

End of Life Care

Adults' Health, Adults' Care and

Housing Overview & Scrutiny Committee

Date: 27 September 2017

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Wards: All Wards

Locality Affected: All Locality Area

Parishes Affected: All Parish Area

1. Purpose and Reasons

1.1 This report provides the Adults Care, Adults Health and Housing Overview and Scrutiny Committee with details of end of life care for patients in Swindon.

1.2 The Committee requested a report on End of Life Care.

2. Recommendations

The Committee is recommended to:

2.1 Note the report.

3. Detail

3.1 We all die and this means that care as we approach the end of our life and during those last few days and hours has to matter to everyone - in health and social care and the wider community.

3.2 End of Life Care can be difficult to define and further guidance and context can be found in Appendix A of this report.

3.3 Local Context

Recent data analysis shows that in Swindon, there are higher levels of emergency hospitalisation in the final months of life than the national average, despite there being higher levels of deaths at home than average. This suggests that there is scope to reduce the level of emergency hospital admissions locally through service development.

3.4 As already outlined in Appendix A, the reasons for the need to change and improve are not difficult to understand but the intricacies of how services are involved in the delivery of care and support adds complexity, all of which are all too often outside the control of the patient and their carer's.

3.5 We know care that people receive at the end of their lives has a profound impact not only upon them but also upon their families and carers. At the most difficult of times, their experience will be made worse if they encounter poor communication and planning or inadequate professional expertise.

End of Life Care

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Date: 27 September 2017

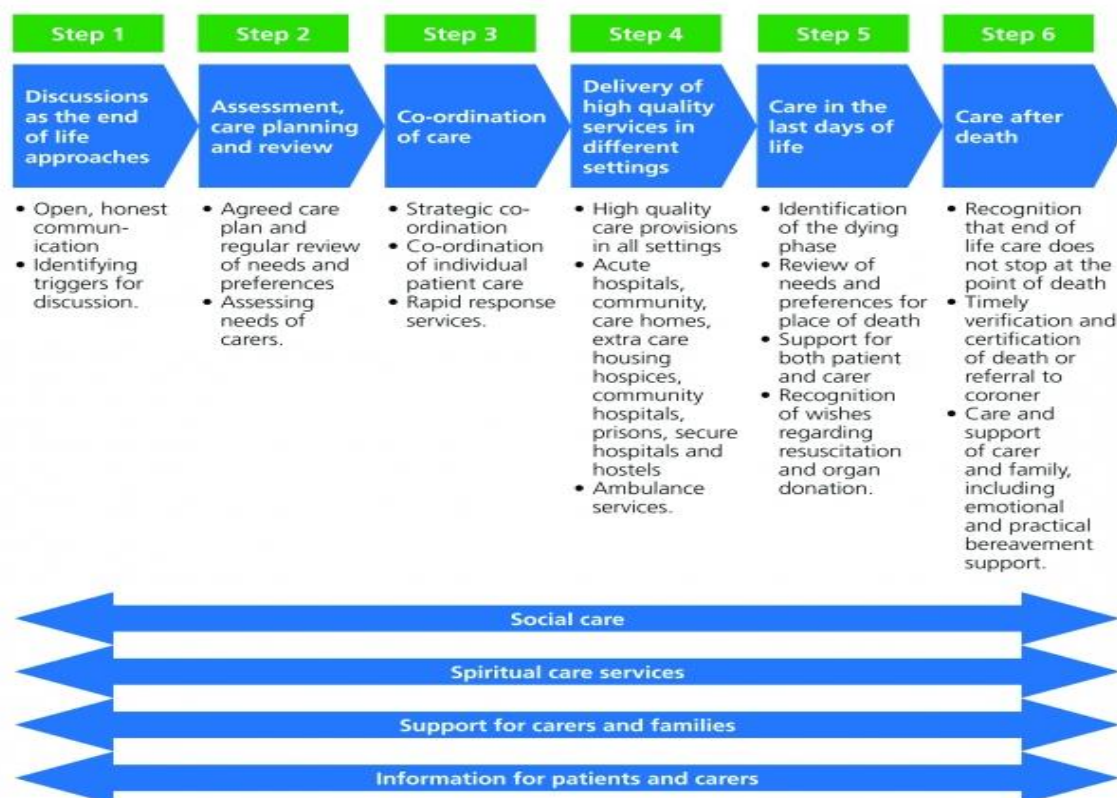
- 3.6 We do need to acknowledge that there are patients and carers now and whom in the past who have and are receiving high quality, compassionate care, but we need to get it right for everyone.
- 3.7 In Swindon, 1,590 people are predicted to require end of life or specialist palliative care per annum. By 2020, this is predicted to rise to 1,685 (6%). When asked directly, where they would wish to die, most people do not choose hospital. For up to 19% of patients who do die in hospital, the preferred location of death was known not to be hospital. The reasons for this are:
- Unpredictability and instability in their condition including rapid deterioration
 - Complexity of support required in the community
 - Applying for funding and accessing carers
 - Lack of availability of other services
- 3.8 The CCG currently commissions a number of services to provide end of life care. This includes care at home and in a number of bed based care settings. There has been a real focus on strengthening all providers to work in a more integrated way, with the intention to stream line referrals, improve care and coordination between providers.
- 3.9 Current end of life care services are provided by community and primary care services supported by specialist patient services provided by Prospect Hospice and Marie Curie. There has been a notable increase in provision of care provided by the Prospect Hospice and their hospice at home team in the last year- a service not currently commissioned. With the implementation of the locality end of life register and offering greater choice to patients, the shift of capacity and resource into the community setting is now required if we are to meet the expected reduction in deaths in hospital and more deaths at home.
- 3.10 In February 2015, the CCG led a mapping exercise to review the current end of life care pathway, resulting in a gap analysis identifying the strengths and limitations of existing provision. The approach used for this mapping exercise centred the Phase of Illness descriptors. This then forms part of a suite of outcome measures which may be used to determine complexity of need, and describes the distinct phases in the patients' illness. The phases are classified according to the care needs of the patient and their family.
- 3.11 The End of Life Care 'pathway' as identified in the Department of Health End of Life Strategy (2008), identifies core aspects of care for patient's thought to be in their last year of life. The standards for these stages are quality measures that illustrate in a practical manner both what is to be achieved and how. The 16 NICE Quality Standards for End of Life Care are included within each of the relevant steps, to provide a more structured approach to each step.

