THE NATIONAL COUNCIL FOR PALLIATIVE CARE

#dyingwithdementia
#dementiachallenge

7th Annual Conference on Dementia & End of Life

Rising to the Prime Minister's Dementia Challenge

Tuesday 4th December
15 Hatfields, London

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Seminar D: Regional approaches to good pain management

Chaired by: Simon Chapman, Director of Policy & Parliamentary Affairs, The National Council for Palliative Care & Dying Matters Coalition

Beke Tshuma, Project Lead, Hertfordshire Partnership NHS Foundation Trust

Laureen Hemming, Specialist Tutor, Oncology and Palliative Care, University of Hertfordshire

Sarah Russell, ABC End of Life Education Project Lead, Mount Vernon Cancer Network

Hertfordshire Partnership
NHS Foundation Trust

Living Well with Dementia:

Why a Grassroots Approach to Pain Management Education

Beke Tshuma
Project Lead: Palliative and End of Life Care
Laureen Hemming
Specialist Tutor: Oncology and Palliative Care

University of Hertfordshire

Behavioural and Psychological Symptoms of Dementia (BPSD)

If however this is a response to:

- AMNESIA
- APRAXIA
- AGNOSIA
- APHASIA

Why BPSD?

- Aggression (Verbal and Physical)
- Inappropriate behaviour
- Weeping and/or moaning
- Screaming
- Reaction to touch
- Increased or decreased movement

- Increased level of confusion
- Unable to settle
- Wandering
- Agitation
- Depression
- Psychosis
- Anxiety

TOTAL PAIN?

"*The suffering that encompasses all of a person's*

- ***physical***,
- ***psychological,***
- ***social,***
- ***spiritual,***
- ***practical struggles***"

(Richmond C. Dame Cicely Saunders. BMJ 2005;33: 238)

Palliative Care

Definition:

The active holistic care of a patients with progressive and advanced illnesses, involving:

- Management of physical pain and other symptoms.
- Provision of emotional, psychological, social and spiritual support.

(Department of Health, 2006)

Behavioural and Psychological Symptoms of Dementia (BPSD)?

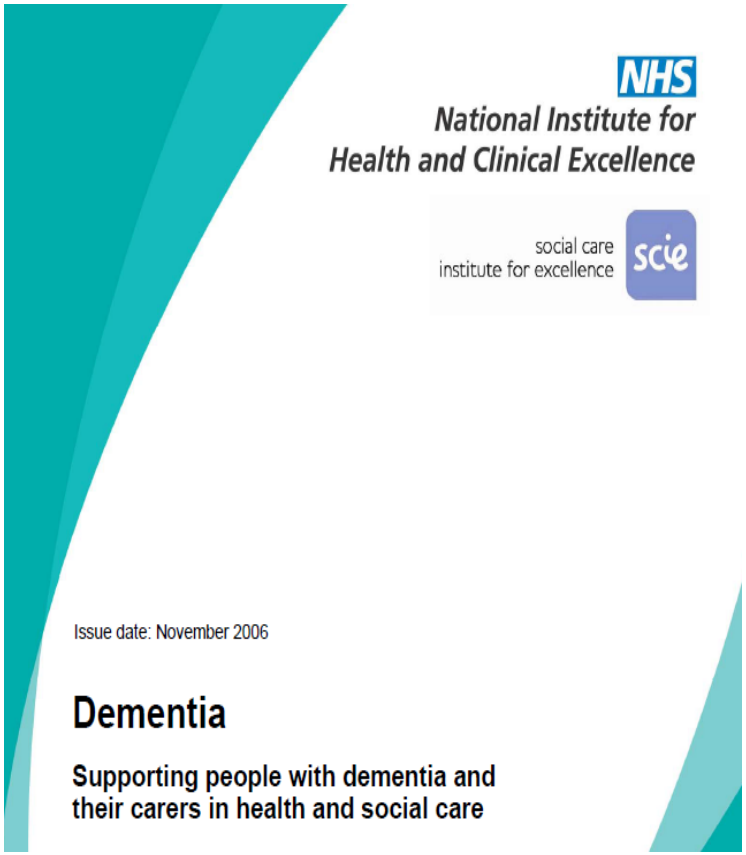
- Aggression (Verbal and Physical)
- Inappropriate behaviour
- Weeping and/or moaning
- Screaming
- Reaction to touch
- Increased or decreased movement
- Increased level of confusion
- Unable to settle
- Wandering
- Agitation
- Depressed
- Psychotic

