

# The Gold Standards Framework in Dementia Training Programme



## Good Practice Guide & Workbook Folder

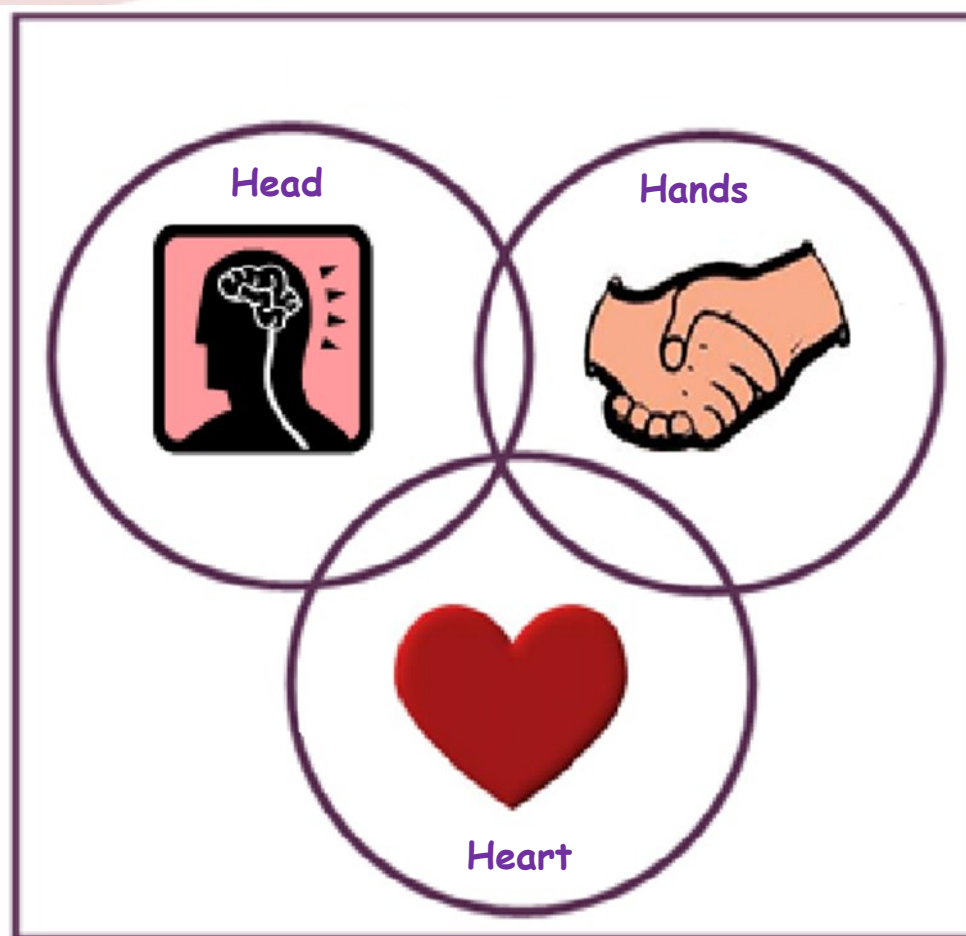
**December 2012**

**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](http://www.goldstandardsframework.org.uk)

Tel: 01743 291 891



### GSF Team

Prof Keri Thomas is National Clinical Lead for the GSF Centre,  
Hon Professor End of Life Care University of Birmingham,  
Royal College General Practitioners Clinical Champion in End of Life Care  
Maggie Stobbart Rowlands GSF Programme Lead  
Lucy Giles Clinical Nurse Advisor  
Pam Poole, Michelle Dorrington, AnnMarie Lawrence and Louise Evans  
Ann Pugh of the GSF Centre

All Rights Reserved. All materials and templates from the GSF Programmes are trademarked and fully copyrighted. Permission to use the work and materials is granted to those registered for the National GSFPC Training programme only. Specific permission for other use should be sought from National GSF Centre. For further details please see information governance section of the GSF Website or contact the National GSF Centre.

