

End of Life Care an organisational perspective within a national context

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The D-word

- Social attitudes towards death and dying have changed over history
- Death (and birth) were accepted as part of the life cycle and occurred mainly in the family home
- In modern western societies death mostly occurs away from the family home usually in a hospital or similar 'clinical' environment
- Death is rather neither seen nor spoken of



The new approach

- A desire to make death 'visible' again....
- in order to give people choice and make this a better experience for the person who is dying and their families...
- In order that a range of resources (not just hospitals) share the responsibility of providing end of life care.
- A holistic and planned approach to end of life



End of Life Care Strategy (DoH 2008)

Aims to improve the services provided to people who die in England , and their families through:

- Identifying people approaching end of life
- Assessing the needs and preferences and agreeing a care plan to reflect these
- Coordinating care and working collaboratively across sectors
- Management of last days of life and care after death
- Support for family carers



Other national initiatives – the Gold Standard Framework (2000)

- A framework for delivering the best possible care to people approaching the end of their lives by:
 1. Improving staff knowledge and collaboration with other agencies
 2. Reducing (unwanted / unnecessary) hospitalization
 3. Advanced Care Planning
 4. Better access to Doctors / out of hours.
 5. After death analysis auditing.



Changes in the demography of our residents

- We provide care to around 750 older people many of whom are physically / mentally frail
- The average age on admission is around 89 (78 ten years ago) and we have a large number of residents over the age of 100.
- The number of deaths are rising. Around 33% in 12 months compared to 23% 10 years ago
- Increasing number of new residents remain in the home for a month or less before they die



Leading to the following challenges

- significant change in type of care needed (more complex clinical care incl. palliative)
- Staff unfamiliar with palliative care and end of life care
- Increased emotional burden on staff due to large numbers of death
- People with dementia not able to express wishes re end of life care
- Staff uncomfortable /unskilled to discuss end of life care with residents and families
- Living in non Jewish state – speedy funeral not always supported due to access to death certification



The End of Life in Advanced Dementia (ELCAD) project

- 3 years funding by Kings Fund and working in partnership with University College London
- Evaluating the impact of an enhanced education programme for nursing and care staff on end of life care for people with dementia
- Evaluating the impact of the above on the well being of the residents and their families and the staff
- Based at Lady Sarah Cohen House – 120 bedded nursing home with 90 staff



The project's goals

- Staff and service users are more knowledgeable about dementia and end of life
- People with advanced dementia and their relative have opportunity to plan EoL care and have this documented.
- Better palliative care through closer collaboration with GP and other professionals.
- Reduce inappropriate / unnecessary hospitalisation
- Empowering residents and staff to make choices regarding care
- Emotional and spiritual support for staff service users and relatives
- Maintain Jewish customs at EoL



Outcomes for residents

- To enjoy the time they have left and spend it in a meaningful way, free of pain and discomfort.
- To be able to be in a Jewish environment amongst familiar people.
- To have the opportunity to discuss end of life issues including care preferences as well as emotion.
- To feel cared for, loved and supported to come to terms with their mortality and approaching end of life.
- Trust that their wishes and religious beliefs will be kept.



outcomes for families

- To feel confident that their relative is receiving the best care and is free of pain and discomfort.
- To feel involved and informed, and avoid feeling helpless and not in control.
- To feel supported to come to terms with the loss of their relatives and other 'emotions' (before and after the death of their relative).
- To feel able to make the arrangements for a Jewish burial according to the Jewish way of life.



Outcomes for staff

- Better understanding of end of life care and palliative care.
- Better understanding of their own attitudes to end of life.
- Have a clear understanding of the wishes, and preferences of the resident and relatives regarding their end of life care.
- Have the knowledge and resources to plan and deliver end of life care according to the needs and wishes of the resident / family.
- Feel confident and empowered as 'end of life care professionals.'



How we get there

- A 10 stage education / training programme has been devised and is led and delivered by a Consultant Geriatrician and other professionals in Jewish Care
- The programme dovetails with the GSF programme and draws on the GSF principles.
- Each session is repeated 4 times (once a week over a 4 week period) to enable all staff from all shifts to attend.
- Each session lasts 1.5-2 hours



Pre-training session

‘Ex-Memoria’

- The short film about a Jewish woman who survived the holocaust and now lives in a care home and has dementia was shown to all staff.
- Filmed from the woman’s perspective, it provokes discussions and gave staff a ‘taster of future sessions.



The 10 Topics

1. What is end of life care?
2. The challenges of dementia
3. The physical process and symptoms of end of life 1
4. The physical process and symptoms of end of life 2
5. Emotional and psychological needs at end of life
6. Planning for end of life care
7. Advanced Care Planning tool
8. Religion and Spirituality at end of life
9. Holistic end of life care
10. Putting it all together



What we have Found...

- The sessions have been well attended (around 75% of staff attended).
- It is harder to release staff from care duties for the day sessions so there may need to to some further repeat sessions.
- Some sessions have been more interactive than others depending on the mix of individuals in the groups.



...and what staff told us

- Many find death hard to talk about and were worried the sessions would be upsetting.
- Staff are positive about the sessions and feel part of the project.
- They would like longer sessions.
- Staff are interested in the project and keen to find out when next sessions are being held.



A few words about the evaluation

- One to one interviews and a series of questionnaires have been conducted with staff, relatives and a number of residents before the training programme has started
- These will be repeated for comparison at the end of the training programme
- This is done by an external researcher



To date:

71 of the 90 permanent nurses and carer took part in the evaluation.

Interviews were well received by staff and became very cathartic for staff to be able to offload and speak to someone in confidence.



Some common themes are:

- Emotionally hard for staff to deal with resident's death
- Staff feel guilty when a resident dies – particular if a new admission to the care home, or if they haven't been on shift
- staff feel 'mean' and worry about passing news of a death onto other residents and relatives
- Staff become attached to residents and they become like family
- Staff's own family experiences affect their perception of caring

And on being non-Jewish working in a Jewish Home:

- Staff enjoy being part of the Jewish culture at work and enjoy taking part in religious festivals with the residents
- Staff respect the Jewish way of life and beliefs of the residents. Whilst recognising this is different from their own, this does not affect the care given or any relationships formed.
- Some staff feel the customs of end of life in the Jewish faith is preferable to their own – supporting the family and immediate burial.

As an organisation

- Committed to improve end of life care for all residents in the Care Homes and other homes apart from Lady Sarah Cohen House are also involved in the National Gold Standard Framework