Why do we calls this CHALLENGING BEHAVIOUR

Why not PAIN BEHAVIOUR

Why not Behavioural & Psychological Symptoms of Distress (not dementia) (BPSD)

NICE clinical guideline 42
Developed by the National Collaborating Centre for Mental Health



Dementia care should:

Incorporate a palliative care approach from the time of diagnosis until death. The aim should be to:

- Achieving the best quality of life for the people with dementia.
- To enable people with dementia to die with dignity and in a place of their choice.
- To support carers during their bereavement in anticipation of and following death.

Palliative care should:

Ensure equal access to palliative care services for people with dementia, as those without .

(NIC Depar t 6)

Pain Management Education:

- Funding : £35, 000 from Bedfordshire and Hertfordshire Workforce Partnership
- Short course: collaboration with the University of Hertfordshire to support a one day course
- Target: 250 – 270 delegates from September – March, from
  - **Mental Health Services**
    - **Liaison Nurses working in the Acute Trust and Intermediate Care Services to support assessments and implementation of care**
    - **Intensive Outreach Team with a remit of prevention of admission, expediting discharge**
    - **Community Specialist Mental Health Teams dealing with complex needs**
    - **Inpatient Services**
  - **Care Homes**
  - **Home Care**

Hertfordshire Partnership
NHS Foundation Trust

Our Premise: underpinning research

90% of people with dementia will over the course of time exhibit at least one aspect of BPSD

University of Hertfordshire
Hertfordshire

Our Premise: underpinning research

- 69% of nursing homes have no policy about managing pain
- 75% of nursing homes do not use pain assessment charts
- 40% of nursing staff have received no training in pain management
- 83% of care assistants have had no training.

Wilcock, Froggatt & Goodman in Downs and Bowers (2010)

Pain Management Education Aims

- To raise awareness of the specific needs of people living with dementia
- To improve the quality of palliative care and of life for people living with dementia
- To initiate/facilitate the development of a structured approach to pain assessment and management to meet the needs of people living with dementia.
- To engender a sense of process ownership thus developing an informed, empowered and effective workforce

Pain Management Education Structure

- Pain theory, experience and response
- Pain assessment principles and tools – Groups exploring different tools and selecting the ones felt to be appropriate
- Pain management theory and principles
- Strategies to alleviate pain
- Case studies – Group work encouraging application of all the tools and principles.

Pain Management Education: Achievement so far

- 110 Staff: Registered Mental Health, Registered Adult Nurses, Health Care Assistance and Support Workers
- Very positive feedback with evaluation showing a 50 – 70% shift in
  - Knowledge base
  - Being able to identify pain behaviour in people with dementia
  - Confidence in using the pain assessment tools
  - Being able to advocate for better management of pain
  - Confidence in challenging colleagues and other professionals eg General Practitioners

Hertfordshire Partnership
NHS Foundation Trust

What the staff said

A reaffirmation that reaction to pain is the same in all of us, we just express it differently.

One does have to be considerate enough to address not only the physical symptoms but also other aspects/dimensions in order to provide good care.

This is the first time I have been on a course like this. You covered everything.

Becoming a champion to be committed and dedicated.

Much improved assessment skills .. Please provide this education for GPs .. Thank you - Excellent !

University of Hertfordshire

Hertfordshire

Striking the balance!

More information about assessment tools, see the implementation of assessment tools in clinical practice.