## Contents

### 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

Awareness

Pain & Distress

Communication  
& wishes

Reducing  
hospitalisation

## 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 its can still be quite a challenge to get this right every time and it does takes 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 where ever 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

Quality Improvement

Quality Assurance

Quality Recognition

### 7 Key Tasks - the 7 Cs



### 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



After Death Analysis (ADA)

Advance Care  
Planning – Thinking  
Ahead



Passport  
Information

	Pt needs	Support from hospital/SPC	Support from GP
Years			
Months			
Weeks			
Days			

Needs Support Matrix

## The Dementia Training Programme

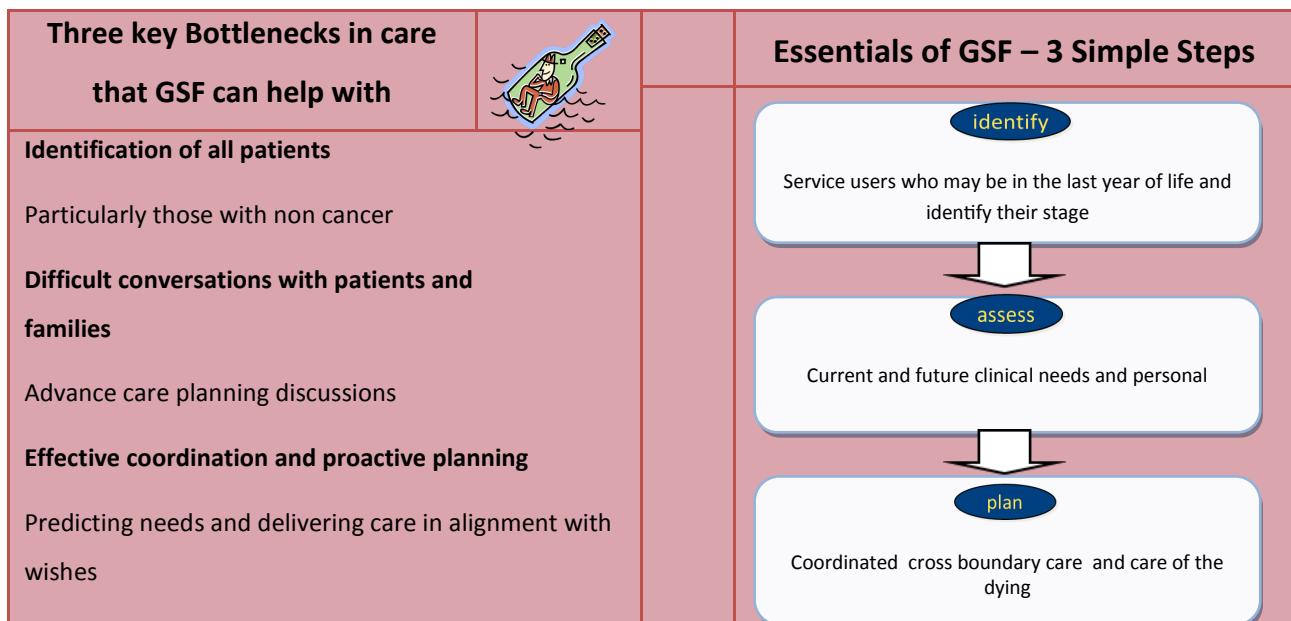
This interactive course in improving care for people with dementia nearing the end of life, is based on the learning of over 10 years of the Gold standards Framework (GSF) Training Programmes in Primary Care (GPs, District nurses etc.), Care Homes (Nursing, Residential etc.) hospitals, (acute, community)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



