

# 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.

**“I 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 longer-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.

ROSEBERY  
END OF LIFE CARE AND CHOICES



IMPROVING THE END OF LIFE EXPERIENCE

ROSEBERY  
END OF LIFE CARE AND CHOICES  
INFORMATION FOR YOU



END OF LIFE EXPERIENCE

## 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.

## 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.

## 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.

## 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.

**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 care 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 (Carers 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.

## FEEDBACK

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

The care plan prepares the family, we knew what to expect.

...very easy and well explained, the layout, wording and design was excellent.

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

The care plan prompted me to discuss and develop my thoughts around Mum’s end of life care.

I found the end of life care plan emotional to fill out but also very grateful that people have taken the time to do such a plan.

Mum’s final days were as we wanted as a family.

Everything was very clear and sensitively worded.

...so it was not only Mum you helped, but also us...we all felt cared for and treated with respect.

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

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.

I didn’t need to ask the family at their time of grief and could concentrate on care and support.

the care far exceeded anything we expected

The care for all of us was excellent...we both look on you all as good friends that we will never forget.

The care plan was very helpful as it focused our minds, and the nurse was very kind and patient, in no way did I feel hurried and it came across as she has the best interests in her patients.

families are treated as partners in care

...plans already documented so you weren’t asking the difficult questions, good insight to patient and family wishes without being intrusive and available for ALL staff to read.

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

...helped me realise that it’s best to be prepared for the inevitable no matter how difficult, it’s comforting to know Mum will be well cared for in a dignified manner and I find solace in the fact I can be with her at anytime.

...it gives me great comfort that my Gran will have the care and respect she deserves at the end of her life.

I think the approach of a nurse going through the document is essential ... it is an excellent opportunity to build a therapeutic relationship which supports the family ...

... to raise any fears and concerns around end of life care and may highlight issues which would preclude families completing document eg literacy issues or English not being first language.

We found the completing of the care plan very useful. Whilst it is a difficult time, it made us think what Mum would like and takes away a lot of the stress at time of passing.

...explains all the things which may occur when the time comes and different options that are available, and just how respectful and caring the nursing staff are at Tippethill.

... the end of life was dignified, we wouldn’t have changed anything.

...made it easier when Mum passed as most of the decisions were made and we could concentrate on MUM