Dementia Community of Practice Event: New Horizons

17 October 2019
WELCOME
Housekeeping

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@Dementiauk

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Why are we here today?
Our aims are to:

- celebrate the community of practice
- develop our thinking about next steps and take action towards implementation
- update key topics and take away resources to support practice in delivery of high quality dementia and end of life care
- have an opportunity to network with peers and learn and share with each other
Living with a diagnosis of dementia: identifying needs, understanding the disease trajectory and support required - Vignettes for learning

Dr Karen Harrison Dening, Head of Research and Publication, Dementia UK
Living with dementia: Understanding needs along the trajectory

17 October 2019

Dr Karen Harrison Dening
Head of Research & Publications
Aims

Trajectory of dementia
Needs along the trajectory of dementia
Milestones & prognosis
Vignettes
Peoples lives with dementia are not all the same.......
Preventing well

- Raising awareness.
- Reducing stigma.
- Health promotion.
- Health checks.
- Disseminating information.
- Carer education.
- Community engagement.
- Preventative management of risks: e.g. Falls, delirium, poor nutrition, reduced mobility, incontinence, polypharmacy, depression, etc.
Diagnosing well

Pre and peri-diagnostic support.

Diagnosis support.

Understanding the impact of diagnosis.

Adjustment & adaptation.

Fostering a positive outlook.

Coming to terms with diagnosis.

Preparing for the future.
Case study – Joe

Carers can often be over-protective of the person they care for and think that avoiding such difficult issues is better for them.

Professionals too can often be over-protective and think that the diagnosis is a huge hurdle to cross so delay talking about future care needs.
Supporting well

Holistic assessment (bio-psychosocial).
Psychosocial interventions.
Family focused interventions.
Maximising quality of life.
Managing & identifying comorbidities & complex needs.
Person-centred care planning.
Developing coping strategies.
Non-pharmacological management of BPSD.
Maximising quality of life and managing comorbid conditions......
When does someone stop living with dementia and start dying of dementia?  
(van der Steen et al 2013)
Case study – Mavis

Lives alone
One daughter
  • Significant carer distress
  • Inability to continue working
Alzheimer’s disease
  • Expressive dysphasia
  • Moderate stage of dementia
Crohn’s disease
  • Frequent urgent hospital admissions
  • Poor management of LTC
A model for palliative care in dementia (van der Steen et al 2014)
A model for palliative care in dementia (van der Steen et al 2014)
Living well

Positive risk taking.
Managing transitions.
Advance care planning.
Building resilience.
Symptom management.
Crisis prevention.
Relationship support.
Promoting independence.
Managing grief, loss & bereavement.
Enabling access to life outside caring.
Promoting/enabling inclusion & Participation.
Maximising quality of life and managing comorbid conditions – what about carers

Carers (with Admiral Nursing) likely to be:
- The main carer is likely to be older
- Caring for a spouse/partner
- Co-habiting with that person
- Providing a high level of personal and physical care
- Caring for 18 hours or more a day

Gridley et al. (2018)
Self management

Main approach in long term conditions
Sense of confidence and control
Involvement of families
Frailty

It is important, therefore, that health and social care professionals conceptualise the provision of care for people with dementia, comorbidity/multi morbidity – including frailty - as a complex phenomenon that affects not just individuals but also older, spousal carers.

Services should aim to increase motivation through focussing on independence and facilitate older to continue carrying out behaviours improve their well-being, as well as provide information, motivation, psychological support and practical support.
Early detection of frailty (i.e., pre-frailty) in older, spousal carers of people with dementia may present an opportunity to introduce effective management to improve outcomes.
And when at the end-of-life ......
Difficult conversations.
Identification of prognostic indicators of end-of-life.
Improved identification & access to preferred place of death.
Symptom identification, management, e.g. pain.
Recognition of end-of-life.
Pre and post bereavement emotional support & counselling for families.
Case study: Elise

Elise is 87 years old.
Admitted to EMU via A&E from a nursing home.
Required assistance with all personal care and eating.
No meaningful communication.
Admitted to hospital by care home, agitation and crying/distress.
Liaison old age psychiatrist asked to see her on the ward:
“can’t do anything with her”.

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DementiaUK
Helping families face dementia
Assessment

First step was to review the medical notes, given Elise could give no account of herself:

History of metastatic breast cancer, spread to liver and bones, pathological fracture of pelvis.

