The Gold Standards Framework in Dementia Training Programme

Good Practice Guide & Workbook Folder

December 2012
Guidance and resources to accompany the distance learning GSF Dementia Training Programme and DVD

Further information is available on the GSF website, www.goldstandardsframework.org.uk
Tel: 01743 291 891
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Welcome, Introduction and Overview of GSF Dementia

**Session 1 – Overview and Introduction to Dementia**

**Learning Outcomes**

1. **What is dementia?** To understand the importance of improving care for people with dementia, learn more about the disease and the impact it has on a person.

2. **Person Centred Care.** To learn more about the person-centred approach in dementia care - seeing the person behind the disease.

3. **Dignity.** To consider ways of enhancing dignity, respect and spiritual care for people with dementia in your place of work.

**Action Plan after Session 1**

**Session 2 – Assessing hidden clinical needs**

**Learning Outcomes**

1. **Decline.** Understanding decline in dementia and recognising and responding to signs of deterioration.

2. **Pain.** Understanding pain in dementia - recognition, causes and management and the use of assessment tools

3. **Other symptoms.** Understand symptom control basics, and the impact of other co-morbid conditions.

**Action Plan after Session 2**

**Session 3 – Assess—Personal**

**Learning Outcomes**

1. **Communication** – Learn more about effective ways to communicate and listen to people with dementia.

2. **Advance Care Planning** Understand more about Advance Care Planning and Best Interest discussions for people with dementia and put these into practice

3. **Carers** understand the particular importance of supporting carers, their needs and the significance of early loss and bereavement

**Action Plan after Session 3**

**Session 4 – Plan—Coordination**

**Learning Outcomes**

1. **Coordination** Explore means of enabling better coordinated cross boundary care and reducing crises

2. **Reducing hospitalisation.** Understand the importance of reducing hospitalisation in people with dementia enabling more to remain safely at home.

3. **Care of the dying** Learn more about ways to ensure a good death for people with dementia in their preferred place of choice.

**Action Plan after Session 4**

For GSF templates and more resources see Library Section and Toolkit on GSF website
Welcome and thank you for joining the GSF Dementia Training Programme

Dear Colleague,

Firstly thank you for taking part in this new GSF Quality Improvement Training Programme. We very much hope you will enjoy this programme, and that it will be a real help to you and your team to enable you to give the best possible care to every one of your service users who has dementia and is nearing the end of life.

People often say they want the best medical care and support, delivered in a human and compassionate way by people with whom they can develop trusting relationships. They want to have some control in their care, be involved in decision making, to be comfortable and minimise suffering from physical symptoms such as pain with no scary emergencies and for things to be as normal as possible so they can enjoy life to the full whilst they still have it, quality not just quantity - to ‘live well to the end of life’.

Many are concerned that they might become a burden to their families or carers, they might fear being alone, or in pain or other serious concerns. Some have unfinished business to sort out, both practical but more often emotional and spiritual and want time to say important things. But most say they would prefer to be at home, feeling safe knowing what to do if they did need help but surrounded by people they love and life-affirming familiar things that remind them of ‘a life well lived and a death worth dying for’ (Terry Pratchett 2010)

For people with dementia this can sometimes be a challenge as they can be disadvantaged by their illness, and they are unable to achieve this for a variety of reasons but they should be able to expect the same choices as everyone else and receive the same level of respect and care at the end of their lives in an appropriate environment.

This is what we aim to do — to enable people nearing the end of life to stay at home and to live out their final days as well as possible in accordance with their wishes. This is not an unreasonable request you might think - but somehow it can still be quite a challenge to get this right every time and it does take some backstage planning — hence GSF!

By looking ahead, providing earlier support for these people, better predicting, assessment, and anticipation of their likely needs and choices and more pro-active planning, then this wish is more likely to be fulfilled for more people.

This is what GSF aims to do - to improve the organisation or ‘hands’ of care, to help the ‘head’ knowledge and ‘heart’ care. so that they all work together to improve the person’s experience of care.

Key Messages in End of Life Care

- End of Life Care is important and affects us all
- Most die of non-cancer, co-morbidity in old age
- Too few people die at home/in their place of choice
- Hospital deaths are expensive, usually not where patients choose to be and often avoidable
- Everyone has a part to play
- GSF helps improve quality and coordination of generalist care
Grass roots development of GSF

GSF was first developed in 2000 from within primary care - it developed from the bed side not the board room, from clinicians not committees! It grew from a strong belief that within primary care we are doing well, but sometimes things aren’t as good as we would like, often due to a lack of organisation that could have been addressed with a bit of forethought. There are now GSF Training Programmes for:-

- Care Homes — nursing and residential homes
- Acute Hospitals
- Community Hospitals
- Others e.g. prisons, for children etc
- Plus a toolkit of transferable GSF tools and resources used in different settings

GSF focuses on improving ‘organisational learning’ – the way that teams and organisations work together with their usual day-to-day systems of care. For people nearing the end of life and their families, there is only one chance to get this right.

With the increasing challenge of the ageing population and the rising death rate (predicted to rise by 17% from 2012), it is vital that we act now to improve the provision of care for the increasing numbers of people with dementia nearing the end of life with ever more complex conditions – Caring for people at home, who are nearing the end of life is becoming increasingly important.

This dementia programme complements all the other GSF training programmes as people with dementia are cared for in all these different settings and the problems experienced by them and their carers are similar wherever they are.

Easy learning, building on what you already know

- This training programme builds on your current work, but helps work towards improved communication, collaboration and co-ordination, especially in cross-boundary areas of working.
- It will give you skills and knowledge, help you know what to do, what might happen in future, and who can help but mainly it will help you gain confidence in your ability to give good care for the most vulnerable people
- Aspiring to the best care we can provide — the ‘gold standard’ of care, knowing that in real life this can be tough, but is always worth aiming for. ‘We only have one chance to get this right!’
- The learning is based on adult learning — self motivated and self directed learning helping you work as a well functioning team (TEAM = Together Everyone Achieves More). It improves organisational systems — the right thing, at the right time and the right person — everyone is involved.
- Continuous quality improvement — we learn most when things go wrong and we can always improve. This is non-judgemental curiosity and creativity — how could we make this even better for our service users? What do our service users teach us? What is important to them? Action planning is a key part of this — a practical way of developing your own ideas for best practice.
What is the Gold Standards Framework?

“It’s about living well until you die”

GSF is a systematic common-sense approach to formalising best practice, so that quality end of life care becomes standard for every person. It helps to identify people in the last year of life, assess their needs, symptoms and preferences and plan care on that basis, enabling them to live and die where they choose. GSF embodies an approach that centres on the needs of service users and their families and encourages inter-professional teams to work together.

“It’s less about what you know and more about what you do.”

Benefits of GSF

- Improve quality of care
- Decrease hospitalisation and cost
- Improve cross boundary working

7 Key Tasks - the 7 Cs

- Communication
- Co-ordination
- Care of the Dying pathway
- Carer Support
- Continued Learning
- Continuity of Care
- Control of Symptoms

GSF is about...

- Enabling Generalists - improving confidence of staff
- Organisational system change
- Patient led - focus on meeting patient and carer needs
- Care for all people regardless of diagnoses - non-cancer, frail
- Pre-planning care in the final year of life - proactive care
- Care closer to home - decrease hospitalisation
- Cross boundary care - home, care home, hospital and hospice

GSF Toolkit

- Prognostic Indicator Guidance – PIG + Surprise Questions
- Use of templates in Locality Registers
- Advance Care Planning – Thinking Ahead
- After Death Analysis (ADA)
- Needs Support Matrix
The Dementia Training Programme

This interactive course in improving care for people with dementia nearing the end of life, is based on the learning of over 10 years of the Gold standards Framework (GSF) Training Programmes in Primary Care (GPs, District nurses etc.), Care Homes (Nursing, Residential etc.) hospitals, (acute, community) and others.

It will supplement the other GSF training programmes by giving you a greater awareness and understanding of some of the particular issues surrounding the delivery of care for people with dementia.

This covers the Skills for Care and Skills for Health Common Core Competencies:

- Care Planning
- Symptom control
- Advance Care Planning
- Communication Skills

The GSF dementia programme, in line with the GSF training programmes considers the 3 key bottlenecks that can occur when delivering end of life.

<table>
<thead>
<tr>
<th>Three key Bottlenecks in care that GSF can help with</th>
<th>Essentials of GSF – 3 Simple Steps</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identification of all patients</td>
<td>identify</td>
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<tr>
<td>Particularly those with non cancer</td>
<td>Service users who may be in the last year of life and identify their stage</td>
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<tr>
<td>Difficult conversations with patients and families</td>
<td>assess</td>
</tr>
<tr>
<td>Advance care planning discussions</td>
<td>Current and future clinical needs and personal</td>
</tr>
<tr>
<td>Effective coordination and proactive planning</td>
<td>plan</td>
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<tr>
<td>Predicting needs and delivering care in alignment with wishes</td>
<td>Coordinated cross boundary care and care of the dying</td>
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</table>

The learning will be based on these principles to help you build on your own current experience and stretch yourself as you learn. It will be delivered via 4 interactive workshops using the Virtual learning Zone. Each session follows the same pattern and contains —

- 3 Learning outcomes
- 3 Activities
- Teaching
- Examples in practice
- Further resources—reading/websites
- Action plan to be completed before the following session
Resources, Support and Evaluation

Resources

Resources and further reading are to be found at the end of each session. There are web links to take you to the relevant sites for downloading the articles/documentation.

Assessment & Evaluation of the programme:

<table>
<thead>
<tr>
<th>Evaluation</th>
<th>Details</th>
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<tbody>
<tr>
<td>Place of work questionnaire before and after</td>
<td>This will evaluate the impact of the programme on:</td>
</tr>
<tr>
<td></td>
<td>• Awareness of people with dementia</td>
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<tr>
<td></td>
<td>• Crisis hospital admissions &amp; outcomes</td>
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<tr>
<td></td>
<td>• Hospital deaths</td>
</tr>
<tr>
<td>Perceptions of dementia before and after</td>
<td>This will show how your perceptions may have changed as a result of the programme</td>
</tr>
<tr>
<td>Confidence in dementia care before and after</td>
<td>This helps to identify gaps in knowledge and competence, and to plan individual training needs.</td>
</tr>
<tr>
<td>Action plan for each session showing plan and what actions have been taken</td>
<td>This will focus your learning on how it can be implemented into your practice</td>
</tr>
<tr>
<td>Reflective essay on each of the four key questions (approx. 400 words for each session)</td>
<td>These will show how care can be reflected on and improved as a result</td>
</tr>
</tbody>
</table>

The baseline evaluations should be completed before the training is commenced and the final evaluations before the ‘bringing it all together’ workshop at the end of the programme.

What you will receive at the end:

- Certificate of completion of the training programme once all evaluations are completed
<table>
<thead>
<tr>
<th>Session</th>
<th>Focus:</th>
<th>Key Question:</th>
<th>Learning Outcomes:</th>
<th>Take Home Message:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Session 1</td>
<td>Introduction to dementia care</td>
<td>What is dementia?</td>
<td>1. What is dementia? To understand the importance of improving care for people with dementia, learn more about the disease and the impact it has on a person. 2. Person-centred care. To learn more about the person-centred approach in dementia care—seeing the person behind the disease. 3. Dignity. To consider ways of enhancing dignity, respect and spiritual care for people with dementia in your place of work.</td>
<td>We understand the importance of providing good end of life care for people with dementia, using a person-centred approach with dignity and respect, and we understand better what we could do in response.</td>
</tr>
<tr>
<td>Session 2</td>
<td>Assessing and responding to underlying needs such as pain and distress.</td>
<td>Are we recognising decline in people with dementia and underlying masked symptoms such as pain and providing them with the right care?</td>
<td>1. Decline Understanding decline in dementia and recognising and responding to signs of deterioration. 2. Pain. Understanding pain in dementia—recognition, causes and management and the use of assessment tools. 3. Other symptoms. Understand symptom control basics, and the impact of other co-morbid conditions.</td>
<td>We can recognise deterioration in people with dementia, and we understand how to detect and care better for their masked symptoms such as pain and distress.</td>
</tr>
<tr>
<td>Session 3</td>
<td>Listening better and assessing personal needs and wishes and those of carers.</td>
<td>How are we listening to people with dementia and understanding their underlying needs and wishes?</td>
<td>1. Communication—learn more about effective ways to communicate and listen to people with dementia. 2. Advance Care Planning. Understand more about Advance Care Planning and Best Interest discussions for people with dementia and put these into practice. 3. Carers. Understand the particular importance of supporting carers, their needs and the significance of early loss and bereavement.</td>
<td>We can improve our communication with people with dementia, hold advance care planning discussions, and better proactively support their carers.</td>
</tr>
<tr>
<td>Session 4</td>
<td>Planning better to reduce crises, reduce hospitalisation and enable people with dementia to live and die well at home.</td>
<td>Are we providing well-coordinated proactive care and enabling better coordinated cross boundary care and reducing crises?</td>
<td>1. Coordination. Explore means of enabling better coordinated cross boundary care and reducing crises. 2. Reducing hospitalisation. Understand the importance of reducing hospitalisation in people with dementia, enabling more to remain safely at home. 3. Care of the dying. Learn more about ways to ensure a good death for people with dementia in their preferred place of choice.</td>
<td>We can give well-coordinated proactive care to keep people with dementia safely at home, reduce crises and in-appropriate hospitalisation, and enable them to die well at home if that is their wish.</td>
</tr>
</tbody>
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Session 1-Introduction to Dementia Care

Key question

How can we provide gold standard /top quality care with dignity and respect, for people with dementia nearing the end of life?

Learning Outcomes

1. What is dementia? To understand the importance of improving care for people with dementia, learn more about the disease and the impact it has on a person.

2. Person-centred care. To learn more about the person-centred approach in dementia care—seeing the person behind the disease.

3. Dignity. To consider ways of enhancing dignity, respect and spiritual care for people with dementia in your place of work. To understand the Importance of dignity and respect when caring for people with dementia at the end of life.