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

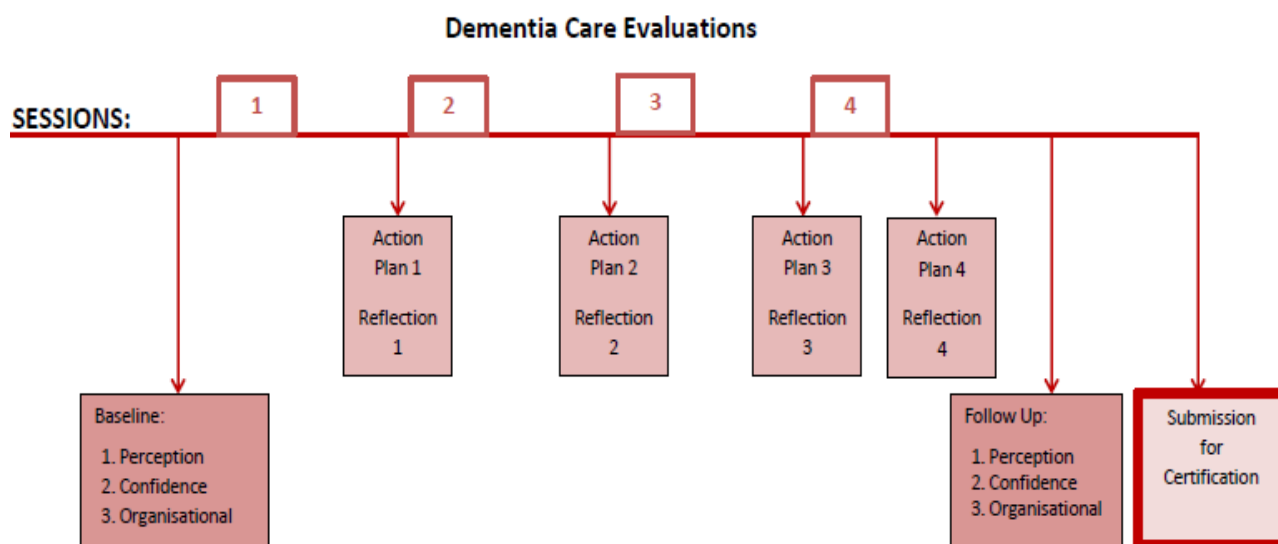


## Resources, Support and Evaluation

### 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:



Evaluation	
Place of work questionnaire before and after	This will evaluate the impact of the programme on: <ul style="list-style-type: none"> <li>Awareness of people with dementia</li> <li>Crisis hospital admissions &amp; outcomes</li> <li>Hospital deaths</li> </ul>
Perceptions of dementia before and after	This will show how your perceptions may have changed as a result of the programme
Confidence in dementia care before and after	This helps to identify gaps in knowledge and competence, and to plan individual training needs.
Action plan for each session showing plan and what actions have been taken	This will focus your learning on how it can be implemented into your practice
Reflective essay on each of the four key questions (approx. 400 words for each session)	These will show how care can be reflected on and improved as a result

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



# Overview of GSF Dementia Training Programme

GSFDC Overview	Key Question	Learning Outcomes	Take Home Message
Session 1 <b>Focus:</b> <b>Introduction to dementia care</b>	<b>Key Question:</b> How can we provide gold standard /top quality care with dignity and respect, for people with dementia nearing the end of life?	<b>Learning Outcomes:</b> 1 <b>What is dementia?</b> 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. <b>Person-centred care.</b> To learn more about the person-centred approach in dementia care- seeing the person behind the disease. 3. <b>Dignity.</b> To consider ways of enhancing dignity, respect and spiritual care for people with dementia in your place of work.	<b>Take Home Message:</b> 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.
Session 2 <b>Focus:</b> <b>Assessing and responding to underlying needs such as pain and distress.</b>	<b>Key Question:</b> Are we recognising decline in people with dementia and underlying masked symptoms such as pain and providing them with the right care?	<b>Learning Outcomes:</b> 1 <b>Decline</b> Understanding decline in dementia and recognising and responding to signs of deterioration. 2 <b>Pain.</b> Understanding pain in dementia- recognition, causes and management and the use of assessment tools 3. <b>Other symptoms</b> Understand symptom control basics, and the impact of other co-morbid conditions.	<b>Take Home Message:</b> 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.
Session 3 <b>Focus:</b> <b>Listening better and assessing personal needs and wishes and those of carers.</b>	<b>Key Question:</b> How are we listening to people with dementia and understanding their underlying needs and wishes?	<b>Learning Outcomes:</b> 1 Communication – learn more about effective ways to communicate and listen to people with dementia. . 2 <b>Advance Care Planning</b> Understand more about Advance Care Planning and Best Interest discussions for people with dementia and put these into practice 3 <b>Carers</b> Understand the particular importance of supporting carers, their needs and the significance of early loss and bereavement.	<b>Take Home Message:</b> We can improve our communication with people with dementia, hold advance care planning discussions and better proactively support their carers
Session 4 <b>Focus:</b> <b>Planning better to reduce crises, reduce hospitalisation and enable people with dementia to live and die well at home.</b>	<b>Key Question:</b> Are we providing well-coordinated care, reducing avoidable hospitalisation and enabling a 'good death' for people with dementia at home .	<b>Learning Outcomes:</b> 1 <b>Coordination</b> Explore means of enabling better coordinated cross boundary care and reducing crises 2 <b>Reducing hospitalisation.</b> Understand the importance of reducing hospitalisation in people with dementia enabling more to remain safely at home. 3 <b>Care of the dying</b> Learn more about ways to ensure a good death for people with dementia in their preferred place of choice .	<b>Take Home Message:</b> 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 .