Medicine card:  X = not given
               3 = refused
Recognition of pain in dementia
Assessing pain in dementia

Asking the person directly is still best.
Poor short term memory, people may not remember their pain.
Speech problems – may have difficulty describing their pain.
May no longer understand the concept of ‘pain’
   May lose abstract concepts of severity.
   May need to use alternative expressions, e.g. ‘sore’ or ‘does it hurt’.
Repeated questioning may worsen agitation or distress.
Ask relatives for any individual pain indicators.
Review health records: what other pain causing conditions are co morbid to their dementia?
Barriers to pain recognition

The person with dementia may not be able to remember pain they experienced earlier.
The person with dementia may not be able to verbally communicate what they are feeling.
The person with dementia may not be able to identify where their pain is located.
The erroneous belief that behaviours resulting from the pain are ‘symptoms of the person’s dementia’.
The myth that ‘people with dementia do not experience pain/their pain is less severe’.
Anxieties around giving analgesia to older people.
Three key areas of uncertainty:

1. **Treatment uncertainty**
   What treatment is the 'right' treatment?

2. **Relational uncertainty**
   Who should do what and when?

3. **Service uncertainty**
   Which setting EoL care should be delivered and by whom?

(Goodman et al. 2015)
Living & dying well with dementia: Enabling good palliative and end-of-life care and managing some of the uncertainty

The main barrier to enabling a person with dementia to both live well and die well is the lack of care continuity across the whole trajectory of dementia.

Continuity in a palliative care approach in dementia is often not achieved well in the UK, largely because of the commissioning divide across health and social care which means that the course of dementia care is often very fragmented.

(Harrison Dening et al. 2018)
BUT – what ever that individual journey, through the combination of end-of-life care and dementia specialisms - in a *community of practice* – we can make a difference.
Thank you for listening

Karen.harrison-dening@dementiauk.org
Key priorities revisited recap on content delivered in the ECHO sessions to date

Liz Bryan, Education Consultant, St Christopher's
The ECHO Story so far.....

StChristopher’s
More than just a hospice
September 2018 - Curriculum Planning

1. 40 replies to curriculum survey
2. Length = 60 minutes (25/40)
3. Frequency = 8 weeks (13/40)
4. Time = between 2-4pm (20/40)
5. We then asked what were the top 5 areas to cover in ECHO’s
* EOL2.ACP/Communicatio
  n (legal/capacity)
* Diagnosis/Managing
  Dementia
* Carers/Family
* Workforce/Education
* Delirium/Behaviour
  /Agitation
* Sharing best
  practice/services
* Practice/service
  development

* Dementia Environments
* Namaste
* Research/tools
* Guidance/Guidelines
* Bereavement
* Technology and
  documents
* Public awareness

Areas of Interest
Formal Presentation:
Resistance and refusal of care: The everyday care of people living with dementia admitted to acute hospital wards
By Dr Katie Featherstone, Reader
School of Healthcare Sciences
Cardiff University

Two Case Presentations:

Session 1 - January 2019
Formal Presentation:

The Senses Framework and how it can support relationship based care for people with dementia

By Professor Tony Ryan, University of Sheffield

Two Case Presentations:
Session 3 - June 2019

Formal Presentation:
Delirium in Dementia
By Dr Victor Pace, Greenwich & Bexley Hospice Darent Valley Hospital

Two Case Presentations
Any Questions?
Tea, coffee and networking
Support with advance care planning: Who, where, when and how? Take away key messages and reference resources

Dr Karen Harrison Dening, Head of Research and Publication, Dementia UK
Support with Advance Care Planning:
Who, where, when and how?

17 October 2019

Dr Karen Harrison Dening
Head of Research & Publications
Aims

Who

Where

When

How
ACP
Advance Care Planning (ACP) is an important part of palliative care and has been present in the clinical literature since the latter half of the 20th century.

ACP differs from general care planning in that it is usually used in the context of progressive illness and anticipated deterioration.

NICE recommend PWD and their families are offered ACP to discuss:
- The benefits of planning ahead.
- Lasting power of attorney (for health and welfare decisions and property and financial affairs decisions).
- An advance statement about their wishes, preferences, beliefs and values regarding their future care.
- Advance decisions to refuse treatment.
- Preferences for place of care and place of death.
- Be offered opportunities to review and change any advance statements and decisions they have made.
Dementia is a progressive and irreversible neurodegenerative disease that is life-limiting.

Approximately 850,000 people in the UK are living with dementia.

It is estimated that 1 in 3 people aged 65 years and over will die either with or from dementia.

Research evidence (and media coverage) suggests that people with dementia may not receive the care they need at the end of life, a factor of this may be the absence of ACP.

NICE recommend: (2018, 1.1.12)
Offer early and ongoing opportunities for people living with dementia and people involved in their care.
Factors that may complicate ACP in dementia:
- Retrospective memory.
- Prospective memory.
- Planning and organising.
- Attention and concentration.
- Communication and speech.
- Decision making and decisional capacity.
- Fluctuating communication and capacity.
- Variable rate of disease progression.
- Unpredictable prognosis.

“Time.....this is the most valuable thing you can give the person with dementia...”
ACP is not seen as part of a services ‘normal routine’, whether that is assessment or conversations...seen as a separate entity.