Activities for Session 1 -

1. Quiz—perceptions of dementia

2. Consider an episode of care—what went well, what didn't go so well, what do you need to modify if it occurs again? Take into consideration:
   - Attitude
   - Behaviour
   - Compassion
   - Dialogue

3. Words associated with dignity - positive and negative
Learning Outcome 1 – What is dementia?

To understand the importance of improving care for people with dementia, learn more about the disease and the impact on the person.

Activity 1 – Perceptions of dementia (part of evaluation to be completed)

Consider the following questions and answer true or false:

1. Most old people get dementia
2. Permanent damage to the brain occurs in most types of dementia
3. People who have dementia will all show the same symptoms
4. People with dementia usually have poor short term memory
5. People with dementia have the same needs as babies
6. If an elderly person becomes confused it means they have got dementia
7. People with dementia often have good memory of the past
8. Dementia can be caused by small strokes
9. Alzheimer’s disease can be a genetic condition
10. Most types of dementia cannot be cured
11. When people with dementia walk around it is always aimless
12. Most people with dementia gradually lose all of their ability to communicate
13. People with dementia who are verbally aggressive, usually become physically aggressive
14. Brain damage is the only factor responsible for the ‘symptoms’ of dementia
15. If a person with dementia becomes agitated they require sedatives
The population is increasingly ageing, people aged 85 and over make up the fastest growing group in the UK. With an ageing population there is inevitably an increase in the incidence of dementia. The average life expectancy following diagnosis of a dementia is 4 ½ years and it is predicted that by 2010 over 700,000 people in the UK will have dementia, and be in the last year of life. Many people also suffer from multiple co-morbidity - 29% of people with Cancer, circulatory or respiratory disease also have dementia.

Increased confusion and behavioural problems is sometimes attributed to the persons dementia when often the cause is an easily remedied physical problem e.g. infection, constipation, depression, pain or other physical conditions, sometimes it could be caused by change in surroundings or familiar faces or the individuals spiritual, psychological, emotional or social needs not being met.

In addition, a high proportion of people with Alzheimer's have visuo-spatial perceptual problems and miscue their surroundings or other people's actions. Through memory loss, they may also be living in their head in a former time and place. Even mild to moderate dementia complicates the giving of care for other life-threatening conditions (Meisen & Jones 2006).

Over half of people with dementia live in care homes, many of these homes are not specifically registered for dementia care, so it is important that the staff in these homes receive some additional dementia awareness training. Utilise the expertise of your local CPN for older mental health, and seek advice/training opportunities from the Alzheimer's Society and the NCPC in some areas there are also specialist dementia nurses – Admiral Nurses

<table>
<thead>
<tr>
<th>Some Statistics</th>
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<tbody>
<tr>
<td>There are currently 700,000 people with dementia in the UK.</td>
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<tr>
<td>There will be over a million people with dementia by 2025.</td>
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<tr>
<td>Two thirds of people with dementia are women.</td>
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<tr>
<td>The proportion of people with dementia doubles for every 5 year age group.</td>
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<tr>
<td>One third of people over 95 have dementia.</td>
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<tr>
<td>60,000 deaths a year are directly attributable to dementia.</td>
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<tr>
<td>Delaying the onset of dementia by 5 years would reduce deaths directly attributable to dementia by 30,000 a year.</td>
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<tr>
<td>The financial cost of dementia to the UK is over £17 billion a year.</td>
</tr>
<tr>
<td>Family carers of people with dementia save the UK over £6 billion a year.</td>
</tr>
<tr>
<td>64% of people living in care homes have a form of dementia. (Alzheimer’s Society 2009)</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Challenges in end of life care and dementia;</th>
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<tbody>
<tr>
<td>Impaired communication of need</td>
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<tr>
<td>Difficulties in assessing pain/other symptoms</td>
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<tr>
<td>Aggressive resistance/ ‘Challenging behaviour’</td>
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<tr>
<td>Poor pain management.</td>
</tr>
<tr>
<td>Physical and mental decline</td>
</tr>
<tr>
<td>Behavioural and psychological symptoms</td>
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<tr>
<td>Prognostic uncertainty</td>
</tr>
<tr>
<td>Ethical and Legal issues</td>
</tr>
<tr>
<td>Nutrition and hydration</td>
</tr>
<tr>
<td>Diagnosing dying</td>
</tr>
<tr>
<td>Discontinuation and conversion of medication</td>
</tr>
<tr>
<td>Pathway drugs / administration (risk assessment)</td>
</tr>
<tr>
<td>Prolonged dying phase</td>
</tr>
<tr>
<td>Bereavement support</td>
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<tr>
<td>Resources</td>
</tr>
<tr>
<td>Education</td>
</tr>
<tr>
<td>Communication skills training</td>
</tr>
<tr>
<td>Engagement with other Services</td>
</tr>
<tr>
<td>management of double incontinence and preserving tissue viability</td>
</tr>
<tr>
<td>positioning, enhanced oral hygiene (NB use of community dentist for advice if required)</td>
</tr>
<tr>
<td>Communication through the senses and emotional support</td>
</tr>
</tbody>
</table>
Symptom progression in Alzheimer's disease. Adapted from Feldman et al

Mild cognitive impairment: Complaints of memory loss, intact activities of daily living, no evidence of Alzheimer's disease

Mild Alzheimer's disease: Forgetfulness, short term memory loss, repetitive questions, hobbies, interests lost, impaired activities of daily living

Moderate Alzheimer's disease: Progression of cognitive deficits, dysexecutive syndrome, further impaired activities of daily living, transitions in care, emergence of behavioural and psychological symptoms of dementia

Severe Alzheimer's disease: Agitation, altered sleep patterns, assistance required in dressing, feeding, bathing, established behavioural and psychological symptoms of dementia

Very severe Alzheimer's disease: Bedbound, no speech, incontinent, basic psychomotor skills lost
Dementia Strategy

The Strategy objectives
The key objectives of the Strategy, addressed in more detail in the full document, are as follows:

1: Improving public and professional awareness and understanding of dementia.
2: Good-quality early diagnosis and intervention for all.
3: Good-quality information for those with diagnosed dementia and their carers.
4: Enabling easy access to care, support and advice following diagnosis.
5: Development of structured peer support and learning networks.
6: Improved community personal support services.
7: Implementing the Carers’ Strategy.
8: Improved quality of care for people with dementia in general hospitals.
9: Improved intermediate care for people with dementia.
10: Considering the potential for housing support, housing-related services and telecare to support people with dementia and their carers.
11: Living well with dementia in care homes.
12: Improved end of life care for people with dementia.
13: An informed and effective workforce for people with dementia.
14: A joint commissioning strategy for dementia.
15: Improved assessment and regulation of health and care services and of how systems are working for people with dementia and their carers.
16: A clear picture of research evidence and needs.
17: Effective national and regional support for implementation of the Strategy.

Dementia Strategy 2009
www.dh.gov.uk/dementia.

Prime ministers Challenge

Key commitments

Driving Improvements in health and social care

- Increased diagnosis rates through regular checks for over-65s.
- Financial rewards for hospitals offering quality dementia care
- An Innovation Challenge Prize of £1m
- A Dementia Care and Support Compact signed by leading care home and home care providers
- Promoting local information on dementia services

Treating dementia friendly communities that understand how to help

- Dementia-friendly communities across the country
- Support from leading businesses for the PM’s Challenge on Dementia
- Awareness-raising campaign
- A major event over the summer, bringing together UK leaders from industry, academia and the public sector

Better research

- More than doubling overall funding for dementia research to over £66m by 2015

Prime Ministers Challenge 2012
Dementia is not a single disease but a syndrome—caused by a variety of diseases or injuries. Symptoms are caused by structural and chemical changes in the brain, causing brain cells to die. It’s generally chronic and progressive in nature and is characterised by deterioration on cognitive function (beyond that seen in normal ageing). It affects memory, thinking, ability to learn new things, language etc and is commonly accompanied or preceded by deterioration in emotional control, social behaviour or motivation and eventually affects global functioning.

### Different types of Dementia

<table>
<thead>
<tr>
<th>Dementia Type</th>
<th>Symptoms and Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alzheimer’s disease</td>
<td>‘Plaques’ and ‘tangles’ develop in the structure of the brain leading to death of brain cells, shortage of the chemical acetylcholine. Problems with recent memory, concentration, decision making, orientation, speech, activities of daily living.</td>
</tr>
<tr>
<td>Vascular Dementia</td>
<td>Problem with oxygen supply causing cells to die. Symptoms can appear suddenly following a stroke or over time through a series of small strokes (TIAs). Symptoms depend on which part of the brain have been damaged – hemi paresis, speech may be severely affected. Concentrating, communicating, depression &amp; physical frailty - progressive memory problems. Progression often ‘stepped’ rather than gradual.</td>
</tr>
<tr>
<td>Dementia with Lewy bodies</td>
<td>Tiny, spherical protein structures develop inside nerve cells causing degeneration and death of nerve cells. Memory loss, concentration etc. Fluctuating cognitive function eg excessive daytime drowsiness, staring into space for long periods, episodes of disorganised speech. Half, or more, will develop signs and symptoms of Parkinson’s disease. Often present with visual hallucinations.</td>
</tr>
<tr>
<td>Fronto—temporal dementia (including Picks disease)</td>
<td>Damage to the frontal and / or temporal lobes. Present with personality changes – rude, selfish, unfeeling, sexually uninhibited, language problems. Often affects those under 65 years old. Memory may remain intact for some time. Later stages similar to Alzheimer’s disease.</td>
</tr>
<tr>
<td>Related to other comorbid conditions</td>
<td>Multiple sclerosis, Motor Neurone disease and Huntington’s disease more likely to develop dementia.</td>
</tr>
<tr>
<td>Other types</td>
<td>Korsakoffs syndrome, CJD, HIV, Binswanger’s diseases and supranuclear palsy. Dementia now seen in people with learning disabilities and Downs syndrome.</td>
</tr>
</tbody>
</table>
Emerging key messages for a national public information campaign

Dementia is a disease.

Dementia is common.

Dementia is not an inevitable consequence of ageing.

The social environment is important, and quality of life is as related to the richness of interactions and relationships as it is to the extent of brain disease.

Dementia is not an immediate death sentence; there is life to be lived with dementia and it can be of good quality.

There is an immense number of positive things that we can do – as family members, friends and professionals – to improve the quality of life of people with dementia.

People with dementia make, and can continue to make, a positive contribution to their communities.

Most of us will experience some form of dementia either ourselves or through someone we care about.

We can all play a part in protecting and supporting people with dementia and their carers.

Our risk of dementia may be reduced if we protect our general health, eg by eating a healthy diet, stopping smoking, exercising regularly, drinking less alcohol and generally protecting the brain from injury.
Dementia Quality Standards

List of statements

Statement 1. People with dementia receive care from staff appropriately trained in dementia care.

Statement 2. People with suspected dementia are referred to a memory assessment service specialising in the diagnosis and initial management of dementia.

Statement 3. People newly diagnosed with dementia and/or their carers receive written and verbal information about their condition, treatment and the support options in their local area.

Statement 4. People with dementia have an assessment and an ongoing personalised care plan, agreed across health and social care, that identifies a named care coordinator and addresses their individual needs.

Statement 5. People with dementia, while they have capacity, have the opportunity to discuss and make decisions, together with their carer/s, about the use of:

- advance statements
- advance decisions to refuse treatment
- Lasting Power of Attorney
- Preferred Priorities of Care.

Statement 6. Carers of people with dementia are offered an assessment of emotional, psychological and social needs and, if accepted, receive tailored interventions identified by a care plan to address those needs.

Statement 7. People with dementia who develop non-cognitive symptoms that cause them significant distress, or who develop behaviour that challenges, are offered an assessment at an early opportunity to establish generating and aggravating factors. Interventions to improve such behaviour or distress should be recorded in their care plan.

Statement 8. People with suspected or known dementia using acute and general hospital inpatient services or emergency departments have access to a liaison service that specialises in the diagnosis and management of dementia and older people's mental health.

Statement 9. People in the later stages of dementia are assessed by primary care teams to identify and plan their palliative care needs.

Statement 10. Carers of people with dementia have access to a comprehensive range of respite/short-break services that meet the needs of both the carer and the person with dementia.
Learning Outcome 2 - Person-centred care

To learn more about the person-centred approach in dementia care—seeing the person behind the disease

Activity 2—difficulty explaining yourself

<table>
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<tr>
<th>Think of a time when you have had struggled with communication</th>
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<tr>
<th>How can you communicate better with people with dementia</th>
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</table>
Knowing about a person not only at the present time but throughout their life can help us understand why a person is behaving or reacting as they are. It can enable us as carers to structure their care and treatments to maximum their effect and benefit with the best possible outcomes for everyone. There has been extensive work done on person centred care to help us in our work.

