REPORT TO THE HEALTH AND WELLBEING BOARD

Date: 31st January 2017

PALLIATIVE AND END OF LIFE CARE: POSITION PAPER

Report Sponsor:	Janet Owen (End of Life Care Clinical Lead) South and West Yorkshire Partnership NHS Trust and Chair of Barnsley End of Life Care Clinical Steering Group
Report Author:	Richard Lynch (Head of Commissioning, Governance and Partnerships) Barnsley MBC
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1.0 Purpose of Report

1.1 To inform the Board of current provision for palliative and end of life care in the Borough, following the recent publication of the Government's response to the recent independent review of choice in end of life care.

2.0 Recommendations

2.1 Health and Wellbeing Board members are asked to:-

- Note the priorities of the Barnsley End of Life Care Strategy and the outcomes of a review of the Strategy, together with the extent to which local service provision for palliative or end of life care, in the Borough, is continually informed through developments in policy, including the Government's recent response to the independent review.

3.0 Background and Context

3.1 In 2008 the Department of Health (DH) published the first National End of Life Care Strategy as a 10 year plan. Following this, in 2010, a Barnsley Strategy was written to provide a vision and direction for local services. In 2015 the Barnsley End of Life Care Strategy was reviewed and refreshed by Barnsley CCG to build on the original recommendations and consider future priorities in light of changes in practice and national reports including "More Care Less Pathway"(2013) and "One Chance To Get It Right" (2014).

3.2 Since then, there has been a number of further reports including Ambitions For Palliative And End Of Life Care Framework (2015) National Institute for

Clinical Care Excellence (NICE) Guidelines For Care Of The Dying Adult In The Last Days Of Life (2015) Commissioner Check List For End Of Life Care (2016) and most recently the DH's response To The Independent Review Of End Of Life Care (2016) and NHS England's Specialist Level Palliative Care: Information for Commissioners (2016). All of these reports have been considered by the Borough's end of life care clinical steering group and informed the development of local services.

3.3 In 2015, a review which was undertaken of the local Strategy reinforced a commitment to provide high quality end of life care for people across the borough irrespective of diagnosis, socio- economic background, religious belief, gender or ethnicity. It focused on patient choice and the development of services which are tailored to individual needs and preferences as part of a fully integrated approach which places Barnsley people at the centre.

3.4 The original scope of the local strategy was to focus on individuals aged over 18 but the review recognised that there are parallels between care for adults and children.

4.0 Current Service Provision In Barnsley

4.1 Palliative or end of life care is provided by a wide range of organisations and services. The strategy makes a distinction between end of life care/palliative care delivered by generalist and specialist services. The specialist team plays an important role in providing education, support and leadership to the generalist teams to facilitate high quality end of life care as well as the provision of direct care for those with complex needs.

4.2 Generalist Services

4.3 A number of generalist services across health and social care providers which deliver end of life care as part of their role. This includes GPs, district nurses, community matrons, care home staff, domiciliary carers, allied health care professionals, social workers, ward doctors and nurses.

4.4 Specialist Services

4.5 The specialist palliative care and end of life care service in Barnsley is jointly provided by Barnsley Hospital, Barnsley Hospice, South West Yorkshire Partnership Foundation Trust (SWYPFT) and Barnsley Council (BMBC). There are close working relationships across the providers which are strengthened by a joint end of life care clinical steering group and an operational /educational group which focus on the development of an integrated and seamless approach for those with end of life care needs.

4.6 The range of care and support provided through specialised palliative and end of life care services is outlined below:

4.6.1 Specialist Palliative Care

Specialist palliative care provision in the community is a 7 day service. The Community Macmillan Specialist Palliative Care Team is employed by SWYPFT and is a multidisciplinary service including clinical nurse specialists, allied health care professionals, a social worker (employed by BMBC) and palliative medicine consultant. The team provides specialist palliative care to patients in a community setting, including clinical nurse specialists specifically for community hospitals and care homes. As part of the SWYPFT's Long Term Conditions Unit, this team is working closely with the new neighbourhood teams which support an integrated community approach.

4.6.2 The Macmillan Specialist Palliative Care Team in Barnsley Hospital provides a 7 day service which includes 5 clinical nurse specialists (3 BHNFT funded and 2 Hospice funded) and a Palliative Medicine Consultant .

4.6.3 Barnsley Hospice provides an inpatient unit (including 10 beds available with 7 day a week admission) and day patient services. The Hospice provides a range of services, including counselling, complimentary therapies, lymphoedema management and a bereavement and family team. A social worker is also employed by BMBC and works at Barnsley Hospice.

4.6.4 Palliative medicine consultants are employed by Barnsley Hospice and work with Hospice, community and hospital teams to provide a district wide service. The Hospice also provides a palliative care advice line and there is telephone advice available from an on call palliative medicine consultant rota.