## Awareness

# 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. 3 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:-
  - A**ttitude
  - B**ehaviour
  - C**ompassion
  - D**ialogue
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 T/F
2. Permanent damage to the brain occurs in most types of dementia T/F
3. People who have dementia will all show the same symptoms T/F
4. People with dementia usually have poor short term memory T/F
5. People with dementia have the same needs as babies T/F
6. If an elderly person becomes confused it means they have got dementia T/F
7. People with dementia often have good memory of the past T/F
8. Dementia can be caused by small strokes T/F
9. Alzheimer's disease can be a genetic condition T/F
10. Most types of dementia cannot be cured T/F
11. When people with dementia walk around it is always aimless T/F
12. Most people with dementia gradually lose all of their ability to communicate T/F
13. People with dementia who are verbally aggressive, usually become physically aggressive T/F
14. Brain damage is the only factor responsible for the 'symptoms' of dementia T/F
15. If a person with dementia becomes agitated they require sedatives T/F

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 misinterpret 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

### Some Statistics

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

### Challenges in end of life care and dementia;

- Impaired communication of need
- Difficulties in assessing pain/other symptoms
- Aggressive resistance/ 'Challenging behaviour'
- Poor pain management.
- Physical and mental decline
- Behavioural and psychological symptoms
- Prognostic uncertainty
- Ethical and Legal issues
- Nutrition and hydration
- Diagnosing dying
- Discontinuation and conversion of medication
- Pathway drugs / administration (risk assessment)
- Prolonged dying phase
- Bereavement support
- Resources
- Education
- Communication skills training
- Engagement with other Services
- management of double incontinence and preserving tissue viability
- positioning, enhanced oral hygiene (NB use of community dentist for advice if required)
- Communication through the senses and emotional support



## Future projections

The number of people in the UK with dementia will double in the next 40 years.

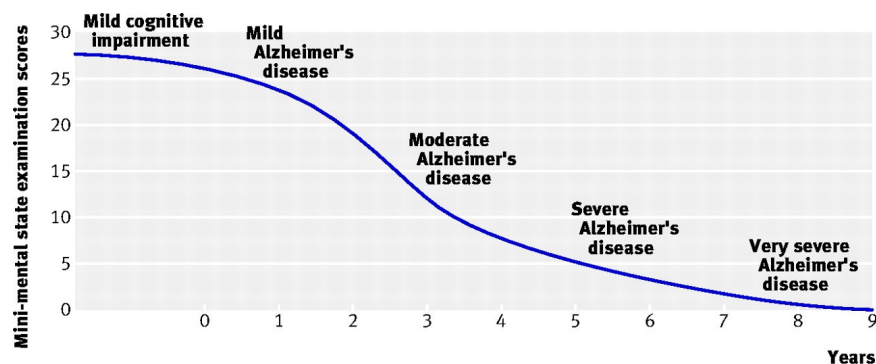
 = 10,000 people



Source: Alzheimer's Society, 2012  
[alzheimers.org.uk](http://alzheimers.org.uk)

Leading the fight  
against dementia  
**Alzheimer's  
Society**

## 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

Burns, A. et al. BMJ 2009;338:b158

BMJ



## 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](http://www.dh.gov.uk/dementia).

*"Dementia is not an illness we can ignore. It has a devastating impact on the people who develop it, and the families who care for them. We all know someone who has been affected, be it a relative, friend or work colleague"*