### Person Centred Care

Dementia = N1 + H + B + P + SP

**NI** = Neurological Impairment

**H** = Health and physical fitness

**B** = Biography/Life history

**P** = Personality

**SP** = Social Psychology (social context)

**The Senses Framework**

Ryan & Nolan 2009

<table>
<thead>
<tr>
<th>Security</th>
<th>Person with dementia</th>
<th>Staff member</th>
<th>Family carer</th>
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<tbody>
<tr>
<td>To feel safe</td>
<td>Emotional demands</td>
<td>Confident</td>
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<thead>
<tr>
<th>Continuity</th>
<th>Person with dementia</th>
<th>Staff member</th>
<th>Family carer</th>
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<tbody>
<tr>
<td>Seamless care</td>
<td>positive experience</td>
<td>Standards maintained</td>
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<thead>
<tr>
<th>Belonging</th>
<th>Person with dementia</th>
<th>Staff member</th>
<th>Family carer</th>
</tr>
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<tbody>
<tr>
<td>Relationships</td>
<td>Team work</td>
<td>Not alone</td>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>Purpose</th>
<th>Person with dementia</th>
<th>Staff member</th>
<th>Family carer</th>
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<tbody>
<tr>
<td>Choices</td>
<td>Therapeutic direction</td>
<td>Dignity and integrity</td>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>Achievement</th>
<th>Person with dementia</th>
<th>Staff member</th>
<th>Family carer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meaningful; goals</td>
<td>Quality care</td>
<td>Done your best</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Significance</th>
<th>Person with dementia</th>
<th>Staff member</th>
<th>Family carer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recognised</td>
<td>Valued practice</td>
<td>Caring role</td>
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</tbody>
</table>
Life story work

Individual biographical approach

Review and evaluation of past life events

Use of past experiences to help cope with life transitions

Used to develop and maintain relationships, promote conversation and pleasurable activity

Can take a number of forms: Life story books, collages, reminiscence boxes

What is Important to Bill
(example from accredited care home)

Guiding Principles of Person Centred care

- Do my actions value and honour people living with dementia?
- Do I recognise the individual uniqueness of the people I work with?
- Do I make a serious attempt to see my actions from the perspective or stand point of the person with dementia?
- Do my actions provide the support for people to feel socially confident and that they are not alone?
Learning Outcome 3 – Dignity

To consider ways of enhancing dignity, respect and spiritual care for people with dementia in your place of work

**Activity 3**

Consider some of the words you associate with dignity. Think of both positive and negative ones

<table>
<thead>
<tr>
<th>Positive</th>
<th>Negative</th>
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<tbody>
<tr>
<td></td>
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</tr>
</tbody>
</table>
Positive words associated with dignity

✓ Modesty ✓ Confidentiality
✓ Respect ✓ Decency
✓ Privacy ✓ Autonomy
✓ Choice ✓ Polite
✓ Decorum ✓ Regard
✓ Compassion ✓ Attention
✓ Consent ✓ Professional
✓ Calm ✓ Self worth
✓ Valued ✓ Clean
✓ Control

Negative words associated with undignified care

X Shame X Insult
X Anger X Confusion
X Humiliation X Ignorance
X Patronise X Smelly
X Exposed X Abuse
X Stereotyping X Neglect
X Rudeness X Exposure
X Injustice X Taunt
X Degraded X Soiled
X offensive
## Dignity Discussions

Adapted from Chochinov MH. Dignity-Conserving Care. JAMA 2002. 287(17):2253-60

### A. Attitudes

**Questions to be asked**
- How would I be feeling in this patient’s situation?
- What is leading me to draw those conclusions? Have I checked whether my assumptions are accurate?
- Am I aware how my attitude towards the patient may be affecting him or her?
- Could my attitude towards the patient be based on something to do with my own experiences, anxieties, or fears?
- Does my attitude towards being a healthcare provider enable or disenable me to establish open and empathic professional relationships with my patients?

**Actions to be taken**
- Make a conscious effort to make these questions a part of your reflection on the care of each and every patient
- Discuss the issue of healthcare providers’ attitudes and assumptions, and how they influence caring for patients, as a regular part of case reviews and clinical teaching
- Include ongoing professional development activities that have you challenge and question your attitudes and assumptions as they might affect patient care
- Create a culture among your colleagues and within your healthcare setting in which acknowledgement and discussion of these issues becomes a standard part of providing care

### B. Behaviour

**Disposition**
- Treat contact with patients as you would any potent and important clinical intervention
- Professional behaviours towards patients must always include respect and kindness
- Lack of curative options should never rationalise or justify a lack of ongoing patient contact

**Clinical examination**
- Always ask the patient’s permission to perform a physical examination
- Always ask the patient’s permission to include students or trainees in the clinical examination
- Although an examination may be part of routine care, it is rarely routine for the patient, so always, as far as possible, take time to set the patient at ease and show that you have some appreciation for what they are about to go through (for example, “I know this might feel a bit uncomfortable”; “I’m sorry that we have to do this to you”; “I know this is an inconvenience”;
- “This should only hurt for a moment”, “Let me know if you feel we need to stop for any reason”, “This part of the examination is necessary because . . . ”)
- Limit conversations with patients during an examination (aside from providing them with instruction or encouragement) until they have dressed or been covered appropriately

**Facilitating communication**
- Act in a manner that shows the patient that he or she has your full and complete attention
- Always invite the patient to have someone from his or her support network present, particularly when you plan to discuss or disclose complex or “difficult” information
- Personal issues should be raised in a setting that attempts to respect the patient’s need for privacy
- When speaking with the patient, try to be seated at a comfortable distance for conversation, at the patient’s eye level when possible
- Given that illness and changing health status can be overwhelming, offer patients and families repeated explanations as requested
- Present information to the patient using language that he or she will understand; never speak about the patient’s condition within their hearing distance in terms that they will not be able to understand
- Always ask if the patient has any further questions and assure them that there will be other opportunities to pose questions as they arise

### C. Compassion

**Getting in touch with one’s own feelings requires the consideration of human life and experience**
- Reading stories and novels and observing films, theatre, art that portray the pathos of the human condition
- Discussions of narratives, paintings, and influential, effective role models
- Considering the personal stories that accompany illness
- Experiencing some degree of identification with those who are ill or suffering

**Ways to show compassion**
- An understanding look. • A gentle touch on the shoulder, arm, or hand
- Some form of communication, spoken or unspoken, that acknowledges the person beyond their illness.

### D. Dialogue

**Acknowledging personhood**
- “This must be frightening for you.” • “I can only imagine what you must be going through.”
- “It’s natural to feel pretty overwhelmed at times like these.”

**Knowing the patient**
- “What should I know about you as a person to help me take the best care of you that I can?”
- “What are the things at this time in your life that are most important to you or that concern you most?”
- “Who else (or what else) will be affected by what’s happening with your health?”
- “Who should be here to help support you?” (friends, family, spiritual or religious support network, etc)
- “Who else should we get involved at this point, to help support you through this difficult time?” (psychosocial services; group support; Chaplaincy; complimentary care specialists, etc)

**Psychotherapeutic approaches**
- • Dignity therapy.
- • Meaning centred therapy.
- • Life review/reminiscence.
Dignity Conserving Care

Kindness, humanity, and respect - the core values of medical professionalism - are too often being overlooked in the time pressured culture of modern health care, says Harvey Chochinov, and the A, B, C, and D of dignity conserving care can reinstate them Harvey Max Chochinov professor, department of psychiatry, University of Manitoba. CancerCare Manitoba, Winnipeg, MB, Canada R3E 0V9 harvey.chochinov@cancercare.mb.ca (BMJ) 28 July 2007 | Volume 335

The best way to understand what dignity means for an individual is to ask each resident and family what are the most important factors for him/her in regard to dying with dignity.

<table>
<thead>
<tr>
<th>Factors and Themes</th>
<th>Dignity-related questions</th>
<th>Therapeutic Interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Symptom Distress</td>
<td>“How comfortable are you?” “Is there anything we can do to make you more comfortable?”</td>
<td>Vigilance to symptom management Frequent assessment Application of comfort care</td>
</tr>
<tr>
<td>Psychological distress</td>
<td>“How are you coping with what is happening to you?”</td>
<td>Assume a supportive stance Empathetic listening Referral to counselling</td>
</tr>
<tr>
<td>Medical uncertainty</td>
<td>“Is there anything further about your illness that you would like to know?” “Are you getting the information you need?”</td>
<td>Upon request, provide accurate, understandable information and strategies to deal with future crises.</td>
</tr>
<tr>
<td>Death anxiety</td>
<td>“Are there things about the later stages of your illness that you would like to discuss?”</td>
<td></td>
</tr>
<tr>
<td>Level of Independence</td>
<td>“Has your illness made you more dependent on others?”</td>
<td>Have residents participate in decision making, regarding both medical and personal issues</td>
</tr>
<tr>
<td>Independence</td>
<td>Cognitive acuity</td>
<td>“Are you having any difficulty with your thinking?” Treat delirium When possible, avoid sedating medication</td>
</tr>
<tr>
<td>Functional capacity</td>
<td>“How much are you able to do yourself?”</td>
<td>Use orthotics, physical and occupational therapy</td>
</tr>
<tr>
<td>Dignity Perspectives</td>
<td>Continuity of Self</td>
<td>“Are there things about you that this disease does not affect?” Acknowledge and take interest in those aspects of the resident’s life that he/she most values</td>
</tr>
<tr>
<td>Role preservation</td>
<td>“What things did you do before you were sick that were most important to you?” See the resident as worthy of honour, respect, and esteem</td>
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<tr>
<td>Maintenance of Pride</td>
<td>“What about yourself or your life are you most proud of?”</td>
<td></td>
</tr>
<tr>
<td>Hopefulness</td>
<td>“What is still possible?” Encourage &amp; enable the resident to participate in meaningful or purposeful activities</td>
<td></td>
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<tr>
<td>Autonomy / control</td>
<td>“How in control do you feel?” Involve resident in treatment and care decisions</td>
<td></td>
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<tr>
<td>Legacy</td>
<td>“How do you want to be remembered?” Life Project (making video, audio, writing letters) Dignity psychotherapy</td>
<td></td>
</tr>
<tr>
<td>Acceptance</td>
<td>“How at peace are you with what is happening to you?” Support the resident in his/her outlook</td>
<td></td>
</tr>
<tr>
<td>Resilience</td>
<td>“What part of you is strongest right now?” Encourage doing things that enhance his/her sense of well being (meditation, light exercise, listening to music, prayer, etc.)</td>
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</tr>
<tr>
<td>Dignity Practices</td>
<td>Living in the moment</td>
<td>“Are there things that take your mind away from illness and offer you comfort?” Allow the resident to participate in normal routines or take comfort in momentary distractions (daily outings, exercise, music etc)</td>
</tr>
<tr>
<td>Maintaining normalcy</td>
<td>“Are there things you still enjoy doing on a regular basis?”</td>
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<tr>
<td>Finding spiritual comfort</td>
<td>“Is there a religious or spiritual community that you are, or would like to be involved with?” Make referral to chaplain or spiritual leader</td>
<td></td>
</tr>
<tr>
<td>Social Dignity</td>
<td>Privacy boundaries</td>
<td>“What about your privacy or your body is important to you?” Ask permission to examine resident Proper draping to safeguard privacy</td>
</tr>
<tr>
<td>Social Support</td>
<td>“Who are the people most important to you?” “Who is your closest confident?” Liberal policies about visitation and rooming-in Enlist involvement of wide support network</td>
<td></td>
</tr>
<tr>
<td>Care tenor</td>
<td>“Is there anything in the way you are treated that is undermining your sense of dignity?” Treat the resident as worthy of honour, esteem, and respect. Adopt a stance conveying this</td>
<td></td>
</tr>
<tr>
<td>Burden to others</td>
<td>“Do you worry about being a burden to others?” Encourage explicit discussion about these concerns with those they fear they are burdening</td>
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<tr>
<td>Aftermath concerns</td>
<td>“What are your biggest concerns for the people you leave behind?” Encourage the settling of affairs, preparation of an advanced directive, making a will, funeral plans.</td>
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</table>
### Dignity in End of Life Care—how using GSF helps improve the dignity of patients

Dignity symbolises many things inherent in good end of life care e.g. respect, autonomy, choice, humanity of each person.

#### Breakdown in dignity comes in:
- Crises / Crisis admissions
- Ambulance deaths
- Trolley deaths
- Out of hours inadequate care e.g. nursing home / locum, etc.
- Inappropriate physical symptom control e.g. over medicalization, tubes investigations, etc.
- Symptoms e.g. terminal agitation leading to over use of sedative drugs
- Not respecting patient wishes - not asking them or not communicating effectively.

#### GSF enables improved dignity of patient by;
- General ethos as above - respect, etc.
- Enhancing choice, control, self determination, etc.
- Earlier identification of residents facing end stage illness
- Advance care planning with team at PHCT / MDT meeting
- Advance Care planning discussion with patient (and family)
- Needs based appropriate care provided
- Assessment of needs and concerns (+ soon dignity thermometer)
- Resident choice at centre e.g. in preferred place of death
- Reduction in crisis admissions
- Reduction in TROLLEY DEATHS (ultimate in undignified care)
- Use of minimum protocol in dying stage to stop non essential interventions, etc.
- Use of enhanced advocacy role of nurses and GPs

#### GSF enables improved dignity of family by;
- Earlier discussion, pre-planning and involvement
- Carer’s needs assessed and carer support specified
- Bereavement support of families
- Advance care planning discussion can help communication with family members

#### GSF enables dignity of staff members by;
- Enhancing skills and confidence
- Giving permission to discuss deep issues
- Providing tools to support more open communication
Speech:
Taming my tongue

Key Questions:
- How can I communicate in a language that is understandable and meaningful to the person in my care?
- What are the issues in this clinical encounter I can address with words and what are the issues that are best met with silence?

Hearing:
Listening Intuitively

Key Questions:
- Is there a sacred component to the patient’s story and how can I honour this in my caregiving?
- How can I attune to the work that God, Higher Power, Spirit might be doing in this patient?

Sight:
Seeing Soulfully

Key Questions:
- Who is the person behind the disease?
- What visual cues of the patient’s story are available to inform my care giving?

Presence:
The Essence of Spiritual Care

Key Questions:
- How is my presence permeating my clinical care?
- How is my patient’s presence affecting the clinical encounter?

Touch:
Physical Means of Spiritual Care

Key Questions:
How is my physical care impacting spiritual well being? What intrinsic qualities are reflected in my physical care?
- How can I effectively and respectfully provide comfort through physical means?

Sight:
Seeing Soulfully

Key Questions:
- Who is the person behind the disease?
- What visual cues of the patient’s story are available to inform my care giving?
Being with people

- We need to give our full calm 100% attention to the person cared for as a fellow human being - we bring our humanity to our jobs as carers (no small task), to provide the kind of care we would like to receive ourselves or for our mother/father/loved one.
- We must try to be fully present with them at that moment, to be able to ‘be’ with them as well as ‘do’ for them. This presence is transmitted in ways other than words – by a touch, the way we listen and look, the inner stillness we bring.
- Silence is an important part of being with people, accompanying them as they try to make sense of things for themselves.
- Questions gently asked are as important as answers received:
  1. What is your understanding of what’s wrong with you/your condition?
  2. What have you found helpful in the past at times of crisis, or when things have been tough for you?
  3. Are any of those things going to be helpful now?
  4. Is there anything else that might be helpful now?
- We are concerned with life stories not just medical stories. We don’t compartmentalise medical/physical and spiritual – one affects the other. We are looking for themes and meaning – making sense of a persons life and what is important to them.

