### Trust Board Meeting in Public: Wednesday 10 January 2019

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<thead>
<tr>
<th>Title</th>
<th>Learning from Patient Experience</th>
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<tr>
<td><strong>Status</strong></td>
<td>For information and learning</td>
</tr>
<tr>
<td><strong>History</strong></td>
<td>Patient stories are presented to the Trust Board or the Quality Committee. This paper focuses on a positive patient experience of the Trust palliative care services.</td>
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<td><strong>Board Lead(s)</strong></td>
<td>Mrs Sam Foster, Chief Nurse</td>
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<td><strong>Key purpose</strong></td>
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Executive Summary

1. The purpose of this paper is to share a patient’s experience of palliative care within the OUH and some of the enhancements in palliative and end of life care across the Trust, enabled as part of the Sobell Hospice Charitably funded End of Life Care project.

2. Julia’s video shares her positive experiences of a number of OUH palliative care services over her illness trajectory

3. There have been a number of enhancements to end of life care including direct, indirect and to the culture of the organisation

4. **Recommendation**
   The Trust Board is asked to reflect on:
   - The Trust Board is asked to reflect on the journey of a palliative patient in our organisation
   - The work of the charity in supporting palliative and end of life care
   - The extensive work being undertaken across the organisation to enhance end of life care across the organisation
Learning from Patient’s Experience.

1. Purpose
1.1 The purpose of this paper is to share a patient’s experience of palliative care within the OUH and some of the enhancements in palliative and end of life care across the Trust, enabled as part of the Sobell Charitably funded End of Life Care project.

2. Background
2.1 Oxford University Hospitals provides palliative care services for the people of Oxfordshire and has a NHS Hospice on site (Sobell House). The Trust has very close links with Sobell House Charity and Katharine House Hospice (an independent hospice in the North of the County which supports Horton Hospital).
2.2 All the palliative care services provided are multi-disciplinary, including doctors, nurses, pharmacist, allied health professionals, psychotherapists as well as integrated administrative support.
2.3 Services include:
   • 18 In-patient beds – for patients with complex symptom needs, and who may or may not be actively dying.
   • Day Service – where patients attend from home once a week for a 12 week individualised programme involving multidisciplinary goal-focused management to build their resilience and capability for self-management in the context of advanced progressive illness. Currently an 8-week educational programme runs once weekly and provides patient-participants who are earlier in their disease trajectory with information and skills to enhance their personal resilience and independence.
   • Hospital Palliative Care Team – who support and advise patients, relatives and all healthcare professionals across the OUH hospitals, in the management of patients with palliative care needs.
   • Community Palliative Care Team – who do the same within people’s own homes and care homes across the county, working collaboratively with GP practices and Oxford Health.
   • Bereavement Team who provide bereavement counselling to patients known across the palliative care service – the majority of this counselling is provided by volunteers with some paid psychological support for more complex cases.
   • Psychosocial team including art and music therapists, social workers and chaplains working across all the services.
2.4 Circa 2500 patients die within the OUH each year, many of whom are supported by palliative care services. The services also provide outreach into the community to enable patients to live as well as possible for as long as possible in their usual place of residence before they die.

3. Julia’s Story
3.1 The following video is from Julia, a patient who has experienced many aspects of palliative care within the OUH over her illness trajectory. The Sobell Charity worked with her and her husband to produce this video which they wanted to share widely to promote the benefits of palliative care at the OUH and the work of the Charity.

[Longer version - Sobell House - COMPLETE.mp4]
4. Sobell House Charity

4.1 Sobell House Hospice Charity provide funds, circa £1.5 million a year, to the OUH to enhance the care of patients with palliative and end of life care needs across Oxfordshire. Including complementary therapies, bereavement service, catering and support with other research such as the Heart Failure project. For their 40th birthday in 2016 they agreed to fund two extra initiatives with the Trust Chief Executive.

4.2 A Garden Annex (circa £5 million investment) adjacent to Sobell House to provide improved facilities for out-patients and 6 in-patient rooms which are designed to enable much closer monitoring of particularly vulnerable patients. Two of these rooms provide bariatric facilities which adds a significant improvement to current inpatient provision at Sobell House.

4.3 An two year End of Life Care Project (circa £1.4 million) to enhance end of life care across the whole of the organisation, this has been extended to three years using the available funding.

4.4 This investment has enabled an increase in workforce and nature of the multi-disciplinary team, including occupational therapists, Consultant pharmacist and chaplain with specific responsibilities for care of dying patients across the Oxford hospitals.

4.5 As agreed, a full business case is in development to present to the board to continue this funding.

5. End of Life Care Improvements in the OUH

There have been some significant improvements in service provision as a result of this project. Some are presented below, under direct support; indirect support and influencing culture, reflecting the End of Life Care Strategy.

6. Direct Support

- A 30% increase in referrals to the palliative care team on the John Radcliffe site in the first full year and a 56% increase in the number of patient visits.
- Daily proactive visits to the emergency department and emergency assessment units, with a resultant increase in referrals from 91 pre project to 424 in year 1 and 489 in year 2. This additional support to the ‘front door’ of OUHFT enables more rapid, efficient and effective care for people who are dying.
- 492 visits by the specialist palliative care occupational therapists to 237 patients, including 84 home visits to support complex discharge of dying patients in their first year in post.
- The expanded team allows for excellent role modelling, opportunistic education as well as bespoke education programmes for multi-disciplinary teams across the organisation, including pharmacists and AHP’s.
- Link chaplains for every ward with resultant increase in spirituality support for patients and their relatives and support to staff.

7. Indirect Support

- Over 40 improvement projects with different teams including working alongside local project groups to enhance end of life care in their areas, for example, critical care, emergency department, cardiac and medicine.
- Ethics approval for research ‘Prospective Cohort Study of Proactive Palliative Care for Hospitalised Adults at Risk of Dying: Evaluation of Patient Outcomes
and Hospital Cost’ (investigating proactive palliative care based on inclusion criteria, rather than specific referral). This commenced on 8th January.
• The project has allowed a greater focus with regard to all aspects of end of life care, including childrens and wider teams such as bereavement, chaplaincy and mortuary and estates. This has provided greater assurance regarding the quality of end of life care

8. Influencing Culture
• Implementation of a bereavement survey, seeking feedback from bereaved relatives about their experiences of end of life care. Feedback, indicates the provision of excellent end of life care, communication and compassion.
• Over 98% of respondents felt their relative was treated with dignity and respect always or most of the time.
• 93.5% of respondents felt that on balance their relative died in the right place
• Active link nurse programme involving nurses from wards across the Trust.
• Agreement of the sunflower as a logo identifying aspects relating to end of life care with a press release planned for January 21st and pilot of sunflower support boxes at the Horton for families of patients who are dying.
• Active involvement from a wide variety of Trust staff in Dying Matter week and Annual Symposiums for End of Life Care

9. Recommendations
The Trust Board is asked to reflect on the journey of a palliative patient in our organisation, the work of the charity in supporting palliative and end of life care and the extensive work being undertaken across the organisation to enhance end of life care.

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