4.6.5 Palliative Home Care Team

4.6.6 The Marie Curie Supportive Care at Home Team is employed by SWYPFT and includes health care assistants and registered nurses. The team provides support for patients in the last days and weeks of life and their families, providing individualised packages of care to enable a person to be cared for in their preferred place and providing carer respite for those with any life limiting illness.

4.6.7 Clinical Support And Education

4.6.8 The End of Life Care Team is employed by SWYPFT but works with all health and social care providers in Barnsley to support the development of high quality, end of life care through education and clinically based

support/coaching for generalist staff . The service has introduced and supports generalist use of tools for improving end of life care across Barnsley.

5.0 Review Of The Barnsley End Of Life Care Strategy (2015)

5.1 In 2015, the Barnsley CCG led a review of the local end of life care strategy. Provision was considered against national and local expectations and key recommendations were identified to further develop the quality of end of life care provided in Barnsley.

5.2 The review recognised the progress already made in the following categories:

- Collaboration and Integration
- Education /Training
- Care Planning.

5.3 The importance of a collaborative and whole borough approach was central to the end of life care strategy and the development of a single integrated pathway has been a significant factor. The refreshed strategy noted some key achievements that have reflected this and which are summarised below:

- The partnership working between health and social care teams
- The development of a district wide end of life care education programme
- The development of a '*My Care Plan'* district wide tool to support individualised care and the development of a personalised care plan for those in the last days or hours of life
- The introduction of the '*Preferred Priorities For Care'* document as a template for advance care planning and the sharing of personal preferences and wishes
- The introduction of a regional '*Do Not Attempt Cardio Pulmonary Resuscitation'* form which is shared by all providers

6.0 Recommendations Of The Strategy (2015 – 2017)

6.1 The strategy review made 5 key recommendations for further service development during this period. The following provides an overview of progress made against these recommendations:

6.2 Recommendation 1: Development of the End of Life Care Clinical Steering Group

- A new end of life care steering group has been established to drive forward the recommendations of the Review. The membership has been broadened and strengthened with representatives from key organisations and supports a collaborative approach to the development of end of life care services. It is hoped that in 2017 integration with social care will be further strengthened by increased engagement with the group. This group reports to the CCG.

6.3 Recommendation 2: Creating consistency and monitoring quality standards

- It has been agreed that the place of death will remain a broad proxy performance measure for developments in end of life care. It is recognised that this does have limitations but is nationally recognised as providing a broad bench mark. Local data has shown a steady trend of increasing numbers of people dying with dignity in their usual place of residence in accordance with their wishes, with a 5 % increase from 2010 to 2015. These local figures are broadly in line with the national average and are higher than most of our comparator areas.
- National minimum data for the whole specialist palliative care service is collated and presented to the steering group. This provides the current national comparator data for analysis.
- Barnsley Hospital is involved in the National Care Of The Dying Audit for acute care and results against national indicators are positive. Action plans for areas of development, identified in the Strategy have been developed which take into account an individual's spiritual needs and advance care planning.
- A range of patient and family feedback, from all areas, is also collated which has shown positive outcomes.
- To develop a future quality monitoring standard, the steering group has agreed that the use of patient outcome measures should be developed, supporting outcome monitoring relating to personalised need. The specialist palliative care teams are beginning to use the validated measures and this will support future outcome measurement and act as the basis of further palliative care development. Nationally, it is anticipated that it may be sometime before bench mark comparisons with other services can be made but this is a positive start. The specialist palliative care team as a whole is working on this development and will provide regular progress reports to the steering group.
- Further data regarding those not involved with specialist services is also required. Here, the steering group has acknowledged that to gain meaningful data to support evaluation and development, a more effective

palliative care template in primary care is needed. It has been agreed by the steering group that the development of GP templates will be prioritised in 2017

- Barnsley Hospital, SWYPFT community services and Barnsley Hospice have all had CQC inspections in the past 2 years and all areas received overall good judgements for end of life care with Barnsley Hospital receiving an 'Outstanding' judgement for the end of life care caring element of inspection and the SWYPFT receiving a similar judgement for end of life care effectiveness. It was acknowledged in the report for community services that greater access for those with a non cancer diagnosis to specialist palliative care should be developed and work is been taken to develop this.
- Baseline monitoring against NICE quality assurance guidelines is provided to the end of life care steering group as well as through a range of audits and annual reports.