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3.12 Alongside the NICE Quality Standards a number of other developments have contributed to the thinking and development underpinning the commissioning plan, notably 'Every Moment Counts' the narrative for 'person –centred coordinated care' produced for NHS England by National Voices in 2014. This sets out critical outcomes and success factors in end of life care, support and treatment, from the perspective of the people who need that care, and their carers, families and those close to them.

3.13 Ultimately the following quote from this review sets the template on which to move towards to support a person centred coordinated care near the end of life

"I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s)"

Plans for end of life care in Swindon

3.14 Commissioning and implementing such change takes time and continual drive, particularly when the change involves a mind-set and cultural shift in care delivery. Our plans, in line with the ambitions nationally, are transformational and based on a delivery plan for the next 1- 5 years.

End of Life Care

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Date: 27 September 2017

- 3.15 The following table provides an outline of what we need to do, providing recommendations to achieve the best possible care for patient and their families with progressive life limiting illness and in the last year of life.

| End of Life Care Pathway Steps | What we need to do. |
|---|--|
| Discussions as the end of life approaches | <p>Review current education and training for End of Life across commissioned services in collaboration with partner organisations to including in advance care planning</p> <p>Evaluate impact of the conversation project at GWH and SEQOL with the aim in understanding if this has increased the confidence of clinicians to identify people who may be near the end of life and to start conversations with their patients about their wishes.</p> <p>All staff who provide palliative and end of life care to people with life limiting conditions should receive training including the different models and forms that are available and their legal status.</p> |
| Assessment, care planning and review | <p>The use of Electronic Care Planning to make it easier to document and share people's wishes and care records between providers and also reduces the risk of an unwanted admission to hospital or failure to act on advance decisions to refuse treatment.</p> <p>The End of Life register in Swindon, previously hosted by Adastra, is in transition to the Single Care Record so that this can be viewed by all provider services (as appropriate indicated clinically on contact).</p> <p>This ensures that visibility of patients wishes can be followed throughout the spectrum of care delivery across Swindon services.</p> <p>Round-the-clock access to specialist palliative care in acute and community settings with the aim to greatly improve the way that people with life-limiting conditions and their families and carers are treated. Crucially their expertise should be more equitably available to people with a non-cancer diagnosis, older people and those with dementia, for whom early identification and sensitive discussion and documentation of their wishes is also important.</p> <p>Treatment Escalation Plans (TEP) and Advance care planning leaflets are now in place.</p> |