Group work boring, work in different areas and at different levels so different opinions

More on drug toxicity in people with dementia

Theory too complicated to understand

Not enough depth

Thank you for Listening

Any Questions

References

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A B C Dementia

Rising to the Challenge

Learning Blending Into Care

Sarah Russell
Mount Vernon Cancer Network
Project Lead: Care Home End of Life Programme
http://www.endoflifecarelearning.co.uk/login/index.php

Director of Education and Research: Hospice of St Francis, Berkhamsted
www.stfrancis.org.uk

To rise to the challenge we need to do more than just ‘train.’
We need to empower leadership skills, provide sustainable education programmes, facilitate relationships, look at new ways of working and be prepared to go out on a limb……and invest in our workforce

1. **What is the ABC programme**
2. **How has it blended learning into care**
3. **How has it risen to the challenge**

The NHS East of England ABC Programme

http://www.endoflifecarelearning.co.uk/login/index.php

- A flexible blended learning end of life care education programme funded by the NHS East of England Multi professional deanery

- 6 modules (7th due shortly)
- Mentorship in Bedfordshire, Hertfordshire, Luton, Essex and Anglia – national open access to e learning platform
- E learning and/or face to face workshops
- Follow up action planning workshop
- Champion support
- Train the Trainer programme

1. Overarching principles
2. Assessment and care planning
3. Comfort and well being
4. Communication skills
5. Advance care planning
6. End of life tools
7. *Due shortly – Caring in the last days of life*
8. Follow up action planning workshop (for the home/individual)

In 2 years across the East of England
2844 staff and 475 homes completed
(1/3rd of all homes)

- ✓ Increase in achievement of documented preferred place of death
- ✓ Very high completion rate (97%)
- ✓ Cost effective
- ✓ Recommended End of Life Care Education programme by Hertfordshire County Council