‘hot potato’

Idiom:
Figure of speech; a problem or situation that is difficult to deal with and causes a lot of disagreement.
However.....

Carers’ ability to accurately predict the person with dementia’s treatment preferences (in the absence of previous discussions or an ACP) was no better than chance (lower than 35% accuracy).

The more psychologically distressed a carer was the less able they were able to predict treatment preferences of the person with dementia in future scenarios and where the treatment was more aggressive, i.e. CPR and tube feeding.

High levels of uncertainty.

(Harrison Dening et al. 2016)
Family carers are often assumed to know what decisions people with dementia would have made had they not lost capacity.

Decisions may often involve complex issues around whether to treat or whether to withhold treatment.

There may be several treatment options to choose from, and in certain contexts the decision will also be important (e.g. in a crisis as compared to states of chronic ill-health).

Overlaid on this are the perspectives, preferences and wishes for future care of the person for whom decisions are to be made.

For clinicians, it may often be difficult to know whether proxy decision-making and treatment choices are consistent with the previously expressed wishes of the person with dementia.
Where (1)
<table>
<thead>
<tr>
<th>Transition points</th>
<th>Healthcare events</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Time of diagnosis of dementia</td>
<td>• Deterioration or decline in the persons condition</td>
</tr>
<tr>
<td>• When undertaking a Lasting Power of Attorney for finance (consider LPA personal welfare)</td>
<td>• Person presenting with complex symptoms</td>
</tr>
<tr>
<td>• Care plan/package review for community home care</td>
<td>• Person presenting with difficulty with nutrition and hydration</td>
</tr>
<tr>
<td>• Changes of care setting; transfer to acute care or residential care setting, etc.</td>
<td>• Decreasing response to anti-biotic treatment</td>
</tr>
<tr>
<td>• Changes in family carers’ situation (illness, death, etc)</td>
<td>• When the question of a need for further medical investigations of treatments arise</td>
</tr>
<tr>
<td></td>
<td>• Discussions about attempting cardio-pulmonary resuscitation</td>
</tr>
<tr>
<td></td>
<td>• Changes to the health status of the family carer.</td>
</tr>
</tbody>
</table>

“Not a ‘one off’ conversation or static in time....giving information...time to process...return to discussions....review.....”
“Health professionals need to think about how they talk about ACP and avoid technical language”.

How (1)

DNAR  Enduring Power of Attorney

Lasting Power of Attorney

Advance Care Planning

Living Will  Wishes & Preferences

Advance Statement

RESPECT  This is me  Anticipatory Care Plan

Coordinate My Care  Goals of Care

Advance Decisions to Refuse Treatment

Escalation Plan
# Advance Care Planning

## When

<table>
<thead>
<tr>
<th>Reactive</th>
<th>Proactive</th>
</tr>
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<tbody>
<tr>
<td>No planning until a problem arises</td>
<td>Advance Care Planning</td>
</tr>
</tbody>
</table>

- AE attendance
- Prolonged hospital stays
- Increased morbidity/mortality
- Increased healthcare costs
- Reduced hospital admissions
- Reduced morbidity/mortality
- Increased QoL
- Healthcare savings

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[1] DementiaUK
Helping families face dementia
Accurate prognostication in older people with non-malignant disease may not be realistic.

No risk prediction tool has been developed of sufficient accuracy, reliability or validity for use in clinical practice.

They may have been frail for so long or declined so slowly – often with previous “false alarms” – that it is hard to recognise or believe.

Waiting for an additional event – unpredictable or “random” time frame.
Don’t forget, the more advanced the dementia or the greater the co-existence of frailty/disability or co-morbidity the more likely that event becomes so has implications for an ACP.

Your knowledge of the patient means you can predict what acute events are most likely to occur.

Your discussions with the patient and/or their family can identify and prepare for how they would wish to be cared for if/when such an event occurs.

Decide what approach suits your service and clients BUT also that has a transferability and common language for all stakeholders surrounding the person with dementia.
Resources:


The main barrier to ACP in dementia is the lack of offer and so facilitation.

Enabling a person with dementia to both live well and die well is the lack of ACP, palliative care and care continuity across the whole trajectory of dementia.

Continuity through a case management approach in dementia is often not achieved well in the UK, largely because of the commissioning divide across health and social care which means that the course of dementia care is often very fragmented.

BUT...even where a case management model exists to resolve these issues, commissioning that relates to sections of the dementia journey prevail causing fragmentation.

(Harrison Dening et al. 2018)
Our Community of practice present and future

Dr Liz Bryan, Education Consultant, St Christopher's and Carole Walford, Chief Clinical Officer, Hospice UK
Overview of Project ECHO
What is ECHO?