Drawing on ourselves as carers

- Carers of people approaching their death have an important role, and can be very important in what they say, in what they do, but even more importantly, in who they are. Your inner being is important here and this is transmitted to others. So the carer needs to ask him/herself:
  1. Where do I get my spiritual strength from?
  2. How do I find conversations with dying people about spiritual matters?
  3. What inhibits those conversations?
  4. What would help facilitate them?
  5. When is it appropriate to call in a professional? (Chaplain, pastor, priest).

SOME CONCRETE STEPS AS CARERS

1. **Relate** to people as fellow humans who are on the same journey as us. Do our jobs well, with kindness, humanity, and awareness of deeper needs. Offer **companionship** - attentive listening and ‘being’, openness not answers.

2. **Inner Life** - Seek ways to nurture the inner life of your service users through advance care planning discussions, life stories, music, storytelling, art, dealing with unfinished business etc. Consider transcendence and transformation.

3. **Spiritual Resources, rituals and sacraments** – Consider what rituals and sacraments your service users may have, and other ways of conveying something of deeper meaning.

4. **Involve local religious leaders** e.g. in services/sacraments and ask for help if appropriate or there are unmet needs.

5. **Nurture your own** spirituality and inner life - draw strength and seek support from others.

Compassion for oneself leads to empathy for others, leads to harmony in the home, leads to joy in living, leads to acceptance of dying, leads to a sense of peace for all.
Following on from Session 1 of the dementia training programme we are asking you to complete the following tasks:

**Your Goals.** Set your personal goals for this programme? What 3 things do you want to achieve or do differently in your own place of work to improve care for people with dementia?

**Person Centred care.** What can you do to improve your understanding of the person behind the disease - the person-centred approach in dementia care? Try a few new things with at least three people with dementia and reflect on their response.

**Dignity.** How can you improve the sense of dignity and respect for the people with dementia that you care for and what new ideas can you try? What might be particularly challenging or confusing for people with dementia in your place of work and what do you find helps improve this in your setting?

This session should have given you a greater understanding of some of the problems and issues encountered by people with dementia, some of the national initiatives that are in place and how we can ensure that dignity and respect is maintained on all times for people with dementia.

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**Take home message**

We understand the importance of providing good end of life care for people with dementia with dignity and respect, using a person-centred approach with dignity and respect, and we understand better what we could do in response.
## Homework Action Plan – Session 1

<table>
<thead>
<tr>
<th>To do</th>
<th>Actions planned</th>
<th>Actions taken</th>
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</thead>
<tbody>
<tr>
<td><strong>1. Your Goals.</strong> Set your personal goals for this programme? What 3 things do you want to achieve or do differently in your own place of work to improve care for people with dementia?</td>
<td>What we plan to do</td>
<td>What we did and what we found</td>
</tr>
<tr>
<td><strong>2. Person Centred care.</strong> What can you do to improve your understanding of the person behind the disease? Try a few new things with at least three people with dementia and reflect on their response.</td>
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<td><strong>3. Dignity.</strong> How can you improve the sense of dignity and respect for the people with dementia that you care for and what new ideas can you try? What might be particularly challenging or confusing for people with dementia in your place of work and what do you find helps improve this in your setting?</td>
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</table>
Useful Websites & Further Reading for Session 1

These references are either for general web sites which have a lot of useful relevant information resources too plentiful to list here or links to specific documents/articles

Learning outcome 1

www.dementiachallenge.dh.gov.uk/
Living well with dementia –a national dementia strategy. 2009. www.dh.gov.uk/publications
Common Core Principles for Supporting People with Dementia
A guide to training the social care and health workforce
Care towards the end of life for people with dementia, an online resource guide
End of life care programme  www.endoflifecareforadults.nhs.uk
Alzheimer's society  www.alzheimers.co.uk

Learning outcome 2

www.ageuk.org.uk
www.dementia.stir.ac.uk/library_dementianow
Www.dementiauk.org/information-support/life-story-work

Learning outcome 3

www.dignityincare.org.uk
www.scie.org.uk/publications/dementia/about.asp
www.rcn.org/development/pratice/dementia

Session 2—Assessing hidden clinical needs
Assessing and responding to underlying needs such as pain and distress

Key question

Are we recognising decline in people with dementia and underlying masked symptoms such as pain and providing them with the right care?

Learning Outcomes

1. **Decline** Understanding decline in dementia and recognising and responding to signs of deterioration.
2. **Pain.** Understanding pain in dementia- recognition, causes and management and the use of assessment tools
3. **Other symptoms** Understand symptom control basics, and the impact of other co-morbid conditions. dementia at the end of life.

Activities for Session 2

1. **Case Study.** It is often difficult to recognise decline in PWD, how does this affect care giving?.
2. **Reflect on a PWD you have cared for who had pain, how did you assess and manage this?**.
3. **Symptom control quiz**
## Learning Outcome 1 – Decline

Understanding decline in dementia and recognising and responding to signs of deterioration

## Activity 1—Case Study

<table>
<thead>
<tr>
<th>What went well?</th>
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<table>
<thead>
<tr>
<th>What were the indicators that this person was deteriorating?</th>
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</table>
Identifying which patients may be in the final years, months of life.

For many people this is the hardest area to get right. Once identified and included on the GP palliative care / GSF register, then the coordinating process is found to be considerably easier. We all find this difficult and we could all improve!

The aim is that you are aware of the GP’s register and that you communicate with the GP regarding those service users that you have identified. Identification was found to be one of the key bottlenecks and weak areas. This showed that we need to:

**Identify more people**

- Only 27% of all deaths were on the palliative care register
- Practices said half of deaths were unpredictable but the National Audit Office says less than 10% are unpredictable
- 15% more missed out on care but could have been predicted

**Identify more people with diagnoses other than cancer**

- 26% who died had cancer vs 69% of people on the register yet 69% of the people on the register had cancer

**Identify people earlier**

- Only 27% of people were on register longer than 6 months

---

**GSF Prognostic Indicator Guidance**

Identifying patients with advanced disease in need of palliative / supportive care / for register

Three triggers:
1. **Surprise question:** ‘Would you be surprised if this person was to die within the next year?’
2. **Patient preference for comfort care / need** — General indicators of decline
3. **Clinical Indicators** — Suggested that all patients on register are offered an ACP discussion

---

**Definition of End of Life Care**

General Medical Council, NICE

People are ‘approaching the end of life’ when they are **likely to die within the next 12 months.** This includes people whose death is imminent (expected within a few hours or days) and those with:

- advanced, progressive, incurable conditions
- general frailty and co-existing conditions that mean they are expected to die within 12 months
- existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- life-threatening acute conditions caused by sudden catastrophic events.

GMC definition — [www.gmc-uk.org/static/documents/content/End_of_life.pdf](http://www.gmc-uk.org/static/documents/content/End_of_life.pdf)
We are aware that there are different illness trajectories in the final years and months of life. People have differing needs at different times during the course of their illness, and yet some of these follow a similar pattern that becomes apparent to healthcare providers. It is inherently difficult to accurately predict the exact stage that someone has reached in their illness trajectory, and yet if this were possible, then there would be more likelihood that the right thing would happen at the right time for every person and that their needs were anticipated and met.

In our experience using the GSF Needs based coding extensively in care homes and in primary care, this simple tool has helped ensure that staff begin to anticipate and predict patients needs earlier and can meet these needs more proactively. It is not about prognostication, but about estimating likely needs at different times, leading to better care.

**Frailty**

Individuals who present with Multiple co morbidities with significant impairment in day to day living and
Deteriorating functional score e.g. performance status EPOC/Karnofksy
Combination of at least three of the following symptoms:
  - weakness
  - slow walking speed
  - significant weight loss
  - exhaustion
  - low physical activity
  - depression

**Dementia**

It is vital that discussions with individuals living with dementia are started at an early stage around their end of life care needs. This is to ensure that whilst they have mental capacity they can discuss how they would like the later stages managed.

There are many underlying diagnosis which result in an individual living with dementia and these should be taken into account. Triggers to consider that indicate that someone is entering a later stage are:

- Unable to walk without assistance and
- Urinary and faecal incontinence, and
- No consistently meaningful conversation and
- Unable to do ADL and
- Barthel score >3

Plus any of the following:
- Weight loss
- Urinary tract Infection
- Severe pressures sores – stage three or four
- Recurrent fever
- Reduced oral intake
- Aspiration pneumonia

Prognostic Indicator Guidance (PIG) © 2011
Dementia Care Needs Support Matrix for End of Life Care

The GSF Needs Support Matrix for end of life care in dementia can be used with the prognostic coding to predict and achieve the right care at the right time every time.

<table>
<thead>
<tr>
<th>Needs</th>
<th>Support</th>
<th>Checklist</th>
</tr>
</thead>
<tbody>
<tr>
<td>Underpinning Plans</td>
<td>Planned framework of care e.g. - Attitude - Patterns of working - Outcomes e.g. dying in the home</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Agreed ethos/ ‘culture of place of care and priority for end of life care for people with dementia Develop an ethos of ‘understanding why the person is behaving in the way they are’ don’t assume due to dementia Systems in place e.g. GSF, LCP, accessing equipment, working with GP and specialists e.g. Psychologists, Geriatrician and Psychiatrist On-going education for staff and at induction on the specific needs of people with dementia On-going addressing of spiritual needs of person and family. A ‘life’ book of patient – ‘This is Me’– the life they had before dementia – better understanding for staff.</td>
<td></td>
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<tr>
<td>A Years</td>
<td>Adjustment to living well with long term condition, with regular review of care. Assessment of disease progression, to optimise care.</td>
<td></td>
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<tr>
<td></td>
<td>Assessment and map out person’s needs to be addressed – comorbidity, high dependency, frailty. Address ‘loss’ of the individual with the family and staff Introduction and preparation for GSF, by staff and relatives. Assessment of needs, person centred - level of dependency and level of care (loss of brain function) Advance Care plan including preferred place of care and DNAR discussion with person, family or advocate (MCA) ethical/legal issues. Communication challenges ‘windows of opportunity’ to discuss issues. Nutrition, hydration, mobility, continence, ADL, SALT – swallowing assessment. Pain assessment – Abbey scale, ADD, CNPI, Doloplus 2 scale, DIS-DAT etc. Assessment of speech and language, dysphasia, aphasia. Spiritual and social needs assessed – ‘what is important to you?”</td>
<td></td>
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<tr>
<td>B Months</td>
<td>Regular proactive review of persons needs and care.</td>
<td></td>
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<tr>
<td></td>
<td>Communication with GP, primary care team, CNS, CPN, Psychologist Advance care plan reviewed with MDT. Assessment of family needs, level of care involvement etc Assessment /or Continuing Care Funding review of care.</td>
<td></td>
</tr>
<tr>
<td>C Weeks</td>
<td>Preparing for final stage- seeing family regularly, focus of comfort care.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Regular Assessment of needs and symptoms at each stage and agreed management by MDT.. Regular discussion within team and increased proactive review by GP, CNS CPN’S Admiral Nurses etc Increased contact with family Advance care plan rechecked and preference for place of care reassessed and enabled Continuing Care Funding review if needed Sending of OOH Handover Form if not already sent Anticipatory prescribing.</td>
<td></td>
</tr>
<tr>
<td>D Days</td>
<td>Preparation for death in preferred place- resisting transfers</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Diagnosing Dying Use of Care Pathway for Final days e.g. LCP/ICP/SCP or minimum protocol Close contact with GP (+OOH Handover form sent DNAR status) Contact with family increased, discuss prognosis and provide some pre-bereavement care. Follow symptom control guidance Spiritual and/or religious care according to needs</td>
<td></td>
</tr>
<tr>
<td>Aftercare</td>
<td>Verification of death procedure clarified Staff protocol for after death care Bereavement care for family, additional loss, guilt issues, Staff support, debriefing Audit of care provision e.g. After death analysis</td>
<td></td>
</tr>
<tr>
<td>A</td>
<td>B</td>
<td>C</td>
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</tr>
<tr>
<td><strong>Assessment of needs, level of dependency and level of care</strong></td>
<td><strong>Regular team monthly review at meeting and needs assessed</strong></td>
<td><strong>Regular team review at least weekly and needs assessed</strong></td>
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<tr>
<td><strong>Advance care plan or leaflet to help planning discussion</strong></td>
<td><strong>Support from district nurses if not involved</strong></td>
<td><strong>Support from district nurses if not involved</strong></td>
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<td></td>
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<td>□</td>
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<tr>
<td></td>
<td><strong>Plan of action developed with GP/DN</strong></td>
<td><strong>Plan of action reviewed with GP/DN</strong></td>
</tr>
<tr>
<td><strong>Assessment of spiritual and social needs – ‘what is important to you?’</strong></td>
<td><strong>Assessment of needs of relatives and support provided</strong></td>
<td><strong>Assessment of needs of relatives and support provided – increased contact</strong></td>
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<td>□</td>
<td>□</td>
</tr>
<tr>
<td></td>
<td><strong>Communication with GP practice team and others</strong></td>
<td><strong>Communication with GP practice team and others</strong></td>
</tr>
<tr>
<td><strong>Assessment of financial need – involvement of social worker</strong></td>
<td><strong>Advance care plan reviewed or leaflet to help planning discussion</strong></td>
<td><strong>Advance care plan reviewed care provided as requested</strong></td>
</tr>
<tr>
<td></td>
<td>□</td>
<td>□</td>
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<tr>
<td></td>
<td><strong>DNAR/AND/ADRT status reviewed</strong></td>
<td><strong>DNAR/AND/ADRT status reviewed</strong></td>
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<td></td>
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<tr>
<td><strong>Check if DS1500/ continuing care funding or other benefits are required</strong></td>
<td><strong>Check if DS1500/ continuing care funding or other benefits are required</strong></td>
<td><strong>Increase care package</strong></td>
</tr>
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<td>□</td>
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<tr>
<td></td>
<td><strong>Increase care package</strong></td>
<td><strong>Specialist equipment-beds/mattress etc</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Specialist equipment-beds/mattress etc</strong></td>
<td><strong>Marie Curie/hospice at home/night sitting service</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Contact numbers for all Out Of Hours teams</strong></td>
<td><strong>Contact numbers for all Out Of Hours teams</strong></td>
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<td></td>
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<td>□</td>
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<tr>
<td><strong>Reduce chance of avoidable hospital admission</strong></td>
<td><strong>Reduce chance of avoidable hospital admission</strong></td>
<td><strong>Reduce chance of avoidable hospital admission</strong></td>
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</table>
Learning Outcome 2—Pain
understand pain in dementia—recognition, causes and management and the use of assessment tools

Activity 2—reflect on a person with dementia you have cared for who had pain, how did you assess and manage this?