Alan Johnson MP

*"Dementia is one of the biggest challenges we face today"*

David Cameron PM

## 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

Alzheimer's disease	'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
Vascular Dementia	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 & physical frailty- progressive memory problems Progression often 'stepped' rather than gradual
Dementia with Lewy bodies	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
Fronto-temporal dementia (including Picks disease)	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
Related to other comorbid conditions	Multiple sclerosis, Motor Neurone disease and Huntington's disease more likely to develop dementia
Other types	Korsakoffs syndrome, CJD, HIV, Binswanger's diseases and supranuclear palsy Dementia now seen in people with learning disabilities and Downs syndrome



## 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

Think of a time when you have had struggled with communication

How can you communicate better with people with dementia

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

$$\text{Dementia} = \text{NI} + \text{H} + \text{B} + \text{P} + \text{SP}$$

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

	Person with dementia	Staff member	Family carer
Security	To feel safe	Emotional demands	Confident
Continuity	Seamless care	positive experience	Standards maintained
Belonging	Relationships	Team work	Not alone
Purpose	Choices	Therapeutic direction	Dignity and integrity
Achievement	Meaningful; goals	Quality care	Done your best
Significance	Recognised	Valued practice	Caring role

## Life story work

Individual biographical approach

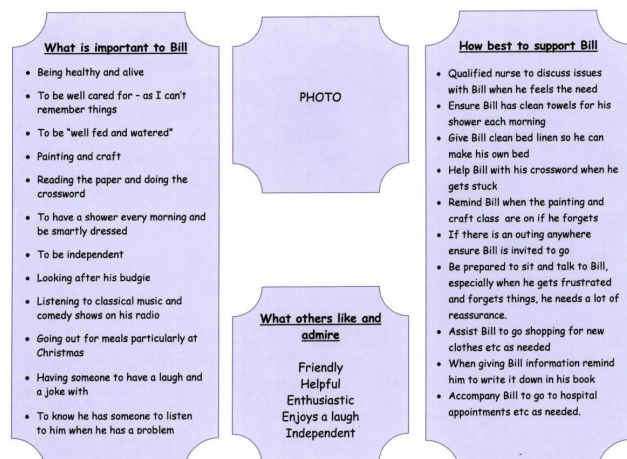
Review and evaluation of past life events

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)



Example of a memory box showing a person's history



## 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

Positive

Negative

## 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	



## D Dignity Discussions

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

A ATTITUDES	<p><b>Questions to be asked</b></p> <ul style="list-style-type: none"> <li>• How would I be feeling in this patient's situation?</li> <li>• What is leading me to draw those conclusions? • Have I checked whether my assumptions are accurate?</li> <li>• Am I aware how my attitude towards the patient may be affecting him or her?</li> <li>• Could my attitude towards the patient be based on something to do with my own experiences, anxieties, or fears?</li> <li>• Does my attitude towards being a healthcare provider enable or disable me to establish open and empathic professional relationships with my patients?</li> </ul> <p><b>Actions to be taken</b></p> <ul style="list-style-type: none"> <li>• Make a conscious effort to make these questions a part of your reflection on the care of each and every patient</li> <li>• 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</li> <li>• Include ongoing professional development activities that have you challenge and question your attitudes and assumptions as they might affect patient care</li> <li>• 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</li> </ul>
B BEHAVIOUR	<p><b>Disposition</b></p> <ul style="list-style-type: none"> <li>• Treat contact with patients as you would any potent and important clinical intervention</li> <li>• Professional behaviours towards patients must always include respect and kindness</li> <li>• Lack of curative options should never rationalise or justify a lack of ongoing patient contact</li> </ul> <p><b>Clinical examination</b></p> <ul style="list-style-type: none"> <li>• Always ask the patient's permission to perform a physical examination</li> <li>• Always ask the patient's permission to include students or trainees in the clinical examination</li> <li>• 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 . . .")</li> <li>• Limit conversations with patients during an examination (aside from providing them with instruction or encouragement) until they have dressed or been covered appropriately</li> </ul> <p><b>Facilitating communication</b></p> <ul style="list-style-type: none"> <li>• Act in a manner that shows the patient that he or she has your full and complete attention</li> <li>• 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</li> <li>• Personal issues should be raised in a setting that attempts to respect the patient's need for privacy</li> <li>• When speaking with the patient, try to be seated at a comfortable distance for conversation, at the patient's eye level when possible</li> <li>• Given that illness and changing health status can be overwhelming, offer patients and families repeated explanations as requested</li> <li>• 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</li> <li>• Always ask if the patient has any further questions and assure them that there will be other opportunities to pose questions as they arise</li> </ul>
C COMPASSION	<p><b>Getting in touch with one's own feelings requires the consideration of human life and experience</b></p> <ul style="list-style-type: none"> <li>• Reading stories and novels and observing films, theatre, art that portray the pathos of the human condition</li> <li>• Discussions of narratives, paintings, and influential, effective role models</li> <li>• Considering the personal stories that accompany illness</li> <li>• Experiencing some degree of identification with those who are ill or suffering</li> </ul> <p><b>Ways to show compassion</b></p> <ul style="list-style-type: none"> <li>• An understanding look. • A gentle touch on the shoulder, arm, or hand</li> <li>• Some form of communication, spoken or unspoken, that acknowledges the person beyond their illness.</li> </ul>
D DIALOGUE	<p><b>Acknowledging personhood</b></p> <ul style="list-style-type: none"> <li>• "This must be frightening for you." • "I can only imagine what you must be going through."</li> <li>• "It's natural to feel pretty overwhelmed at times like these."</li> </ul> <p><b>Knowing the patient</b></p> <ul style="list-style-type: none"> <li>• "What should I know about you as a person to help me take the best care of you that I can?"</li> <li>• "What are the things at this time in your life that are most important to you or that concern you most?"</li> <li>• "Who else (or what else) will be affected by what's happening with your health?"</li> <li>• "Who should be here to help support you?" (friends, family, spiritual or religious support network, etc)</li> <li>• "Who else should we get involved at this point, to help support you through this difficult time?" (psychosocial services; group support; chaplaincy; complementary care specialists, etc)</li> </ul> <p><b>Psychotherapeutic approaches.</b> • Dignity therapy, • Meaning centred therapy, • Life review/reminiscence.</p>

