

Hospices are stepping up their dementia care

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Last year Hospice UK published 'Hospice enabled dementia care – the first steps' and since then there has been a surge of enthusiasm by hospices to share ideas as to how to adapt their care to support people living with dementia.

The publication suggests that hospices have skills and expertise that map onto different stages of the dementia journey. For instance, confidence with advance care planning, carer support services, and expertise in the last weeks of life in various settings (care homes, hospital and home) are all opportunities for hospice and dementia care to cooperate.

The enthusiasm has been harnessed by a Hospice UK Dementia Community of Practice, with over 60 members from hospices, NHS teams, dementia services and care homes.

Last week a day of learning was held, with a number of enlightening presentations:

Data and death certification

Tanya Khera-Butler (@TanyaKB2), senior analyst from the National Dementia Intelligence Network, outlined key findings from the Dying with Dementia report which will be published shortly. The key messages from this presentation were:

- From 2001 to 2014, death certificates which included any mention of dementia rose from 6.6% of all deaths in 2001 to 15.8% in 2014.
- Listing dementia and its subtypes on death certificates is really important as it is this data that supports an understanding of unmet need.
- Place of death of people dying with dementia in the UK is linked to an individual's country of birth. There is a much higher proportion of deaths in care homes of people born in the UK who are dying with dementia compared to people dying in the UK who were born in India and Pakistan – they have a higher incidence of deaths at home. This may tell a story of family structures.

The forthcoming report will recommend that the capability of community support is reviewed so that people with dementia can be cared for at home if this is their preference.

Rules of thumb or 'heuristics'

Dr Rammya Mathew (@RammyaMathew), academic clinical fellow in general practice at University College London, shared a fascinating project looking at 'rules of thumb' or 'heuristics' in order to guide better decision making in the care of people with dementia. Alzheimer's UK and Marie Curie are funding this 18-month research project.

Rules of thumb are different from detailed evidence-based guidelines, which often don't help with complex ethical decisions. 'Rules of thumb' simply suggest concepts to think about and could be very useful as we move from protocol-driven care to more person-centred models.

These rules or heuristics have to be in line with current evidence but also have to be easy and accessible to use in practice and, crucially, include the lived experiences of families with direct experience of dementia end of life care.

They base outcomes on a few key predictors and one of the best examples is the F.A.S.T heuristic to support early stroke treatment (Facial weakness, Arm weakness, Speech change, Time – hurry up and get to hospital!).

Heuristics provide a structural framework to “make tacit knowledge explicit” according to Dr Mathew.

Heuristics are being developed on feeding and swallowing, agitation and restlessness, routine care at the end of life and ending life sustaining treatment.

For example the ‘feeding and swallowing’ heuristic starts off with an important statement: “Don’t let eating/swallowing problems come as a surprise”. It then simply asks if the swallowing problems are related to dementia. If yes, then consider comfort measures rather than PEG referral, but if not related to dementia, consider what might be reversible. Some of these ‘think’ steps are often missed out, resulting in overtreatment with little benefit.

The hope is that widespread introduction of heuristics, for example in care homes, might reduce reflex admissions to hospital, and a shift in attitude that sometimes it is OK not to treat.

European Certificate in Holistic Dementia Care

Sue Foster, head of education at the Northern Ireland Hospice, shared the details of their eight-week online dementia course.

The course is suitable for all professionals, in all settings, who wish to improve their confidence and knowledge of dementia care. There is a wealth of resources for students, an online discussion forum, eight intensive weeks of online learning, a reflective portfolio and an assessment at the end.

Delegates were encouraged to sign up people from their own organisation to complete the course but also to consider becoming a host site to run the course. This would raise money for their hospice and could start to build local clusters of holistic dementia competence.

The next course begins on the 3 October 2016.

Updates from projects supported by St James’s Place Foundation dementia grants

Sandra Jones and Sheila King from East Cheshire Hospice presented their dementia buddy programme to support dementia carers. The hospice runs an eight-week dementia carer wellbeing programme, while the ‘buddies’ support the patient living with dementia. Expansion of the programme to support more people in the community is the next step.

Lyn Andrews, head of nursing, and Samantha Bemrose, dementia lead at St Andrew’s Hospice in Grimsby, described the journey of their hospice that not long ago thought dementia was not their business and how they subsequently changed the hearts and minds of all staff through a structured process of engagement and culture change. They now have dementia champions throughout their service, a dementia lead nurse, have just established a ‘dementia board’ and are working in partnership with local dementia services and care homes.

Reflections of a care home carer

Niamh O'Donoghue, care assistant, gave a compelling personal account of her experiences of being a dementia personal carer in a care home.

Niamh is a psychology graduate who has worked as a carer in a care home for several years and she shared reflections on the challenges of the routines in care homes that can inhibit person-centred care.

Niamh shared techniques and stories used to enter the world of the person with dementia, and the sadness and joy in her work. She felt the greatest challenge and satisfaction lies in preserving the unique identity of those in her care. She made us laugh and cry!

The Dutch model of dementia case management in the community

Dr Karen Harrison-Dening (@KDening), chief Admiral Nurse at Dementia UK and head of research and evaluation, has supported our Community of Practice at Hospice UK from the start.

She shared insights from Holland on the role of the nurse case manager in community dementia care. The nurse supports the family unit from the point of diagnosis until the patient dies at home or moves to another care setting.

Care homes in Holland are considered specialist units supported by a dedicated multi-disciplinary teams led by 'care home physicians'. The care home population is recognised as having complex needs that warrant a multi-disciplinary approach.

Karen contrasted this with the UK model where care homes are predominantly in the private sector, caring for elderly patients with the most complex physical and psychological issues, and yet have little access to systematic multi-professional expertise. This needs to change.

In summary, a hugely informative and provocative day.

If you would like to join the Dementia Community of Practice please email Marie Cooper at m.cooper@hospiceuk.org

A dementia forum will be set up on our new Hospice IQ website very soon, meanwhile a valuable website to explore is Dementia Partnerships