

Section 7.3 End of life care

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Recommendations for consideration by commissioners

1) Who is at risk and why?

According to the World Health Organization (2012):

“Palliative Care (or End of Life Care) is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”

The conditions of these patients are unresponsive to curative treatment. Such patients die in different settings, sometimes in accordance with their preferences and unfortunately sometimes not. The national End of Life Strategy (Department of Health, 2008)¹ outlines a way forward to attempt to address some of the issues that create challenges to supporting deaths in the preferred place of the patient.

In the South Gloucestershire local authority area, 53.27%² of patients currently die in hospital as opposed to in their residence or another community setting. For 2012/13, hospitals have been set a target to reduce the number of deaths in hospital to 51%. It is hoped that the target; a focus of end of life care planning with an electronic register; and current investment in community based services, will help to improve the co-ordinated and timely discharge of patients at the end of their life in accordance with their preferences.

¹ Department of Health 2008 End of life care strategy

² http://www.endoflifecare-intelligence.org.uk/profiles/2/Place_of_Death/atlas.html 2008-2010

2) The level of need in the population

In meeting the new target for hospitals, we will see an increase of 1.14% or about 18 deaths in community settings, and these patients will be cared for by existing end of life care service provision.³

3) Current services and assets in relation to need

Current services are in place to support end of life patients in the community. These include St Peters Hospice, the Palliative Care Home Support Service, community nursing teams, Continuing Health Care, and a basic nursing care service delivered by Marie Curie. North Bristol Trust has eight specialist beds for end of life care patients with complex needs. As a large charity, St Peters provides services for a number of patients in South Gloucestershire. With respect to NHS commissioning, children's palliative care and adult services are managed by the Clinical Commissioning Group and Commissioning Support.

4) Projected service use and outcomes in 3-5 years and 5-10 years

See Section 2 of the JSNA Summary for predicted disease and death rates.

5) Evidence of what works

Marie Curie is in the process of evaluating the end of life co-ordination centres associated with their Delivering Choice programme. The centres and the electronic end of life register are valued by the local palliative care consultants who have both hospital and community roles via the hospice in the care of end of life patients.

6) User views on needs, services / assets and gaps

A South Gloucestershire public consultation which included residents and carers groups took place in 2009. The key findings highlighted the following issues for end of life care in a community setting.

- A need for 24 hour care in the place of residence
- The lack of knowledge by others of the patient's wishes
- The inability of some carers to cope without intensive support
- The availability of appropriate equipment
- Good pain management to avoid hospital admissions.

Providers of palliative care are required under their contracts to review and act on user feedback.

³ http://www.endoflifecare-intelligence.org.uk/profiles/2/Place_of_Death/atlas.html
calculations based on the dataset 2008-2010

Recent research carried out on behalf of the local authority with voluntary sector groups has indicated a need for bereavement counselling which is based more locally. Bereavement counselling services are currently based in Bristol, as opposed to South Gloucestershire.



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7) Equality Impact Assessments

National research has shown that socio-economic deprivation is a major determinant of where, when, and how people die; and across England those living in the most deprived quintile of the population are around 4-7% more likely to die in hospital as opposed to the rest of the population.⁴ One potential conclusion is that these patients may not have equivalent access to end of life care services in the community. The data to determine whether this is true at a local level is not readily accessible. However, with respect to the BME population in South Gloucestershire community services do appear to be serving a representative patient cohort for palliative care.⁵

There has been a recent national focus on the palliative care needs of young people. The Teenage Cancer Trust has identified particular national challenges with respect to palliative care for teenagers and young adults as follows.⁶

- Transition problems from hospital to community-based care
- Lack of specialist paediatric palliative care services
- Lack of agreement between staff about allowing teenagers and young adults to die on the Unit
- The need to establish better communications between Principle Treatment Centres and community-based services
- Insufficient teenage and young adult specific hospice care - a gap in services for 16-18 year olds
- The range of services may result in lack of clarity about the 'best' option.

To start to address these challenges in South Gloucestershire, the children's and adult hospices are working together to review their care planning and treatment pathways for young people, and the clinical management of transition for patients from children's palliative care services to adult services. This work is being facilitated by the regional Palliative Care Steering Group.

⁴ National end of life care intelligence network (2012) Deprivation and Death: Variation in place and cause of death

⁵ Office of National Statistics (2007)

⁶ University of Lancaster (2011) Evaluation of level of current provision of palliative care provision from teenagers and young adults

8) Unmet needs and service gaps

Following the public consultation in 2007, Marie Curie now provide a night sitting service to support 24 hour care; and St Peters Hospice and the Palliative Care Support at Home services provide complex care in the patient's place of residence.

A plan of work has been agreed with the Clinical Commissioning Group for end of life care in 2012/13 by current commissioners.

The Clinical Commissioning Group in South Gloucestershire is reviewing the use of the end of life electronic register, and working through how to meet the new NICE information standard⁷ for sharing information with other services on end of life care preferences. Information on patient preferences for the care has to be accessible to all the relevant services by December 2013. The promotion of both advance care planning and the end of life electronic register aim to facilitate the sharing of patient preferences between services, and provide the opportunity for patients to have their wishes recorded and acted on.

There is a PCT cluster wide focus on improving anticipatory prescribing by GPs to maintain good symptom management and avoid admissions. Learning from other areas where on-site 'just in case' drug boxes are being used in pilots will be applied to current systems in South Gloucestershire.

National research has shown that patients with non-malignant disease are less likely to die outside hospital and do not access palliative care services such as hospices to the same degree as cancer patients.⁸ This conclusion is supported by local data. Providers of end of life care are being targeted in their contracts to increase their proportion of patients with non-malignant disease to improve access to community-based palliative care services for this group of patients.

9) Recommendations for consideration by commissioners

Following funding from the Marie Curie Delivering Choice programme, North Somerset has an end of life co-ordination centre which is a model that could be replicated in various different forms in South Gloucestershire. North Somerset has reduced the number of deaths in hospital to 46%.⁹

Commissioners must continue to monitor the access by non-malignant patients to end of life services; and also review the possibility of commissioning a local bereavement counselling service.

10) Recommendations for further needs assessment work

Further research needs to be carried out by service commissioners to confirm that the current service provision can meet the planned increase in the deaths of palliative patients in their place of residence.

⁷ NICE (2012) Information Standard 1580

⁸ National end of life care intelligence network (2012) What do we know now that we didn't know a year ago? New intelligence on end of life care in England

⁹ http://www.endoflifecare-intelligence.org.uk/profiles/2/Place_of_Death/atlas.html 2008-2010

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References

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- 2) http://www.endoflifecare-intelligence.org.uk/profiles/2/Place_of_Death/atlas.html 2008-2010
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- 4) National end of life care intelligence network (2012) Deprivation and Death: Variation in place and cause of death
- 5) Office of National Statistics (2007)
- 6) University of Lancaster (2011) Evaluation of level of current provision of palliative care provision from teenagers and young adults
- 7) NICE (2012) Information Standard 1580
- 8) National end of life care intelligence network (2012) What do we know now that we didn't know a year ago? New intelligence on end of life care in England
- 9) http://www.endoflifecare-intelligence.org.uk/profiles/2/Place_of_Death/atlas.html 2008-2010