Measurement

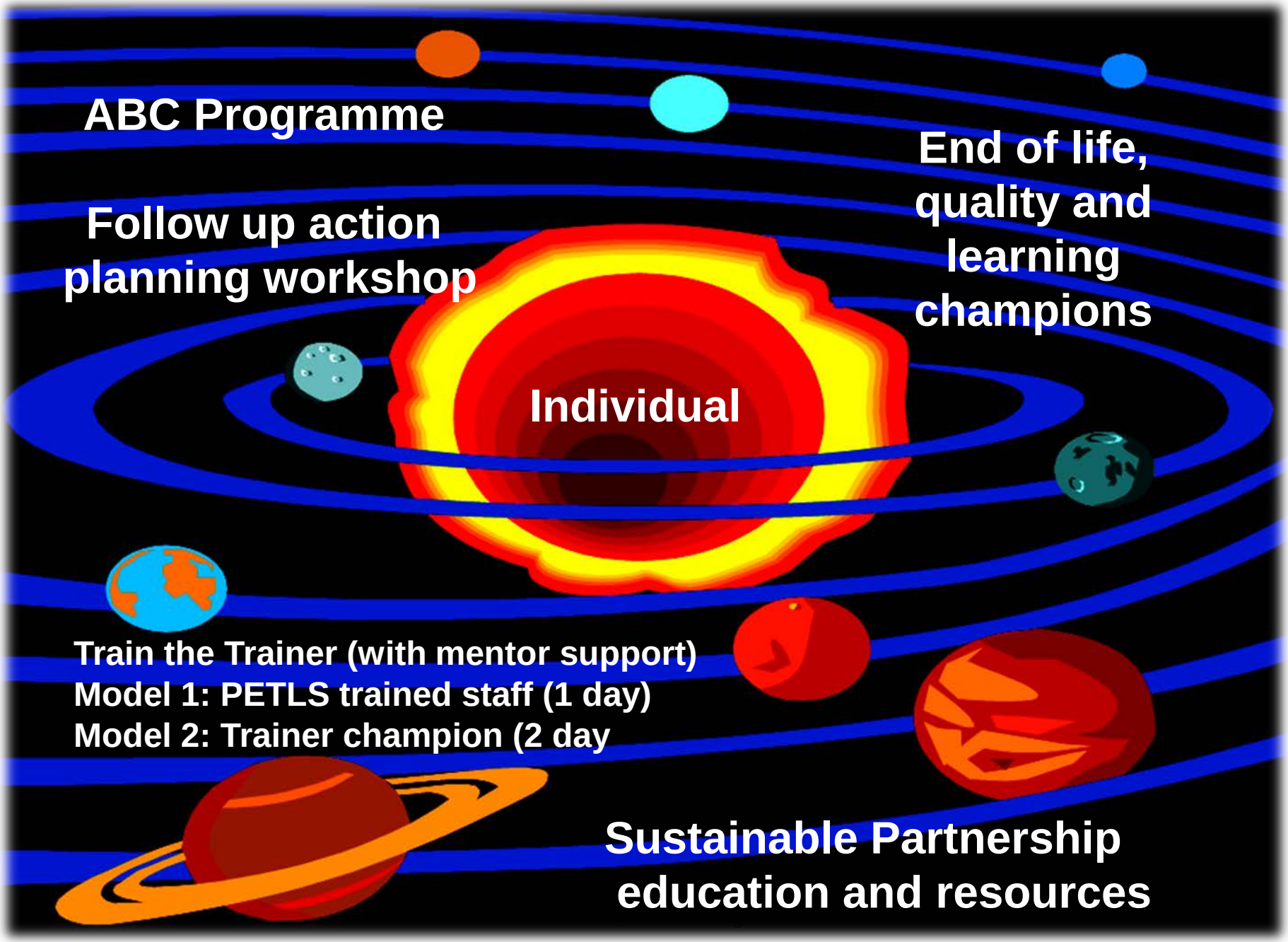
- Pre and post programme learners self confidence
- Post programme learners and managers evaluation
- Deceased resident advance care planning audit pre, during and post programme (impact assessment)
- Pre and post programme policy and procedures benchmarking
- Hospital admission data

Development Streams:

