>Date</th>
<th>Initialled</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Session 1.</strong> Living and dying</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Session 2.</strong> Capacity and incapacity</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Session 3.</strong> Making decisions, advance statements and Adults with Incapacity (Scotland) Act 2000</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Session 4.</strong> Communication and pain assessment</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Session 5A.</strong> An end-of-life case study</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Session 5B.</strong> End-of-life care (alternative option for staff only)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Session 6.</strong> Planning care</td>
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</tbody>
</table>

This is to certify that .................................................................

has attended sessions numbered ..............................................

Signed .................................................................

Designation .................................................................

Dated .................................................................

What have you learned from the sessions you have attended?

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How will it affect either your care practice or your role as a relative?

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Appendix A: Big Ideas

Keep a record here of any ‘big ideas’ generated by your group, then use the action plan in Appendix B to help you successfully implement some of these new ideas.
Appendix B: Identified areas for improvement: action plan template

Throughout this three-day education programme, you have been asked to record some of the group’s suggestions for improving practice in the ‘big ideas’ section the back of the workbooks. Look at this list of ideas now, and prioritise up to three ideas that you would like to introduce within your care setting. It may be helpful to make the simplest idea priority 1 as you and your colleagues are likely to gain encouragement from a ‘quick win’ to get you started. You may also find the SMART approach (Specific, Measurable, Attainable, Relevant and Time bound) helpful in framing your thinking. This involves making sure that each point is specific, measurable, achievable, relevant and time-bound.

We hope that you will be able to take part in subsequent action learning sessions, which will focus on your successes in implementing the changes identified in your action plan. Staff-members should share the completed action plan with participating relatives from their care setting.

Use the following template for each of your priorities.

<table>
<thead>
<tr>
<th>Palliative and end of life care action plan</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>What we will achieve</strong></td>
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<td>..................................................................................................................</td>
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<tr>
<td><strong>How we will do it</strong></td>
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Key milestones

Assessment and review

Outcomes

For more information about dementia, including information in different languages, visit:

- www.alzscot.org
- www.alzheimers.org.uk
- www.alz.co.uk
- www.dementiacareaustralia.com
- www.alzheimers.org.au
Use this page for your additional responses to, or comments on, the exercises and discussions in this workbook.

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