Cambridgeshire Community Services NHS Trust

TRUST BOARD **and**

Title:	**Supporting a family to care for a loved one at the end of their life.**
Action:	**FOR DISCUSSION**
Meeting:	**20th November 2019**

Purpose:

The purpose of bringing patient stories to Board members is:

- To set a patient-focused context for the meeting.
- For Board members to understand the impact of the lived experience for the patient, family and friends.
- For Board members to reflect on what this experience reveals about our staff, morale and organisational culture, quality of care and the context in which our clinicians work.
- To review and recognise any shared learning and recommendations relevant to this story.

Recommendation:

To receive the patient story and note the context from which it was generated.

	Name	Title
Author:	Lisa Wright	Patient Experience Manager
Executive sponsor:	Julia Curtis	Chief Nurse

Trust Objectives

Objective	How the report supports achievement of the Trust objectives:
Provide outstanding care	This paper demonstrates where our District Nursing team have provided outstanding care in terms of their nursing care and excellent listening skills.
Collaborate with other organisations	This paper highlights a potential opportunity to further collaborate with our general practice colleagues.
Be an excellent employer	This paper highlights how the Trust has developed a well regarded District Nursing team.
Be a sustainable organisation	Not covered in this paper.

Trust risk register: N/A

Legal and Regulatory requirements: N/A

Equality and Diversity implications:

Objective	How the report supports achievement of objectives:
Achieve an improvement in the percentage of service users who report that they are able to access the Trust services that they require	Not referenced in this report
To introduce people participation in our diversity and inclusion initiatives to capture the experience of hard to reach/seldom heard/varied community groups.	The Learning from Deaths approach taken by the trust includes families and carers in any investigation and related learning
Introduce Disability Passport Scheme to record agreed reasonable adjustments.	Not referenced in this report
To utilise the diverse experience and backgrounds of our Trust Board members in promoting an inclusive culture.	Not referenced in this report

Are any of the following protected characteristics impacted by items covered in the paper – yes								
Age	Disability	Gender Reassignment	Marriage and Civil Partnership	Pregnancy and Maternity	Race	Religion and Belief	Sex	Sexual Orientation
☒	☐	☐	☐	☐	☐	☐	☐	☐

1. Introduction

1.1. EM, aged 95 was discharged from hospital following an end stage cancer diagnosis to her daughter's home where she was cared for by Luton District Nursing Team for a week before her death.

1.2. Her daughter and granddaughter are keen to share their experience of being supported to care for their loved one at home during the last week of her life.

2. Background to our Service

2.1. District nursing teams assess, plan and provide nursing clinical care to those people who are often housebound due to ill health, either in their own home, or in a care setting that does not provide nursing care.

2.2. The Community Nursing Service provides routine and complex, scheduled and unscheduled care working collaboratively with GPs, social services, and a range of other hospital and community health services.

2.3. Examples of care provided include:

- Routine Care: such as diabetes care, post operative care, simple/complex wound care, leg ulcer management, catheterization, bowel management and management of patients requiring enteral feeding.
- Complex care including end of life care to patients with cancer and palliative care needs,
- Scheduled Care i.e. planned interventions as identified in the patient's care package
- Unscheduled Care i.e. intervention(s) required in addition to the identified care package for example catheter blockage in the out of hours period, administration of medicines including intravenous/central line therapy, syringe driver and injection

3. The Patient's Healthcare Journey

3.1. On the first visit the nurse undertook a thorough clinical assessment and a plan of care was discussed with EM. Decisions regarding equipment needed were discussed with the family. The nurse provided necessary supplies to last the rest of the weekend. Following the initial visit one of the District Nurses visited every other day.

3.2. "She listened about previous experience with Dad". The family's previous experience of caring for a dying loved one was discussed and during the conversation it emerged that they were very anxious about not receiving the "terminal pack" in time. The "terminal pack" was the family's term for the medication provided at the end of life which includes pain relief, sedatives, anticholinergics etc. In their previous experience they had not received the kit in time. The nurse therefore ensured that they received this early which was a huge relief to them.

3.3. The family report that the nurse included all the appropriate family members in discussions regarding EM's care and encouraged them to participate as fully in this as they wanted to.

3.4. The nurse co-ordinated care by liaising with the GP to request a visit in order to avoid the need for a post mortem examination. This is routine practice for patients receiving palliative care when they are expected to die. She also arranged for the necessary medication and dressings to be prescribed.

3.5. EM's daughter reflected, "the nurse wasn't frightened to reach across the table and hold my hand". We had honest, open discussions where 'end of life care' was discussed with a sense of choice and empowerment. The nurse encouraged & enabled the family to make the most of the time they had, to provide favourite foods, spend quality time together and

her daughter reflects “I don’t think they realise the difference they make, they make a difficult situation as good as it can be”.

4. Carer’s Voice

4.1. Both the daughter and granddaughter will accompany Lisa Wright and will attend the Board in person to discuss their positive experience of the District Nursing Service.

5. Learning Points for the Wider Trust Services

5.1. From the family’s perspective, the learning for the Trust is that they want to highlight that we have provided an excellent service, for which they are very grateful. They feel that there should be an easier way for the Nurses to make contact with the GP service when needed as they witnessed the Nurse take 20-30 minutes of her visit trying to get through to the surgery by phone.

5.2. NB the service has changed the way in which staff can access GPs through our Coordinator of the Day role in Luton adult services through a dedicated phone number.

6. Recommendations for Potential Improvement

6.1. The Luton District Nurses should share with their team, the positive experiences of this family within the month after this story has been shared with the Board.

Lead Author
Lisa Wright – Patient Experience Manager

Content and story provided by
Daughter
Grandaughter