<table>
<thead>
<tr>
<th>How did you assess and manage their pain?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>What else might have been useful?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>
Pain in advanced dementia is a common symptom but is often poorly recognised and under treated. This may be a result of poor communication, lack of recognition or misinterpretation of pain. Carers need to work hard to understand a persons verbal and non verbal signs that they are in pain as uncontrolled pain can have a seriously detrimental effect on someone's functional ability and quality of life. Pain can manifest itself in many ways not only as a sensory experience but also by causing psychological distress.

It is important to determine the difference between pain and distress so that the persons symptoms can be addressed and managed correctly. If a person is unable to express their pain, observational tools such as Abbey, Doloplus or DISDAT can be very useful to determine someone's level of pain, how it affects them and how well the management of that pain is working. The full assessment tools can be downloaded from the internet. All these tools include different combinations of observations which could be indicators of pain.

<table>
<thead>
<tr>
<th>Types of observation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Physiological eg breathing pattern, sweating</td>
</tr>
<tr>
<td>2. Facial expressions eg wincing, grimacing, frowning</td>
</tr>
<tr>
<td>3. Body movements eg pacing, rocking, repetitive movements</td>
</tr>
<tr>
<td>4. Verbalisations/vocalisations eg moaning, screaming, asking for help</td>
</tr>
<tr>
<td>5. Changes in interpersonal interactions eg aggression, resisting care</td>
</tr>
<tr>
<td>6. Changes in activity patterns or routine eg wandering in, altered sleep pattern</td>
</tr>
<tr>
<td>7. Mental status changes eg crying, increased confusion, irritability</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Table 1. Twenty most common distress behaviours documented using the Disability Distress Assessment Tool (DisDAT) in 79 participants with severe dementia (n=79)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Documented behaviour of distress</td>
</tr>
<tr>
<td>----------------------------------</td>
</tr>
<tr>
<td>Frown</td>
</tr>
<tr>
<td>Louder words or shouts</td>
</tr>
<tr>
<td>Restless</td>
</tr>
<tr>
<td>Tearful or cries</td>
</tr>
<tr>
<td>Grimaces</td>
</tr>
<tr>
<td>Becomes tense</td>
</tr>
<tr>
<td>Moans or groans</td>
</tr>
<tr>
<td>Eats less or won't eat</td>
</tr>
<tr>
<td>Frightened expression</td>
</tr>
<tr>
<td>Screams</td>
</tr>
<tr>
<td>Stares</td>
</tr>
<tr>
<td>Flushed skin</td>
</tr>
<tr>
<td>Hits out</td>
</tr>
<tr>
<td>Faster breathing</td>
</tr>
<tr>
<td>Tries to bite staff</td>
</tr>
<tr>
<td>Clammy skin</td>
</tr>
<tr>
<td>Rigid posture</td>
</tr>
<tr>
<td>Swears</td>
</tr>
<tr>
<td>Won't allow anyone to come close</td>
</tr>
<tr>
<td>Startled expression</td>
</tr>
</tbody>
</table>

Treating pain in people with dementia should be no different from treating anyone else and if pain is complex or difficult to control involve palliative care or chronic pain specialists for advice.

"Self reporting of pain is the gold standard method for identifying pain in those with mild to moderate cognitive impairment. When people with severe cognitive impairment can self report pain, the reports are valid."  
British Pain Society and British Geriatrics society. 2007

"In the older person with severe cognitive impairment, carers who are familiar with the patient may detect the presence of pain and the changes in pain."  
British Pain Society and British Geriatrics society. 2007
Learning Outcome 3 –other symptoms
Understand symptom control basics and the impact of other co-morbid conditions

Activity 3 –Symptom Control Quiz

Consider the following statements and questions

1. People with dementia express symptoms in the same way as other people T/F

2. People with dementia have the same symptoms at the end of life as other people who are dying eg: from cancer T/F

3. What are some of the challenges you can have when assessing symptoms in someone with dementia? – Name 3
   1. 
   2. 
   3. 

4. Where someone with dementia displays behavioural changes such as aggression or wandering they should be given sedative drugs to calm them down T/F

5. People with dementia often lose weight – this is an inevitable process T/F

6. Tube feeding will improve functional status and comfort T/F

7. Tube feeding will prevent or improve pressure sores T/F

8. Severe dementia increases mortality following pneumonia T/F

9. Antibiotic therapy will prolong survival in residents with severe dementia T/F

10. People with dementia don’t have as much pain as other people so don’t require as much analgesia T/F

11. What assessment tools can be used to assess :

   Distress?

   Nutritional status?

   Constipation?

   Depression?

   Pain?
Assessment tools

Assessing symptoms and the needs of the people with dementia that you care for is a normal part of your regular care. You may already use some but in this section we will discuss some you may not have used before but could be useful in your area of practice.

The assessments fall into two groups - specific and holistic. The tools and templates suggested in this session are all optional suggestions, to be used if wanted.

Holistic

The PACA assesses patients problems and concerns and identifies what is a problem or concern for the person or carer and what impact it has on their life at that time, as this may be different from what the professional may identify as a problem of concern.

The PEPSICOLA checklist is a holistic guide to considering all areas, not just physical. It has been found to be of use in many areas and we include one adapted example from Brisbane Australia.

The Distress Thermometer has been adapted for use with the elderly in care homes and has been found to be useful to many staff in assessing areas that otherwise might not come to light, and developing a therapeutic plan to help resolve them. It is used often by psychologists for care of cancer patients. It is self explanatory and can examine the impact of certain issues and conditions on patients and there are other forms available for other conditions.

Specific

These include the pain charts, body charts, etc. Patients with dementia may become agitated by pain so full assessment using the Doloplus or Abbey Scale can help determine whether pain is the cause of agitated behaviour.

Other assessment tools are referenced at the end of this session and can be found and downloaded from the internet.

Common symptoms at end of life

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Confusion</td>
<td>83%</td>
</tr>
<tr>
<td>Pain</td>
<td>64%</td>
</tr>
<tr>
<td>Urinary incontinence</td>
<td>64%</td>
</tr>
<tr>
<td>Constipation</td>
<td>59%</td>
</tr>
<tr>
<td>Low mood</td>
<td>61%</td>
</tr>
<tr>
<td>Loss of appetite</td>
<td>57%</td>
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</tbody>
</table>

Faull & Woof 2002
Ten Top Tips in End of Life Care and Dementia

Every patient and carer is individual. Barbara Pointon, who cared for her husband Malcolm, offers these ten top tips which worked for them:

1. Feeding.

It is the most trustful thing in the world to open your mouth to be fed. Malcolm would refuse food from a new carer, so continuity of staff is vital. Up to one hour may be required to patiently feed pureed food by the teaspoonful; cold thickened drinks may be more easily sensed and controlled than tepid ones. Use metal not plastic teaspoons in case of clamping down.

2. Space

84% of people with Alzheimer’s have visuo-spatial perceptual problems and don’t know where they are in space. Rolling a patient on the bed to change an incontinence pad can be alarming and cause resistance for some - we used a standing hoist right to the end. (Each person will be different in this) The change of position also helped Malcolm to cough productively. A mobile hung from the ceiling helps to give some sense of position.

3. Weight loss

in severe dementia is inevitable. Relatives of care home residents need to understand that it is not necessarily a sign of neglect.

4. Medication

All of Malcolm’s medication had to be reduced to paediatric sized dosages/preparations in line with weight loss and/or severity of dementia. Adult doses became the equivalent of overdosing, with unwanted side effects. Even Malcolm’s final syringe driver had only a half dose in it. This is very individual.

5. Loss of mobility

should not mean confined to bed. Alternate with a recliner chair and wheelchair. Good pressure relief, the right size and absorbency of incontinence pads, scrupulous cleansing and six major changes of position each day.

6. Constipation

It is not your normal constipation; the brain no longer understands the signals from the gut to co-ordinate muscles for consciously bearing down. An assessment by a dementia-aware continence adviser can help as can a special regimen, similar to that for a paraplegic.

7. Sounds

Even if the patient is mute and may have little understanding of speech, continue to talk to them. The sound of a kindly voice is a fundamental human need. Music (of their taste) will still get through.

8. Stimulation

With normal levels of cognition shot to pieces, sensory and emotional needs become more important. Stimulate each of the five senses in an appropriate way – Malcolm loved his aromatherapy sessions – and encourage eye-contact, talking and gentle touch, especially from visitors who are unsure what to do.


Most people with dementia become terrified of being anywhere other than in familiar surroundings. Breaks for the carer should be arranged through having replacement care at home, preferably given by the same person each time. For the same reason, at the very end of life, admission to a noisy, busy hospital should be avoided if possible. A calm and tranquil environment is important.

10. Making time.

At any stage, time is the greatest gift you can give to people with dementia. Make time just to be alongside as a tangible, comforting presence, especially when life is drawing to a close.
Action Plan for your area of work

Following on from Session 2 of the dementia training programme we are asking you to complete the following tasks:

**Recognising decline.** How would you recognise deterioration in someone with dementia? Using the GSF coding, how you would know someone with dementia was declining eg from unstable (green) to deteriorating (amber) or to the dying phase (red). What would you need to do in anticipation to meet their needs each phase? (write this in your Workbook Needs Support Matrix)

**Recognising and treating pain** Which assessment tools do you find work best for you in assessing a person’s pain and distress? Try other tools and discuss the results and how you can incorporate the routinely in your work

**Treating other symptoms.** Discuss and try out other ways of managing other symptoms; reflect on your experience- which work best and why?

This session should have given you a greater awareness of the some of the assessment tools that can help you recognise a person with dementias decline and manage their pain and other symptoms

Take home message

We can recognise deterioration in the people with dementia, and we understand how to detect and care better for their masked symptoms such as pain and distress.
<table>
<thead>
<tr>
<th></th>
<th>To do</th>
<th>Actions planned</th>
<th>Actions taken</th>
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</thead>
<tbody>
<tr>
<td><strong>1</strong></td>
<td>Recognising decline. How would you recognise deterioration in someone with dementia? Using the GSF coding, how you would know someone with dementia was declining e.g. from unstable (green) to deteriorating (amber) or to the dying phase (red). What would you need to do in anticipation to meet their needs each phase? (use the GSF Needs Support Matrix)</td>
<td></td>
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<tr>
<td><strong>2</strong></td>
<td>Recognising and treating pain</td>
<td>Which assessment tools do you find work best for you in assessing a person’s pain and distress? Try other tools and discuss the results and how you can incorporate the routinely in your work</td>
<td></td>
</tr>
<tr>
<td><strong>3</strong></td>
<td>Treating other symptoms.</td>
<td>Discuss and try out other ways of managing other symptoms; reflect on your experience - which work best and why?</td>
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</tbody>
</table>
Useful Websites & Further Reading for Session 2

These references are either for general web sites which have a lot of useful relevant information resources too plentiful to list here or links to specific documents/articles

**Learning outcome 1**
- Prognostic indicator guide [www.goldstandards framework.co.uk](http://www.goldstandards framework.co.uk)
- Modified needs support matrix [www.goldstandards framework.co.uk](http://www.goldstandards framework.co.uk)
- Definition of end of life care [www.gmc-uk.org/static/documents/content/End_of_life.pdf](http://www.gmc-uk.org/static/documents/content/End_of_life.pdf)

**Learning outcome 2**
- Abbey Pain Scale [www.demetaicareaustralia.com](http://www.demetaicareaustralia.com)
- DISDAT [www.disdat.co.uk/](http://www.disdat.co.uk/)
- Pain in Older people [www.britishpainsociety.org](http://www.britishpainsociety.org)
- Pain in advanced dementia [www.scie.org/publications/dementia/endoflife/pain](http://www.scie.org/publications/dementia/endoflife/pain)
- Pain in older people and people with dementia [www.dementia.stir.ac.uk](http://www.dementia.stir.ac.uk)
- Painad [www.geriatricpain.org/Content/Assessment/Impaired/Pages/PAINADToolInstructions.aspx](http://www.geriatricpain.org/Content/Assessment/Impaired/Pages/PAINADToolInstructions.aspx)
- General pain assessment [www.goldstandardsframework.co.uk](http://www.goldstandardsframework.co.uk)
- [www.ncpc.org.uk/publication/how-would-I-know](http://www.ncpc.org.uk/publication/how-would-I-know)

**Learning outcome 3**
- [www.nhs.uk/Dementia](http://www.nhs.uk/Dementia)
- [www.ncpc.org.uk](http://www.ncpc.org.uk)
- **Paca** [www.goldstaandardsframework.co.uk](http://www.goldstaandardsframework.co.uk)
- **Pepsicola** [www.goldstaandardsframework.co.uk](http://www.goldstaandardsframework.co.uk)
- Distress thermometer [www.goldstaandardsframework.co.uk](http://www.goldstaandardsframework.co.uk)
- End of life care programme [www.endoflifecareforadults.nhs.uk](http://www.endoflifecareforadults.nhs.uk)
- MUST [www.bapen.org.uk/pdfs/must/must_full.pdf](http://www.bapen.org.uk/pdfs/must/must_full.pdf)
- Waterlow [www.judy-waterlow.co.uk/the-waterlow-score-card.htm](http://www.judy-waterlow.co.uk/the-waterlow-score-card.htm)
- Bradford dementia project [www.brad.ac.uk/health/dementia/](http://www.brad.ac.uk/health/dementia/)
Session 3—Communicating well and assessing the needs and wishes of the person
Listening better and assessing personal needs and wishes of the person and those of carers

Key question
How are we listening to people and understanding their needs and wishes

Learning Outcomes
1. Communication learn more about effective ways to communicate and listen to people with dementia
2. Advance care planning understand more about Advance Care Planning and Best Interest discussions for people with dementia and put these into practice
3. Carers understand the particular importance of supporting carers, their needs and the significance of early loss and bereavement

Activities for Session 3
1. Consider the key principles of good communication with people with dementia
2. Discuss ACP for people with dementia and how can ACP help to provide the right care?
3. What impact does dementia have on those caring for a person with dementia and how can you help support them in their role
Learning Outcome 1 – Communication
Learn more about effective ways to communicate and listen to people with dementia

Activity 1—consider the key principles of good communication with people with dementia
Communication is more that just talking and 90% of our communication is non verbal such as facial expressions, hand gestures and touch. Non verbal communication is particularly important for people with dementia who are losing their language skills and it vital that behaviour is recognised as a way of communicating something.

