Rosebery End of Life Care and Choices
A person-centred end of life care plan for people with dementia, their carers and their nurses

Marilyn Higham, Deputy Charge Nurse, Tippethill Hospital.

“Have the right to end of life care that respects my wishes”
(Standards of Care for Dementia in Scotland 2011)

About us
Rosebery wing at Tippethill Hospital is an NHS mental health unit, the only specialist long-term female dementia unit in West Lothian. We provide care for women experiencing stress and distress from advanced dementia including in the last stages of their illness.

Our aim
- Ensuring patients receive timely holistic person-centred end of life care.
- Supporting carers to plan for the expected future change of clinical deterioration and death.
- Enabling nurses to provide person-centred end of life care, dignity, choice and control.

Introduction meeting
Relationship-centred care, providing clarity on the documents and opening channels of communication on palliative care, death and loss.

Carers report they feel:
- Treated as partners in care
- Informed
- Listened to
- Supported
- Better prepared for the end of their loved one’s life.

Method
- Quality improvement: iterative testing and change
- Co-produced with focus group of Rosebery carers
- Piloted with Rosebery patients, carers and nurses
- Questionnaires to capture and measure the experience and impact on patients, carers and staff at 3 stages:
  - Carers being introduced to the documents and completing the care plan
  - Staff use of the care plan
  - Carer opinion on the end of life care.

Outcomes
- 2 part document:
  - Care Plan
  - Information for You
- 3 stage process of improved palliative care and support.

Other documents: Guidance Notes and a Follow-up Phone Call Feedback Form accompany the Rosebery End of Life Care and Choices.

Essential to ensure staff have confidence and competence in undertaking sensitive communications regarding end of life planning with families, and that the process is embedded in practice and sustainable, therefore a lesson plan devised for training.

Adheres to the four principles of the Scottish Government Guidance ‘Caring for people in the last days and hours of life’ (2014), the Strategic Framework for Action on Palliative and End of Life Care in Scotland 2016-2021 (Scottish Government 2015), the National Dementia Standards (Scottish Government 2011) and the Triangle of Care (Careers Trust Scotland 2013).

With thanks to the patients, carers and nurses of Rosebery, and to Patricia Brooks Young, Lead Nurse and Clinical Researcher in Palliative Care.

Content
Care plan - carers share information with nurses. We ask for contact arrangements, any funeral plans and what carers wish the staff to do with belongings. We ask about environmental and sensory aspects, spiritual needs and pet visits. Prompts and suggestions in blue side-columns help the carers consider all the available options.

Information For You - nurses share information with carers. We give information regarding end of life, end of life care and agree what a “good death” entails. We explain the Lothian Bereavement Services documents “What Happens When Someone Is Dying” and “When Someone Has Died”. There is an invitation to participate in providing the end of life care and an explanation of “expected death” with a promise that in these circumstances, if the family cannot be with their loved one, a nurse will be. Also, practical advice about the facilities available on the ward and other information supporting the questions in the care plan.

The care plan

- The greatest gratitude to all staff for the care and dignity. Staff provided privacy...were very attentive...the care was very personal.
- The care plan was straightforward and enabled staff to carry out end of life care in a more peaceful, relaxed manner, knowing the family’s wishes were being followed.
- The care plan was very easy and well explained, the layout, wording and design was excellent.
- The care plan prepares the family, we knew what to expect.
- It was not only Mums who helped, but also...we all felt cared for and treated with respect.

The care was everything and more than we’d hoped for.

We’re so happy that gran received such wonderful care.

The staff treated my wife with utmost love and I emphasise ‘love’, that wasn’t just care.

Everything was very clear and sensibly worded.

We’ve so happy that gran received such wonderful care.

Nurses refer to care plan
People with dementia receive timely holistic person-centred end of life care which considers their personal preferences and choices.

Nurses report they are:
- Informed
- Better enabled to focus on providing highly personalised compassionate end of life care for patients and support for carers
- Able to use feedback for revalidation.

Follow-up phone call
To carer, a few weeks after the death of their loved one.

- A human kindness
- Demonstrates respect
- Provides further support
- Obtains feedback from which improvements will happen if required.

“Everything was very personal.
We had the opportunity to provide care and support.
I didn’t need to ask the family at their time of grief and could concentrate on care and support.
…”It makes the biggest difference in the way that I feel and that I can cope”

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“…”It made it easier when Mum passed as most of the decisions were made and we could concentrate on Mum.”

OTHER DOCUMENTS: GUIDANCE NOTES AND A FOLLOW-UP PHONE CALL FEEDBACK FORM ACCOMPANY THE ROSEBERY END OF LIFE CARE AND CHOICES.

FEEDBACK

The care plan clearly outlines the whole team’s culture of a person-centred approach.

The care plan was very clear.
…”It made it easier when Mum passed as most of the decisions were made and we could concentrate on Mum.”

The care plan was very easy to follow, the content was helpful.
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The care plan fell short of what you would have expected.
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