End of Life Care

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Date: 27 September 2017

| | |
|---|---|
| Coordination of care | Agree a future model of care in Swindon to include a single point of contact that includes a central coordinating function. |
| Delivery of high quality services in different settings | <p>Access to 24 hour generic community nursing services.</p> <p>Ensure sustainable, longer term funding for the hospice sector as part of the Government's response to the Palliative Care Funding Review fully recognising the importance of the voluntary sector. Swindon CCG in 2014/15 agreed a three-year contract with the Prospect hospice.</p> |
| Care in the last days of life | <p>The possibility that a person may die within the coming days and hours is recognised and communicated clearly, decisions about care are made in accordance with the person's needs and wishes, and these are reviewed and revised regularly by doctors and nurses.</p> <p>Sensitive communication takes place between staff and the person who is dying and those important to them.</p> <p>The dying person, and those identified as important to them, are involved in decisions about treatment and care.</p> |
| Care after death | <p>Improve Bereavement support for families, including greater awareness amongst health and social care staff of the impact of bereavement, as well as universal access to bereavement services.</p> <p>Under take a needs assessment for bereavement services to better understand and inform future commissioning intent.</p> |

NHS Swindon Clinical Commissioning Group

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Overview & Scrutiny Committee

Date: 21 June 2016

Dying Well Community Charter

- 3.16 Swindon Clinical Commissioning Group (CCG) has placed end of life care as one of its key priorities. Since developing a bid to become a Dying Well Community Charter pilot site in 2014, in which it was unsuccessful, all partners involved have continued to work together to design and implement, with stakeholder support, a local Dying Well Community Charter.
- 3.17 Towards the end of 2014 the National Council for Palliative Care (NCPC), working in partnership with Public Health England, set out the idea of a National Dying Well Community Charter and invited communities to bid to become one of 7 pilots to establish a 'Charter' in their areas. The purpose of the Charter is aimed at helping the local community to work together to improve their support to people with a life-limiting illness, those who support them and those who have been bereaved, something that is fully aligns with Swindon CCG's aims.
- 3.18 The Swindon Dying Well Community Charter (DWCC) sets to outline a visible commitment by individuals, communities and organisations, working together to support the community we all live in, the people with a life-limiting illness, their families and carers. The Charter is a nationally led idea, but the ideas and commitments within it are ones that many local organisations will recognise as important and valid for our local community of Swindon. So a group of local organisations came together to look at how we could create a Swindon Charter. These organisations on the working group include representatives from the Clinical Commissioning Group, Great Western Hospital, Healthwatch Swindon, Prospect Hospice, Public Health Swindon, SEQOL and the Swindon Carers Centre.
- 3.19 Appendix B provides further detail of the Dying Well Community Charter.

3.2 Supporting Information

3.2.1 None

4. **Alternative Options**

4.1 None

5. **Implications, Diversity Impact Assessment and Risk Management**

Financial and Procurement Implications

5.1 None

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Overview & Scrutiny Committee

Date: 21 June 2016

Legal and Human Rights Implications

5.2 None

All Other Implications (including Staff, Sustainability, Health, Rural, Crime and Disorder)

5.3 None

Diversity Impact Assessment

5.4 None

Risk Management

5.5 None

6. Consultees

6.1 The Board Director, Resources (Section 151 Officer) and Director of Law and Democratic Services (Monitoring Officer) are consulted in respect of all reports.

7. Background Papers

7.1 None

8. Appendices

8.1 Appendix A – Further guidance and context to end of life care.

8.2 Appendix B – Dying Well Community Charter