In residential care it has been shown that less than 8% of peoples time is spent in communicating in any form. Its important that we remember that everyone can communicate, no matter how severe the dementia and if staff or family say ‘he can’t communicate’ they need support & education to facilitate this.

People with dementia “sometimes seem to have a heightened awareness of body language, and often their main meanings may be conveyed non-verbally. In the case of those who are very severely impaired, it seems probable that the words and sentences are at times more of an accompaniment or adornment than the vehicle for carrying the significant message” Kitwood (1997)

### Communication Changes in Dementia

| Loss of language – names, faces, objects | Principles of communication |
| Loss of ability to start / end conversations | ♦ Maximise a persons sensory ability |
| Loss of ability to start / end sentences | ♦ Are they in the right setting |
| Increased reliance on questions | ♦ Are they ready emotionally and physically for conversation |
| Increased reliance on gestures | ♦ Don’t rush– allow time |

### Behaviours that can disable communication in people with dementia

♦ Interrupting what they are saying
♦ Speaking on behalf of them
♦ Reinterpreting their words
♦ Using too technical or complex language
♦ Talking out of earshot
♦ Taking sides in discussions
♦ Ignoring them
♦ Ridiculing what they are saying
♦ Not including the person with dementia in the discussion
**Learning Outcome 2—Advance Care Planning**

discuss ACP for people with dementia and how can ACP help to provide the right care?

**Activity 2**—consider advance care planning for people with dementia. How can this help you deliver care?
An Overview of Advance Care Planning Discussions
To assess patients’ personal needs and preferences through Advance Care Planning including preferred place of care

“Failing to plan is planning to fail”

Advance Care planning (ACP) is essentially a process of discussion between an individual and their care providers, which may include family/friends, about the kind of care they would like to receive now and in the future.

DH Guidance on Advance Care Planning. End of Life Care Programme 2008

The aim is to increase the number of people who are offered advance care planning discussions within primary care, especially those with dementia or who have declining capacity to make decisions in future.

To do this, it is recommended that every patient on the GSF Supportive/ Palliative care register is offered an ACP discussion.

By having this discussion, a shared understanding can be reached, so that current and future care can be tailored to the person’s individual needs and preferences, some difficult situations or crisis events can be averted and communication with others is made easier. The process of holding advance care planning discussions to ascertain wishes is strongly recommended as it enables the decision-making process to be initiated, recorded, and communicated to others involved in care. This then ensures that the person’s wishes are more likely to be met, and they receive a higher quality of end of life care.

The opportunity to discuss ACP should be offered to everyone as normal practice, with the appropriate degree of respect and sensitivity, though everyone has the option to decline. Some may decline or defer to another time, and staff should always be sensitive to this.

With the individual’s agreement this discussion should be documented, regularly reviewed and communicated to key persons involved in their care.

This is particularly relevant for people in the last year of life. GPs and primary care teams might be involved in confirming these ACP discussions and helping to provide care aligned to preferences.

Advance care planning discussions are different from resuscitation/ DNACPR forms and policies. If your patients want to talk about this you will need to refer this to their GP or hospital consultant

The persons wishes are paramount, but it is also helpful to confirm who else might be involved in the decision-making process, and might be consulted in case of lack of capacity of the person in future

The benefit of ACP is that others caring for the person in differing situations e.g. in care homes, hospitals etc. can refer to the ACP to produce a consistent approach to care - to know what the person wants and or who to ask if they are unable to express their views.

The Mental Capacity Act (Oct 07) requires staff to support people so that they can make decisions for themselves as far as they are able. The process of ACP is important here as it relates to the possibility of future lack of capacity of the resident. If they can make a decision they should – if they cannot, it ensures that their wishes are already noted through the earlier ACP discussion, and are thereby more likely to be respected.

There are many tools available for advance care planning including the GSF ‘Thinking Ahead’, and Preferred Priorities of Care among others. Many PCTs have local documents which are recognised in all areas of care
Statements of wishes and preferences helps formalise what people (and their families/carers) do wish to happen to them as they near the end of life. It helps to provide personalised, individual care, tailored to their needs and preferences as death approaches.

Although not legally binding, it indicates preferences and as part of the Mental capacity Act, can be used if the person no longer has capacity in the future.

Advance Decisions helps formalise what people do not wish to happen to them and is a legally binding document. It can include guidance on resuscitation (DNACPR).

Advance Decisions to refuse treatment must be valid and applicable and drawn up correctly. Must be specific to circumstance and treatment. And identify that the person knows that their life may be at risk if they refuse treatment.

Lasting Power of Attorney is a formal confirmation of a named person you have chosen who might speak for you if you no longer have capacity to make decisions yourself about your health care and welfare. This includes decisions to consent to or refuse treatment on your behalf, including deciding where you live when you no longer have the capacity to do so for yourself.

**Advance Care Plan’s Benefits**

- Improves communication with service users and families early on
- Improves planning of care
- Reduces crises and inappropriate hospital admissions
- Helps formalise discussion using a tool
- Can initiate realistic communication about ‘allow a natural death’ vs resuscitation
- People have a sense of control and relief that their wishes are expressed and will be abided by
Advance care planning with people with dementia

The DH Dementia Strategy addresses some of the end of life care issues for people with dementia and recommends that the person with dementia and their carers/family should be involved in planning end of life care. (DH Living well with dementia: A National Dementia Strategy 2009).

ACP discussions can be very helpful for people with dementia. Such decisions can take place even though the individual may have quite advanced dementia, as long as they have capacity – the ability to understand and speculate about the decision to be made. Evidence suggests that people with early dementia are interested in participating in ACP discussions, and that they make similar decisions to people without dementia. Therefore we should not hold back from asking people with dementia their views.

Discussions need to take place on more than one occasion in comfortable, unhurried surroundings. People with dementia do not lose all ability to communicate and their ability to engage in discussions can vary from day to day or even during the course of the day. Use words that the individual understands and regularly check their understanding, take cues from their non verbal responses and involve the resident’s next of kin or advocate wherever possible – they are likely to have a good knowledge of the person and what their views and wishes were previously. There is evidence to suggest that people with dementia tend to make similar decisions to those without dementia, so we should not avoid asking people with dementia what their views are (Fazel et al 2000). Consider the appropriateness of interventions and the benefits of those interventions to that individual, e.g. the admission to a busy acute hospital ward of a person with dementia in the final stages of their life is very likely to exacerbate confusion and disorientation leading to increased fear, anxiety and agitation.

Staff who care for people with dementia have difficulties in ascertaining wishes and preferences especially for those people who have no family. They also spoke of difficulties that arose when GP’s were reluctant to make advance decisions. Staff were well aware of unnecessary distress that can be caused by sending a person with dementia out of their environment to hospital and were in many cases keen to have advanced discussions documented. Staff spoke of their own distress and powerlessness at seeing people with dementia being sent to hospital in their last 48hrs of life because of lack of documentation relating to resuscitation status.

Tips for successful Advance Care Planning discussions

- The person needs to be ready
- Discussions usually takes place over more than one occasion
- It’s not a check list exercise
- Be comfortable and unhurried
- Optimise communication and sensory function
- Use a step by step approach
- Truthfulness, respect, compassion and empathy
- Use a tool to introduce the concept
- Use language the person understands
- Clarify any terms or expressions used by the person
- Give sufficient information about when an ACP will be used
- Give sufficient information about their options
- Look out for clues that the person wishes to end the discussion
- Summarise and check what has been said
- Document if the person wishes
- Consider other methods of recording their wishes
- Plan for a review

“Introducing Advance Care Planning into our work place as normal practice has been one of the most important things we have done- its crucial to helping us focus on the needs of service users it helps discussions with families and it changes the way we do everything. Even though it may be hard at first, we would very strongly recommend it for every care provider.”

Care Home Matron Phase 3

“I need to make those decisions while I have enough mental capacity to be able to do that and to understand the implications of it before I get too far down the line. So it has given me the time to think about that. That is important.”

(person with dementia)
Advance Care Planning in Dementia

Many of the best practice points generally applicable to Advance Care Planning (ACP) discussions will apply to people with dementia but there are others that also need to be taken into account in addition:

**Skilled interviewer**

Those undertaking ACP with people with dementia will need to have appropriate knowledge and skills to understand the issues around communication in dementia.

**The right time**

As with all ACP discussions they need to be held at the right time but in dementia these discussions need to be held early on in the illness when the person still has the capacity, cognition and language to hold meaningful discussions and make informed decisions. Ideally the ACP discussions in people with dementia should be part of a supportive post diagnostic counselling processes within e.g. a Memory Clinic.

**The right place**

People with dementia often have visuospatial problems that are associated with their dementia so it is important to hold the discussions in a quiet and unthreatening place with no distractions of noise and interruptions that can hinder their concentration.

**Involvement of family**

Once a person is deemed and assessed to no longer have capacity, decisions will need to be made in their ‘best interest’ and the Mental Capacity Act framework for determining best interests applied. A Lasting Power of Attorney (LPA) with appropriate authority (Personal Welfare) may be empowered to make decisions behalf of a person with dementia based on their knowledge of the person and on what they believe the person would or would not have wanted for themselves.

**Take time**

People with dementia will require more time for any ACP discussions; these may need to be done over some period of time with some repetition and clarification.

Karen Harrison-Dening, Consultant Admiral Nurse

**Scenarios**

People with dementia may need examples of situations which they need to consider in making an ACP; e.g. Clinical vignettes illustrating cardiac resuscitation or PEG feeding for example for them to conceptualise and apply to their own situation. This has been done using pictures, video clips and narratives.

**Life Story**

Much information that is of relevance to developing an ACP can be gained from undertaking Life Story work with people with dementia. Family members can be involved in this work also.

**Recording**

When a person with dementia does not have the capacity to undertake ACP a note should be made in the ACP document of who was involved in the discussion (e.g. as in the Gold Standard ‘Thinking ahead’ document). It should be noted that due to cognitive impairment most information was obtained from a named relative/other rather than the person with dementia.
Talking with patients about their views on how they would like to be cared for towards the end of their lives is rarely an easy task. What follows is a basic structure which might help you to engage in such conversations. It is important to remember, though, that no two discussions on this topic will be the same and that you need to take your cue from the person and to be flexible in responding to their needs.

**Preparing the ground**

Speak to the person beforehand to explain what it’s all about. This might also be a good time to check their understanding of their situation and get a feel of the language they use to talk about it.

*NB If the patient has specific communication needs, e.g. they have limited English or they are hearing impaired, you should check whether an interpreter or signer is needed, both for this interaction and the main meeting.*

Set up a time to meet and ask who (if anyone) they would like to be present. This might include family, friends or even an advocate.

Make sure that you can meet in a private and comfortable room and that you have set aside enough time for the meeting.

**Using the Plan**

Start with general greetings and by introducing yourself, if necessary, to any family, friends or others who have attended. Find out who they are, too! Remind all present of the purpose of the meeting. Let them know that you will be making some notes in the meeting so that you can be sure you have an accurate record of what is said.

Ask the patient whether s/he has given any thought to how s/he would like to be cared for in the future. This will give you some idea of their priorities.

Address the issues outlined in the Advance Care Plan. You might want to work through systematically, or you might prefer the resident to talk for a while and then to bring up any aspects that have not been touched on. Adjust the language used in the Advance Care Plan as appropriate for the person’s understanding. You might need to check that they understand terms like Advance Directive and Enduring Power of Attorney or you might need to explain what resuscitation involves.

Check that you understand what the person says, e.g. if they use the term ‘dying with dignity’ you might need them to explain what that means to them.

Make notes as appropriate, but try not to do this while they are speaking. Ensure that your notes are legible and unambiguous to others who might need to refer to them.

**Wrapping up**

Summarise the main points of what has been said and check that you have understood them correctly.

Ask if there are any questions.

Make it clear that you know that their views might change over time and they should let someone know e.g. their GP or carer, if this should happen, so that the Plan can be amended.

Either read aloud what you have written or, if they prefer, let them and one other person present read it themselves before asking them to sign the Advance Care Plan.
Discussion of Resuscitation - DNACPR and AND (Allow Natural Death)

Guidelines to support the decision-making process for staff working in adult care homes involved in cases where resuscitation may be considered inappropriate

Madeline Bass, Head of Education, St. Nicholas Hospice Care, Bury St. Edmunds Suffolk

(Updated guidelines April 2009 GSFCH)

These guidelines have been written to support staff involved with the resuscitation decision-making process for adults. It applies to all adults, and can be applied to all diseases and diagnoses, malignant and non-malignant.