EXTENSION OF COMMUNITY HEALTHCARE OUTCOMES

Not for profit movement to improve care by gathering a community of practice together online, for learning and support with the goal of improving decision-making by collaborative problem solving.
Extension of Community Healthcare Outcomes

At ECHO, our mission is to democratize medical knowledge and get best practice care to underserved people all over the world.

Our goal is to touch the lives of 1 billion people by 2025.
The Model

**Amplification** – Use **Technology**

to leverage scarce resources

**Case Based Learning**
to master complexity

Share **Best Practices** to reduce disparity

**Web-based Database** to Monitor Outcomes

www.hospiceuk.org
What is ECHO?
Moving knowledge and support not patients and staff

ECHO IS...A community of the willing
ECHO IS...Democratising “specialist” knowledge
ECHO IS... Building a Community of Practice
ECHO IS... Tele-Mentoring
Increased knowledge and specialisation expands the definition of the “underserved” and the reality of the post code lottery.
Building Networks for Transformation

300 Network meetings this year

P1RTNSHIP WORKING PROVIDES A SOLUTION.

Impact Age Well

www.hospiceuk.org

Constipation
- The tests:
  - Calcium
  - CT scan
  - NOT colonoscopy
  - PERT Sigmoidoscopy
- Secondary care vs Primary
  - Colonic transit study

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The ECHO Team

Champion

Presenter

Administrator

IT person

Facilitator
What is ECHO

- Spoke and hub members have initial meeting at which establish a curriculum, times, dates, evaluation and responsibility for spokes presenting at each meeting
- Start ECHO meetings
- 75-120 minutes long
- 20-30 minutes powerpoint teaching from topic expert
- 2-3 case presentations and discussions based on template
- Start and finish on time
- Facilitated by dedicated facilitator
- Supported by dedicated IT person and admin person
- All sessions filmed and along with additional materials forms an online library that grows with the sessions
ECHO model is not ‘traditional telemedicine’.
Treating Physician retains responsibility for managing patient.
What is Project ECHO? How is it different from telemedicine?

**Telemedicine**
- Focus is direct service delivery
- Usually one-to-one
- Unidirectional flow of information
- Usually one-and-done, or time-limited/specific
- Single expert providing opinion

**ECHO**
- Focus is on education and capacity building
- One-to-many (hub and spokes)
- Multidirectional flow of knowledge
- Ongoing, based on learner’s needs
- Multidisciplinary expert team providing mentoring, advice and support
Lunch and networking
Future planning ECHO series 3

Discussion in three groups led by each ECHO hub lead
Project ECHO
Moving forward …
## What is Project ECHO? How is it different from telemedicine?

### Telemedicine
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[www.hospiceuk.org](http://www.hospiceuk.org)
Communities of practice are people who share a passion for something they do and who interact regularly to learn how to do it better.

1. **Shared Focus**: Membership involves commitment to a shared competence that distinguishes members from others.

2. **The community**: Members engage in joint activities and discussions, help each other, and share information. They build relationships that enable them to learn from each other.

3. **The practice**: Members of a community of practice are practitioners. They develop shared resources: experiences, skills, knowledge, tools, ways of addressing recurring problems—a shared practice.
Why communities of practice are essential
Opinions on ECHO after six months

• 96% (25/26) reported gains in learning
• 89% (25/28) felt that ECHO had improved the care they provided for patients
• 82% (23/28) would recommend ECHO to other CHNs or other HCPs
• 89% (24/27) found ECHO a good medium to access teaching / education from a different location from where they worked despite 44.4% (12/27) having experienced technical difficulties – affected 2 out of 9 sites in particular (internet connectivity and bandwidth)
Contact details for the HUK London ECHO team

- Hazel Webb  
  h.webb@hospiceuk.org.uk
- Max Watson  
  m.Watson@hospiceuk.org.uk
Education needs: Carers, staff training, OU dementia and EoLC courses

Anita Hayes, Head of Learning and Workforce, Hospice UK
Education needs:

A Curriculum for UK Dementia Education

Developed by the Higher Education for Dementia Network (HEDN)
Core topic 9: End of life palliative care

Rationale
To ensure a ‘good death’ for people with dementia. In particular at the end of life it is important to understand the needs of the family of the person who is dying and demonstrate the support they need.
Key Content

- Principles of palliative care
- Care-giving skills for people at the end of life
- Use of end of life care pathways and individualised care plans
- Loss and bereavement and the needs of bereaved families
- Recognition and management of pain people with advanced dementia
- Advance decisions/directives and best Interest decisions
- Concerns and needs affecting younger people with dementia at the end of life
Table conversations and mapping

What training have you accessed to support you in delivering high quality end of life care for people living with dementia?

What are the training gaps?

What is available for carers?

Please capture on post it notes on your tables 15 mins
Be prepared to feedback
Key messages and next steps

Carole Walford, Chief Clinical Officer, Hospice UK
Thank you

Have a safe journey home