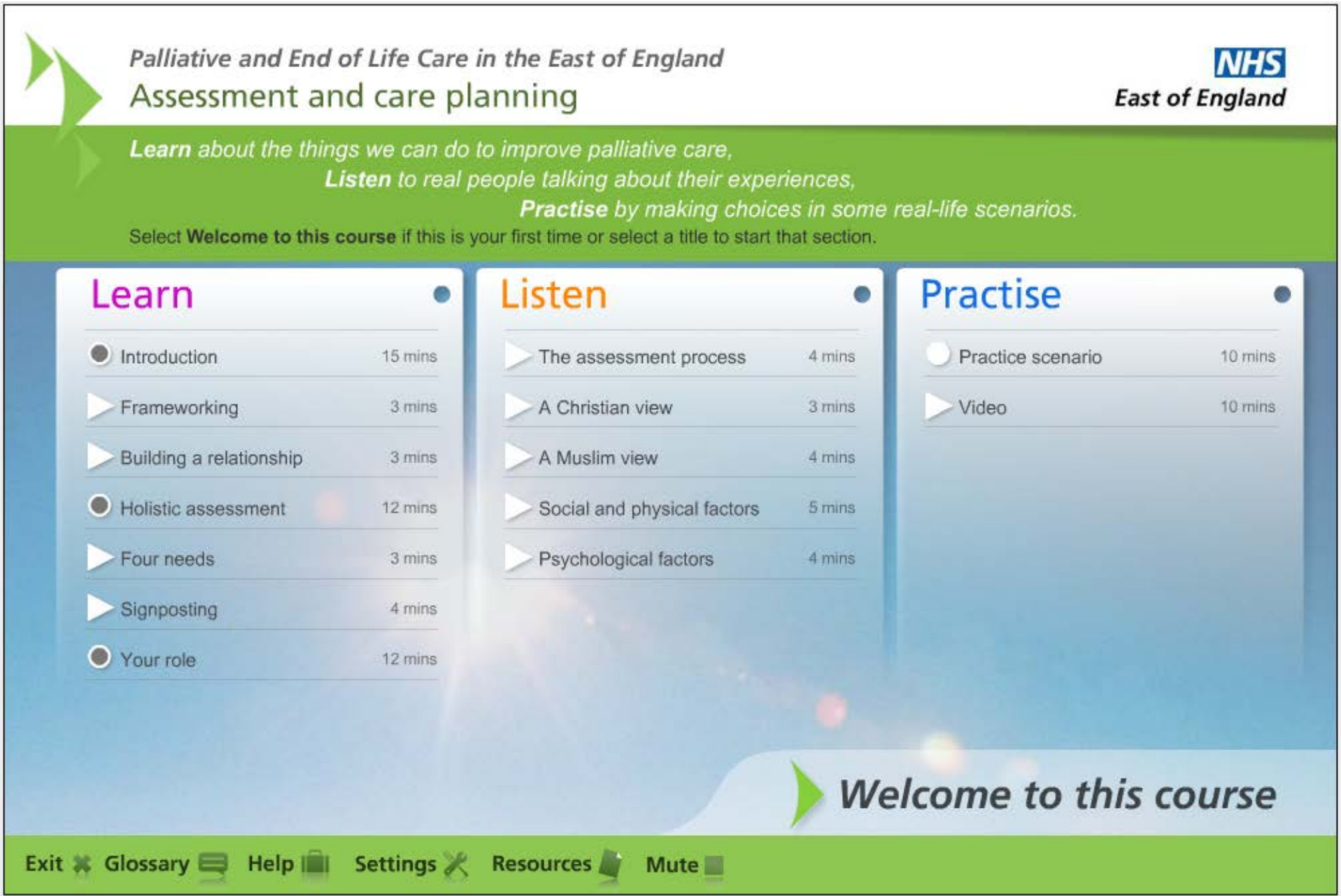
1. Three strand development
   - New homes education
   - Sustaining current homes
   - Enhanced end of life education

Evaluation streams:

a. **Satisfaction** *"best course I have ever been on, the facilitators were fantastic" " I want more"*
b. **Change in attitudes** *" it is more than an education programe it is about a change in beliefs, attitudes and behaviors"*
c. ***Changes in behaviors*** *"I am now proactively talking with GP's and introducing new tools"*
d. ***Clinical leadership*** *" I am now revising all our policies, taking part in the train the trainer programme and thinking how we can continuously demonstrate and improve our care"*


ABC Programme
Follow up action planning workshop
End of life, quality and learning champions
Individual
Train the Trainer (with mentor support)
Model 1: PETLS trained staff (1 day)
Model 2: Trainer champion (2 day
Sustainable Partnership education and resources

http://www.endoflifecarelearning.co.uk/login/index.php



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Palliative and End of Life Care in the East of England

Assessment and care planning

NHS East of England

Introduction: The basics of assessment

Assessment is just another way of describing what you already do – care about people's needs.

Assessment is a continuous process – you don't stop caring and the residents' needs keep changing.

Assessment is resident led – residents will voice their needs if you let them speak.

Assessment helps you see the whole picture – the needs, values, beliefs and expectations of everyone involved.

Assessment gives a comprehensive history of the resident's normal behaviour and coping mechanisms.

Assessment covers past, present and future – past history, present realities and future expectations.

Assessment helps you be sure you're delivering the right care.
Click Restart to play the animation again or click Next to continue.