They aim to give health professionals guidance on when a Do Not Attempt Resuscitation (DNAR) decision needs to be discussed with the doctor in charge of that care episode, or with the person or their family carers.

Identifying when resuscitation is appropriate and likely to be successful, and when it is inappropriate and futile, is the main focus of the guidelines.

Until October 2007, in England, an adult with capacity could not appoint a person in advance to make a later decision for them whether to refuse treatment should they then lack capacity to make that decision later. All someone could do was to express their wishes, which healthcare professionals then should have taken into account.

From 1\textsuperscript{st} October 2007, under the Mental Capacity Act (MCA) 2005, it is possible for an adult with capacity to appoint another person under a Lasting Power of Attorney for Personal Welfare Decisions to make healthcare decisions. However, they can only ever represent the view the resident would have taken if they still had capacity to make the decision. The MCA also gives a statutory basis for an adult to decide in advance to refuse a treatment should they later lack capacity to make that decision. There are requirements for each, which should be complied with, to make them valid and applicable to a particular treatment.

“It can be difficult discussing DNAR with people but it is important to discuss this beforehand to try to prevent a distressing situation that arises out of a crisis”
Summary

Resuscitation applies only to cardiac massage and artificial respirations. It does not include other aspects of nursing or medical care, or medication changes.

It is not necessary to burden the patient with resuscitation decisions if the clinical team is as certain as it can be that resuscitation will not be successful. This must never prevent communication by the team with the patient and family carers about their illness, including information about resuscitation itself if they wish this.

In cases where the circumstances of an arrest can be anticipated and there is a chance of it being successful, it is essential to obtain the patient’s view. The only exceptions to this are: if the person is not competent, or does not want to discuss the matter.

Twenty-five per cent of ALL resuscitation attempts in hospital are successful but only a small amount of these survive to discharge. If the event is due to irreversible disease or damage CPR will not succeed.

The senior clinician in charge of that patient’s care is the only one who has the authority to make the final resuscitation decision (this is probably going to be the GP, and it should be decided by local policy who this is going to be), but it is wise to reach a consensus with the patient, staff and family carers. Only use the courts as a last resort.

It is unethical to simply carry out CPR in the absence of a previous decision. If a decision has not been made, and the patient’s wishes are unknown, basic life support should be carried out, and the emergency team called. CPR should be stopped if it is felt to be inappropriate, and the doctor, or senior clinician, on duty at the time must attend to document this decision.

It is, therefore, essential to identify patients for whom cardio-pulmonary arrest represents a terminal event in their illness and in whom CPR is inappropriate. It is also vital to encourage the involvement of patients, the staff and people close to them in decision-making, and to ensure the communication of decisions to all relevant health professionals.” (BMA et al, 2001).

When death occurs as a result of illness it may still be an expected and natural event, especially when at the end of a terminal condition from which the individual was not expected to survive.

“Do Not Attempt Resuscitation” (DNAR) decisions can be a source of misunderstanding and dissent amongst doctors, nurses and others involved in the care of patients. Many of these difficulties can be avoided if advance decisions are made appropriately and sensitively, especially when the patient is in the terminal phase of their illness and is not expected to recover. In such cases it is not usually appropriate for healthcare professionals to attempt CPR procedures” (BMA et al 2001).

Such decisions can be made early on but should be made, where possible, with the patient themselves, if they have capacity for that decision. In terms of CPR decision, this should only be offered as an option to the if the clinical team are as certain as they can be that there may be a chance of success. Although capacity may be difficult to assess it is of paramount importance that “protective responsibility” (Holm, 1997) exists, i.e. that there is professional responsibility to protect vulnerable people from harm. The MCA also states that all actions or decisions made for a person who lacks capacity must be in their best interests and sets out what should be taken into account in assessing best interests.
Moving from disease-focused to person-focused care

In all aspects of clinical care, there can be a tendency to over treat at times – just because something is available does not always mean that this is appropriate for this particular person, or would be their choice or in their best interest long term. Achieving the right balance for each person can be difficult, and takes reflection, planning and careful consideration, rather than the knee jerk reaction of sometimes ‘over-medicalised’ care. Too many people, especially the frail elderly and those with dementia, receive excessive interventions, resuscitation or find themselves in hospital wards or in ITU when this would not have been their choice, whilst others might seek such appropriate interventions that might not be available due to heavy demand. It is a fine balance, and an increasing problem, with the increasing complexity of options for clinical interventions and treatments available to us, and as an ageing population with increasing co-morbidities.

Most people in our society now die from cumulative co-morbid conditions. As we move from the clinically focused ‘disease orientated’ model of care (ref Tinetti 2003) to the era of integrated individually tailored model, we may need to refocus our care on the person’s goals of care, in line with a less medicalised view of the kind of care they require.

One means of achieving this - assessment of the Patient’s Goals of Care

Assessment of the ‘goals of care’ for each person is a way to enable the focus to remain on their priorities and not ours. It can help focus on the purpose and level of appropriate intervention required, in line with the patient’s personal preferences, as discussed in their Advance Care planning discussion. This will vary at different stages of people’s lives, at different stages on the illness trajectory, for different people in different settings. Using these goals of care can help reduce the chances of over-interventions and over-medicalisation of care, and can help redirect appropriate intervention at other times. These discussions about the goals of care are best negotiated with the person and their families, and need to be reconsidered at times of key decision making and changes of plan.

The concept of ‘goals of care’ are used in many countries to support such decision making. And vary in some details, with some having a section for patient noted priorities. One example is shown used by Brogan at al in Australia is shown below

The 4 goals of care:

1. Length of life To extend length of life as long as possible,
2. Functioning To maintain as ‘normal’ a life as possible
3. Comfort care To remain symptom free and comfortable with minimal interventions.
4. Quality of life To maintain quality of life in the present moment

When we consider Advance Care Planning we should also consider Goals of Care and how the person feels about the burden of their disease or age.
Learning Outcome 3—Carers

Understand the particular importance of supporting carers, their needs and the significance of early loss and bereavement of carers; the importance of supporting carers

Activity 3—what impact does dementia have on those caring for a person with dementia. How can you help support them in their role
There are many different ways and organisations that we can turn to that can help us support families and their carers - formal and informal.

**Carers assessment and support is a crucial area and one that will often require further specific efforts by primary care teams**

This is one of the most important aspects of the care provided by primary health care teams. Carer breakdown is THE key factor in prompting institutionalised care for dying people. This is the experience of most health care professionals and is reflected loudly and clearly in the literature.

There is strong evidence that without support from family and friends it would be impossible for many patients to remain at home. Those without carers are less likely to be able to remain at home to die—they present particular difficulties.

Carer’s anxiety is rated alongside service user symptoms as the most severe problems by both service users and families. Despite their natural feelings of trepidation beforehand, there can be a great sense of satisfaction in bereavement for the carer in fulfilling the wishes of their loved one who expressed a preference to stay at home during their final days. However this places a great strain on carers, both emotionally and physically.

The family will usually be registered as patients of the GP practice as well, and often a special relationship remains after the person has died, which may be therapeutic in the grieving process.

<table>
<thead>
<tr>
<th>Main needs of the Carers</th>
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<tbody>
<tr>
<td>Recognition - of their value and importance</td>
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<tr>
<td>Being involved - in devising care plans (one in three carers felt their comments and concerns were not taken into account)</td>
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<tr>
<td>Information - sources of support, decision making about medical care, relevance of symptoms, what to do in an emergency etc.</td>
</tr>
<tr>
<td>Support - practical, emotional, social, financial, spiritual</td>
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<tr>
<td>Training - e.g. in lifting, giving medication etc.</td>
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<tr>
<td>Confiding in and being listened to - needs expressed and supported often outside the home</td>
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<tr>
<td>Coping strategies— both internal (faith, positive attitude etc.) and external (social networks)</td>
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<tr>
<td>Personal health—time out to sleep, socialise eat well etc.</td>
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</tbody>
</table>

**Family care:**

- Written Information regarding what symptoms can happen as someone comes to the end of their life
- Who else can help
- Charities
- Benefits advice
- Developing partnership working
- Referral to others - e.g. GP

“I get no freedom. He is very loving and caring but very demanding. I have one day off a week. I don’t really need more time off and I don’t need help at night.”
Supporting Carers

### Caregiver Toolkit approach
- Allow carers to assess what is important for them
- Help them to manage the situation they face (problem solving)
- Deal with carer information issues
- Deal with carer practical issues (skills and tools)
- Address carer wellbeing issues
- Address carer relationship issues
- Address other important issues

### Gold Standards Framework

**a) Emotional support** Carers are supported, listened to, kept fully informed and encouraged and educated to play as full a role in the patient’s care as they wish. Where appropriate, they are regarded as an integral part of the team.

**b) Practical support** Practical hands-on support is supplied where possible e.g. respite, benefits advice etc.

**c) Bereavement** Planned support e.g. hospital protocol, visiting, notes tagged, others informed etc.

**d) Staff support** is inbuilt and nurtured leading to better teamwork

### Community approach - a public health view to supporting carers
- Encourage the community to be inspired by positive behaviour and agreed interventions to support itself
- Encourage carers to make connections (Third Sector/faith based groups)
- Employers and Family support
- Friends and Neighbours
- Educators
- Media
- Dementia Friends

### Community approach
- a) Emotional **support** Carers are supported, listened to, kept fully informed and encouraged and educated to play as full a role in the patient’s care as they wish. Where appropriate, they are regarded as an integral part of the team.

- **b) Practical support** Practical hands-on support is supplied where possible e.g. respite, benefits advice etc.

- **c) Bereavement** Planned support e.g. hospital protocol, visiting, notes tagged, others informed etc.

- **d) Staff support** is inbuilt and nurtured leading to better teamwork
Following on from Session 3 of the dementia training programme we are asking you to complete the following tasks:

- **Communication** Consider what you might do differently in the way you communicate with people with dementia in your care. Observe other colleagues, examine factors in your place of work and discuss this with families.

- **Advance Care Planning** Plan to have an advance care planning discussion with a person with dementia, decide on which tools and resources to use, and do this, accompanied by another member of staff. Reflect on how this went and might this be improved further?

- **Supporting Carers** What can you do to improve your support for carers and families of people with dementia? Try using other assessment tools or resources that might be helpful and explore how you might help any unmet needs they might have.

Dementia is a growing problem for society as a whole and many will be affected by it either through your work or on a persona level. This final session will have made you aware of the inappropriateness of admitting people to hospital at end of life especially when they have dementia and the detrimental effect it can have on them. Also inappropriate treatments which may be offered to people with dementia which will not improve their quality of life.

**Take home message**

We can improve our communication with people with dementia, hold advance care planning discussions and better proactively support their carers.
Useful Websites & Further Reading for Session 3
These references are either for general web sites which have a lot of useful relevant information resources too plentiful to list here or links to specific documents/articles

**Learning outcome 1**

**Talking mats** www.talkingmats.com
**Communication skills** www.endolifecareforadults.nhs.uk/education-and-training/communication-skills
www.e-lfh.org.uk/projects/e-elca/index.html

**Learning outcome 2**

**Thinking Ahead.** www.goldstandardsframework.co.uk
**Looking ahead document for ACP in dementia** www.stchristophers.org.uk/steps/steptwo
www.dyingmatters.org.uk
**Mental Capacity Act LPoA** www.alzheimers.org.uk
**Advanced Decisions to Refuse Treatment** www.adrt.nhs.uk
**Model patient leaflet.** www.resus.org.uk/pages/deccprmd.htm
**Advance Care Planning in End of Life Care.** Keri Thomas. ISBN 978-0-19-956163-6
**Time to Talk: Starting end of life care conversations with people affected by dementia.** Dying Matters
**Difficult conversations for dementia** www.ncpc.org/dementia

**Learning outcome 3**

**Carer Support**
www.dementiauk.co.uk
www.dementiafriends.org.uk
www.ncpc.org.uk/library
www.scie.org.uk/socialcaretv/video-player.asp?guid=6cddd9aa-041e-446e-b637-d47ab7b37643
www.dyingmatters.org/
**Bereavement support**
www.crusebereavementcare.org.uk/
**Dementia: workers and carers together.** A guide for social care workers on supporting family and friends carers of people with dementia. Spring 2012. www.skillsforcare.org.uk/developing_skills/dementia/supporting_people_with_dementia.aspx
**Dementia & carers: workers’ resources-Information for care workers supporting family and friends carers of people with dementia.** Spring 2012. www.skillsforcare.org.uk/developing_skills/dementia/supporting_people_with_dementia.aspx
## Homework Action Plan – Session 3

<table>
<thead>
<tr>
<th></th>
<th>To do</th>
<th>Actions planned What we plan to do</th>
<th>Actions taken What we did and what we found</th>
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<tr>
<td>1</td>
<td><strong>Communication.</strong> Consider what you might do differently in the way you communicate with the people with dementia in your care. Observe other colleagues, examine factors in your place of work and discuss this with families</td>
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<td>2</td>
<td><strong>Advance Care Planning Discussions.</strong> Plan to have an advance care planning discussion with a person with dementia, decide on which tools, and resources to use, and do this, accompanied by another member of staff. Reflect on how this went and how this might be improved further</td>
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<tr>
<td>3</td>
<td><strong>Supporting Carers.</strong> What can you do to improve your support for carers and family of people with dementia? Try using other assessment tools or resources that might be helpful and explore how you might help any unmet needs they might have.</td>
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Session 4—Reducing hospitalisation enabling more to live and die at home

Planning better to reduce hospitalisation and enable people with dementia to live and die well at home

Key question
Are we providing well-coordinated care, reducing avoidable hospitalisation and enabling a ‘good death’ for people with dementia at home?