## 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](mailto: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.

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

## 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

# The Five Senses of Spiritual Care

## 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?



## 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?



## 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?





## 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 person's 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).

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.

## 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.

## Action Plan for your area of work

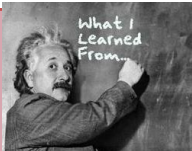
Following on from Session 1 of the dementia training programme we are asking you to complete the following tasks:

**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.



## 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

	<b>To do</b>	<b>Actions planned</b> <i>What we plan to do</i>	<b>Actions taken</b> <i>What we did and what we found</i>
1	<b>Your Goals.</b> 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?		
2	<b>Person Centred care.</b> 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.		
3	<b>Dignity.</b> 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 ?		



## 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/](http://www.dementiachallenge.dh.gov.uk/)

**Prime Ministers challenge on dementia 2012.** [www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_133170](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_133170)

**Living well with dementia –a national dementia strategy.** 2009. [www.dh.gov.uk/publications](http://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](http://www.endoflifecareforadults.nhs.uk)

**Alzheimer's society** [www.alzheimers.co.uk](http://www.alzheimers.co.uk)

### Learning outcome 2

[www.ageuk.org.uk](http://www.ageuk.org.uk)

[www.dementia.stir.ac.uk/library\\_dementianow](http://www.dementia.stir.ac.uk/library_dementianow)

[Www.dementiauk.org/information-support/life-story-work](http://Www.dementiauk.org/information-support/life-story-work)

**Graham Stokes.** And Still the Music Plays: Stories of People with Dementia. Pub Hawker Publications ISBN-10:91874790884

**Graham Stokes.** Challenging Behaviour in Dementia: A Person-centred Approach . Pub. Speechmark Editions . ISBN—10:0863883974.

### Learning outcome 3

[www.dignityincare.org.uk](http://www.dignityincare.org.uk)

[www.scie.org.uk/publications/dementia/about.asp](http://www.scie.org.uk/publications/dementia/about.asp)

[www.rcn.org/development/practice/dementia](http://www.rcn.org/development/practice/dementia)

**Chochinov** [www.dignityincare.ca/en/the-abcds-of-dignity-in-care](http://www.dignityincare.ca/en/the-abcds-of-dignity-in-care).

**Tom Kitwood:** Dementia Reconsidered: The Person Comes First (Rethinking Ageing). Pub open University Press. ISBN—10: 0335198554