Restart

Exit | Glossary | Help | Settings | Resources | Mute | Menu | Back | 4 of 15 | Next

http://www.endoflifecarelearning.co.uk/login/index.php

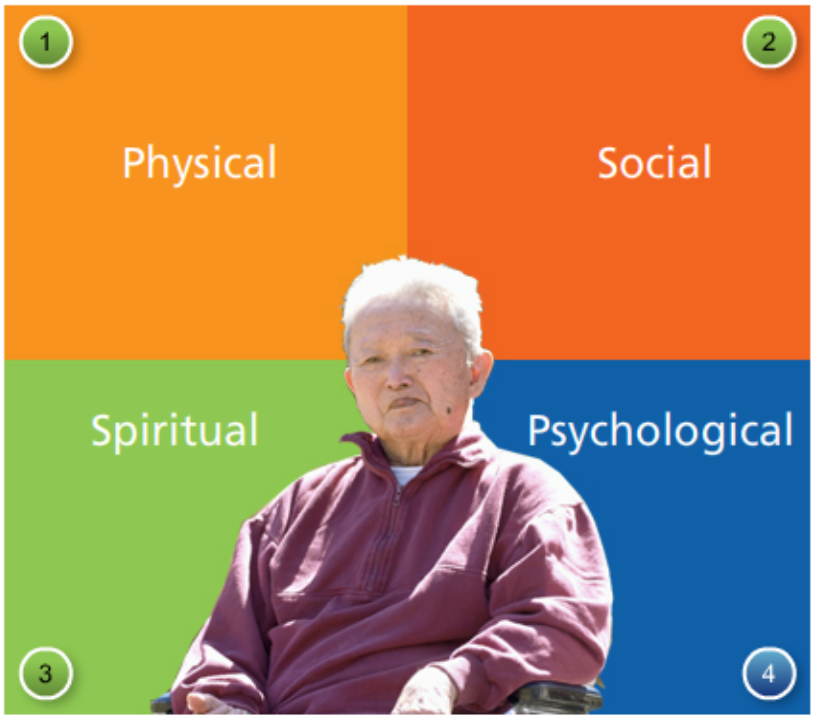
Palliative and End of Life Care in the East of England

Assessment and care planning

NHS East of England

Holistic assessment: Working in four dimensions

So now you can see that making a **holistic** assessment of a resident involves a **4 dimensional view** in which you consider not just the **physical** aspect, but the **social, psychological and spiritual** dimensions as well.



The **psychological factors** of the holistic assessment deal with what is going on **in the person's mind**.

Are they feeling **stressed, anxious, scared or worried**? If so, **why**? What are the main things making the person anxious?

These are questions you may **also need to ask about relatives and carers** as well.

Click on the numbers to find out more.

Plus

- Currently being mapped into national skills for care end of life qualifications so that staff take their learning with them nationally

http://www.skillsforcare.org.uk/qualifications_and_training/adultsocialcarequalifications/end_of_life_care_qualifications.aspx

- Partnership working with other experts…eg Beke and Laureen
  - e.g. staff complete ABC and then pain management or vice versa
- Partnership working with other resources
  - e.g. pain assessment tools, symptom control guidance, advance care planning documents
- Partnership with other organizations
  - e.g. communication handover tools between the hospital and care homes re individuals with dementia

Underpinned by

- Collaborative interactive discussion and planning
- Sustainable ongoing education and development
- Empowering leadership skills

Thoughts …….

1. Think wider than just end of life and dementia knowledge and skills
2. Facilitate leadership skills
3. Link the process into tools
4. Spend a lot of time planning
5. Monitor, measure and report
   - activity
   - satisfaction
   - outcomes/impact
6. Empower your trainers to be innovative
7. Be clear about core objectives so you can then stretch them
8. Have a structure including timelines
9. Be brave, be prepared to fail…..*failure is preparation for success*
10. **Partnership working with other providers at both grassroots and strategic level and SHARE ideas and knowledge**

To rise to the challenge we need to do more than just ‘train.’
We need to empower leadership skills, provide sustainable education programmes, facilitate relationships, look at new ways of working and be prepared to go out on a limb……and invest in our workforce

Before I did this programme I would never have thought about their care in this way.

Now I will do……..

A B C Dementia

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