Learning Outcomes
1. **Coordination** explore means of enabling better coordinated cross boundary care and reducing crises
2. **Reducing hospitalisation** understand the importance of reducing hospitalisation in people with dementia enabling more to remain safely at home
3. **Care of the dying** learn more about ways to ensure a good death for people with dementia in their preferred place of care

Activities for Session 4

1. Reflect on a person with dementia that you have cared for, who was admitted to hospital. Was it appropriate, what was the outcome if they returned to you
2. Pros and Cons of hospital admissions.
3. Reflecting on a person with dementia you have cared for and who died, what signs and symptoms did they display as death approached?
### Learning Outcome 1 – Coordination
Explore means of enabling better coordinated cross boundary care and reducing crises

### Activity 1—reflect on a person with dementia, that you have cared for, who was admitted to hospital. Was it appropriate, what was the outcome if they returned

<table>
<thead>
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<th>Was the admission appropriate?</th>
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<th>What was the outcome?</th>
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As people move across different areas of care there may often be gaps in the transitions which can lead to significant problems. It’s rather like travelling across different countries with different languages, cultures and currencies—and people often struggle across the boundaries of care. It can be a nuisance and sometimes distressing to have to repeat information on several occasions. But serious failures in information transfer and service provision can lead to inadequate clinical care, excessive hospitalisation and poor quality of life. For people with dementia this is especially important as they may be unable to communicate their needs and wishes regarding care. This may lead to inappropriate or poor care because of lack of understanding and knowledge of the history of the person involved.

A typical scenario that can happen is illustrated by Bill

- At home – dementia worsening
- Poor quality of life and repeated crisis admissions to hospital because of falls, infections etc
- When in hospital, becomes confused and aggressive, moved from ward to ward. Not eating. Staff struggle to understand his needs, sedated to control his wandering
- Each admission leads to a worsening of his dementia
- Ad hoc visits from different GPs within the practice – no continuity from someone who knows Bill
- No future plan discussed with Bill or his family about where he will be cared for as his dementia worsens
- His elderly wife is struggling to cope and despite support from her children she is becoming exhausted
- There has been no advance care planning or life closure discussions
- There’s a crisis at the weekend when his condition worsens – family call 999 and paramedics admit him to hospital-
- Staff treat immediate symptoms and send to acute ward as no other more appropriate bed available.
- Staff find it difficult to understand and meet Bill’s needs because of his dementia
- Because of pressure on beds in the hospital he is moved from ward to ward
- While decisions are made about the best place of care for Bill, he takes a sudden turn for the worse and dies
- Family given little support about how this happened as they had thought he was getting better and would be discharged
- No reflection by teams - no improvement
- Expensive for NHS - inappropriate use of hospital bed
Benefits of Cross Boundary Integrated Care using GSF
A vision of patient centred best practice

Benefits to Patients
- Improved quality and experience of care
- Empowerment and better listening through advance care planning discussions
- Enabling more to live and die where they choose and reduce hospitalisation
- Recognised as VIPS - ‘gold patients’
- Earlied identification and clarification of needs
- Fewer crises and unplanned events
- Better experience for families and carers
Learning Outcome 2—Reducing hospitalisation
Understand the importance of reducing hospitalisation in people with dementia, enabling more to remain safely at home

Activity 2—Pros and Cons of hospital admissions

Scenario 1
Dorothy and Harry have been married for 60 years and are very close. It was several years before Dorothy had a formal diagnosis of Alzheimer’s even though she had been becoming increasingly confused and forgetful for some years. They felt that they knew each other inside out but had never had specific discussions about future care for Dorothy. Dorothy, while she was in hospital for a chest infection, developed pneumonia, and she stopped eating and drinking. She was not responding to her IV antibiotics and the doctors wanted to insert a PEG tube so that she could be fed, telling Harry that this would help her get over her infection. Harry felt that this should not be done as he knew that Dorothy had ‘had a good life’ and that she was no longer enjoying her quality of life now.

How would you advise Harry?

What would be the consequences of having a PEG tube or not having one inserted?

Scenario 2
Joan Seymour, a retired optician, aged 80, was diagnosed with Alzheimer’s disease three years ago.

Shortly after her diagnosis Joan filled in an advance care plan and made it clear that in the event of her no longer being able to speak for herself she would like to be kept comfortable but she did not want any “aggressive treatment” to keep her alive.

Over the next year her dementia slowly worsened to the point when she was only able to recognise her husband, but none of the rest of the family. At this time the district nurses noticed that Jane was passing blood in her faeces and she became jaundiced.

One of the nurses felt Joan should go for tests to find out what was causing the problem but another felt that she should just be kept comfortable.

How would you decide what advise?

What would be the most suitable place of care for Joan at this time?
Transferring people with dementia to hospital is not always the best outcome for them and can, in reality, have a negative impact on their well being. It is known that people with dementia receive different end of life care in hospital than those who do not have dementia—they are less likely to be referred for palliative care and will receive less medication to control symptoms. It may be appropriate to consider the goals of care as discussed in session 3 as to what is right for the person.

Some of the common reasons why people with dementia are transferred to hospital for what could be considered inappropriate reasons are:

- Falls
- Problems with swallowing
- Chest infections or pneumonia
- Carer breakdown
- End of life

Mortality rates are significantly increased compared to people of a similar age as dementia increases mortality by 7 times and increases the more severe the dementia. Hospital admission can result in a decline in psycho-physiological functioning including: mobility and transfers, toileting, feeding and grooming and weight loss. None of these functions improve significantly back to base line when they are discharged.

For those patients admitted with a hip fracture those who are not cognitively impaired have a 12% mortality rate against 55% for those people with dementia.

**Admission Avoidance Measures**

- Use of Advance Care Plan with patient and family - preventing difficult discussions in crisis and knowledge of a persons preferences for care
- Coding of patients to anticipate likely stage of illness and alerting to needs
- Planning meetings
- Use of Needs Support Matrix - especially for those in Code C (weeks) to prevent crises in final days
- Anticipation of problems and enabled to die in place of choice
- Discussion and GP recording of Do Not attempt Resuscitation/ Allow a Natural Death (DNAR/AND)
- Training and education to increase confidence of staff in caring for seriously ill people
- Guidelines and policy for acute illness
- Staff policies on crisis calls to 999
- Anticipatory prescribing especially for Out of Hours
- Handover form sent to Out of Hours provider
- Handover form sent to ambulance
- Regular audit/ reflection of admissions
- Close communication with family related to ACP
- Use of care pathway/Liverpool Care Pathway (LCP)/GSF minimum protocol for the dying to ensure care in dying phase is of high standard
- Communication and involvement of out of hours providers, night staff etc.
- Collaboration with primary care teams, DNs etc.

**Reducing Length of Stay and encouraging Rapid Discharge**

Develop close link with Social Worker/hospital to enable rapid transfer back home?

Copy of their ACP/ Leaflet/letter to go with person into hospital to explain plans for earliest transfer back.

Advance care Plan noting preferred place of care highlighted to staff

Phoning ward / visiting to discuss with staff

Loud colour information transfer to hospital form e.g. amber

“The awful truth is that ...people with dementia are going into hospital unnecessarily, staying too long and coming out worse. Supporting people with dementia in the community will prevent them reaching crisis point and needing costly hospital care. This is not only beneficial for the person but it makes financial sense for an NHS stretched to breaking point.”

Alzheimer’s Society

BMJ 2013;346:f453
Learning Outcome 3—Care of the dying
—learn more about ways to ensure a good death for people with dementia in their preferred place of care

Activity 3 —reflecting on people with dementia you have cared for, what signs and symptoms did they display as death approached

What signs and symptoms did they display as death approached
It is difficult to identify when someone with dementia is approaching the end of life but they will have the same signs and symptoms of dying as other people. Unfortunately they do not always receive the same end of life care and management of those symptoms. They will often be unable to communicate their wishes which is why advance care planning can be so important.

To ensure that a person with dementia receives the best end of life care there are various tools available that may be of help such as the GSF Minimum Protocol, integrated care plans for final days or the Liverpool Care Pathway.

For people with dementia one of the key features of ensuring a good death is being cared for in familiar surroundings, by familiar people. It is also vital to recognise the stress that their carers can experience at this time.

People give priority to:
- Being treated with humanity, dignity and respect
- Having good communication with health care professionals
- Being given clear information about their condition
- Receiving best possible symptom control
- Receiving psychological support when they need it

### Signs of approaching death
- Profound Weakness
- Bedbound
- Needs assistance with all care
- Diminished intake of food and fluids
- Drowsy or reduced cognition
- May be disorientated in time and place
- Difficulty concentrating
- Scarcely able to co-operate with carers
- Gaunt appearance
- Difficulty swallowing medicine

### Signs of imminent death
- Change in complexion with colour draining from the face
- Extremities becoming cold
- Extremities developing bluish tinge
- Pulse becoming thready and difficult to feel
- Breathing pattern changing, with long gaps between breaths (Cheyne Stokes respirations)

### Pathway criteria

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Yes/No</th>
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<tbody>
<tr>
<td>Taking hardly any food</td>
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<tr>
<td>Taking less fluids and having difficulty with oral medication</td>
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<tr>
<td>Increasing weakness</td>
<td></td>
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<tr>
<td>Spending more time during the day sleeping than awake</td>
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</table>

Those caring for the person realise that the gradual deterioration and increasing weakness, despite all care, is indicating that the person will not get better and that he/she is now dying. The person himself/herself may also be indicating the same.

In the opinion of the care team an in full discussion with the person/family/friends further investigations/interventions are inappropriate, and the person is considered to be dying.

Symptom management, psychological and spiritual support, continual reassessment of needs and family and carer support is essential for this part of care.
What problems may occur when someone is dying?

**Pain at the end of life**
When a person is dying it is very important that they are kept comfortable, both for them and for their family. They may have had pain for a long time (chronic pain caused by arthritis, immobility, heart failure, cancer etc) which they have learned to manage and live with. However as a person nears the end of their life their pain can change and one of the fears as someone is dying is that they will be in pain and it will not be controlled properly. It is important that as a person becomes less able to swallow medication that their analgesia is delivered via another route eg transdermal, rectal routes or through a syringe driver.

**Noisy, moist breathing (death rattle)**
This is very distressing to relatives and should be treated promptly as it is easier to prevent secretions forming than to remove secretions that have gathered. People themselves are rarely distressed by noisy secretions and it is helpful for the family to know this. The family should be told that the person is not choking. Despite re-positioning the person, and using all available medication, some people will continue to breathe noisily. General measures include re-positioning the person and giving reassurance to the relatives.

**Restlessness / agitation in the terminal phase**
Eliminate all possible REVERSIBLE CAUSES with particular attention to pain and discomfort from a full bladder or rectum. Sometimes it may be necessary for the GP or nurse to consider sedation, this should be discussed with the person and family if possible.

**Breathlessness**
This is a common and distressing symptom in advanced cancer, chronic obstructive pulmonary disease, and heart failure. At this stage looking for a reversible cause for the breathlessness is usually inappropriate and the goal of care is clearly comfort. Many of the non-drug methods, such as oxygen, a fan or an open window or positioning are difficult in the last few days and, in general, will be controlled with drugs.

**Nausea and vomiting**
It is normally important to try and work out the cause of a person’s nausea and vomiting so that an appropriate choice of treatment can be started. However when a person is dying this is usually too difficult and it is important to treat the symptom quickly to ensure that the person is kept comfortable. The commonest causes of nausea and vomiting at the end of life relate to the build up of toxins in the system as kidney function deteriorates or to stomach or bowel inactivity.

**Psychological needs**
Some people are fearful of dying – what will it be like? Will I suffer? How will my family manage? Family members, partners and friends may also need help to cope with their fear and anger at the situation. They need to feel involved in care and decision-making, which is essential in order to avoid additional grief in their bereavement. The service user, families, partners and friends can be helped to say their goodbyes, to be given the opportunity to heal rifts and to complete unfinished business. Working together to enable a person to die at peace with themselves is a fundamental goal. People’s anxiety can be increased if:
- They are unaware of the diagnosis, but feel that people are lying to them
- They have certain distressing symptoms such as breathlessness, bleeding and constant nausea or diarrhoea
- There is a “weak” religious faith. (Convinced believers and convinced nonbelievers have less anxiety)
- They are worried about dependant relatives
- They have “unfinished business” to attend to, such as writing a will
Following on from Session 4 of the dementia training programme we are asking you to complete the following tasks:

- **Improving cross boundary care.** What barriers do you find to enabling good communication and coordination of care with others in your area and how can you improve this? What can you do to avoid crises—try at least 3 new things and observe the effects.

- **Reducing hospitalisation.** Make a list of ways that you can avoid inappropriate hospital admissions for people with dementia—try them out and reflect on progress. What do you think are the most helpful improvements and how could you integrate this into your daily work?

- **Care of the dying.** How do you provide best care for the dying in the final days—what tools are useful here and can you improve this further? How can you improve support for their carers and families at this time and in bereavement?

This final session will have made you aware of the inappropriateness of admitting people to hospital at end of life especially when they have dementia and the detrimental effect it can have on them. Also inappropriate treatment s which may be offered to people with dementia which will not improve their quality of life.

**Take home message**

We can give well-coordinated proactive c to keep people with dementia safely at home, reduce crises and enable them to die well at home if that is their wish.
<table>
<thead>
<tr>
<th></th>
<th>To do</th>
<th>Actions planned</th>
<th>Actions taken</th>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>Improving cross boundary care what barriers do you find to enabling good communication and coordination of care with others in your area and how can you improve this/ what can you do to avoid crises—try at least 3 new things and observe the effects</td>
<td>What we plan to do</td>
<td></td>
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<tr>
<td>2</td>
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Learning outcome 1
This is me. http://www.alzheimers.org.uk/thisisme

Learning outcome 2

Learning outcome 3
GSF Minimum Protocol www.goldstandardsframework.org.uk
Integrated care plan for final days www.stchristophers.org.uk/steps/stepthree
Liverpool Care Pathway www.mcpcil.org.uk/
www.scie.org.uk
www.endoflifecareforadults.nhs.uk


Bereavement information
www.crusebereavementcare.org.uk
www.dyingmatters.org.uk
www.dementiauk.org/

Useful Websites & Further Reading for Session 4
These references are either for general web sites which have a lot of useful relevant information resources too plentiful to list here or links to specific documents/articles