6.4 Recommendation 3: Robust education and training for clinicians to embed service development

- A district wide education and training programme has been developed which is inclusive of all health and social care providers across Barnsley. This approach supports integration and partnership working. In 2015 – 2016 a total of approximately 1000 staff accessed formal end of life care training. In addition, there was a significant amount of practice based training/coaching to support implementation of good practice. Recently, the programme has included the roll out of a 1 day advance communications skills training session for senior staff which is an accredited course and has been attended by 72 staff including 21 consultants. A further 6 sessions are planned for 2017.
- The education programme supports the use of various end of life care tools, including the Amber Care Bundle which is a nationally recommended tool for use in acute care. It was developed by Guys and St Thomas' Hospital to support improved treatment planning for those reaching the end of life. Integral to this is the need to have open and honest conversations with the person and their family to support personalised planning and respect of personal preferences and wishes. This has now been introduced in all the medical wards in Barnsley Hospital and additional fixed term facilitator funding from the CCG is supporting further embedding of this approach.
- Locally, following the independent review of the Liverpool Care Pathway a care plan template has been developed to support a personalised approach to end of life care. This has been introduced in all care settings,

locally. Families are encouraged to be involved particularly in considering the holistic needs of the person and their own needs. The “My Care Plan” approach has, recently, been reviewed and updated in response to the latest NICE guidance. The use of the care plan and education about the provision of last days of life care is supported by the Palliative and End of Life Care Teams, who have a visible presence in clinical areas.

- Personalised care planning has been the focus for end of life care development for a number of years and this has included education in all areas regarding advance care planning. In the last year there has again been support particularly in the community and care home sector.

6.5 Recommendation 4: Review and implementation of an Electronic Palliative Care Coordination System

- ‘Planning My Future Care’ templates have been developed for community teams to support the documentation and sharing of practice in advance care planning and to support care/treatment in a way which reflects the individual’s preferences. Our objective is to develop broader ownership of this information to include the hospice, primary care, acute care, social care services and out of hours services, through interoperable ICT systems.It is a national recommendation for local areas to introduce an EPaCCS system by 2018.

6.6 Recommendation 5: Embedding improvements into local service delivery

- In the past year, 7 day provision has been extended to include Hospital and Hospice Specialist Palliative Care Teams and significant benefits are being seen from this development
- A gap analysis has been completed against a number of recent documents which has included an end of life care commissioner check list (2016), NICE guidelines for care of dying adults in the last days of life (2015), Government response to the Independent review of end of life care (2016) and NHS England Specialist Level Palliative Care: Information for Commissioners (2016). This will result in the development of outcome measures, further development of district wide guidelines and district wide audit, shared referral criteria and increased collaborative working.
- To enhance service responsiveness and support for both patients and other professionals, the community team has developed an advice line which is operated by a duty nurse from 9am to 5pm Monday to Friday. Further, the Hospice has established a dedicated triage nurse to discuss admissions to the inpatient unit, together with incorporated telephone advice availability into doctors rotas.

- Within the neighbourhood teams and community services, there is a requirement to identify a key worker for all patients to provide additional capacity in the coordination of care for those with palliative and end of life care needs. Recent experience, in Airedale has shown that positive outcomes can be achieved with the introduction of a one number advice line for palliative/end of life care patients and this practice is under consideration, locally.
- The local palliative and end of life service specification will be reviewed for effectiveness, in 2018/9 as palliative care currencies and outcome measures are developed nationally.

7.0 Further Developments In Palliative Or End of Life Care In The Borough

7.1 The end of life care steering group is currently considering the key priorities for development of the service in 2017/18 and these are to be presented to the CCG in the next few months. These are likely to include the following:

7.1.1 Personalised Care Planning

- Further development of Electronic palliative care coordination system across all providers
- Further development of patient outcome measures for specialist palliative care services
- Need for continued education embedding of AMBER care bundle and advance care planning

7.1.2 Access To Services

- To consider access to a single point of advice for individuals approaching the end of their lives and their families
- The development of multidisciplinary out patient clinics including palliative medicine, nurse and other practitioner involvement to improve geographical accessibility
- To continue to improve access for those with a non cancer diagnosis, through integration into long term condition service specifications, further development of the Map of Medicine and further work to support the recognition of palliative/end of life care need .
- Development of access to psychological and spiritual care

7.1.3 Extending Choice

- To evaluate the need for specific beds (for example in care homes) identified for palliative care and led by palliative care services to allow increased choice regarding place of death.
- To further support the development and models of working in care homes to develop clinical leadership for care home residents who are approaching the end of life
- To link end of life care developments to current work being completed by the *'Living With And Beyond Cancer'* work stream
- To further consider links to personalised budgets for palliative and end of life care

8.0 Independent Review Of Choice In End Of Life Care: Government's Response

8.1 The Government's response to the Independent Review highlighted the need to prioritise end of life care, work collaboratively and provide integrated services. It also made a commitment regarding expectations at the end of life which are summarised below:

- Honest discussions between care professionals and dying people
- Dying people making informed choices about their care
- Personalised care plans for all
- The discussion of personalised care plans with care professionals
- The involvement of family and carers in dying peoples care
- A key contact so dying people know who to contact at any time of day

9.0 Conclusion And Next Steps

9.1 This report sets out the developments which have resulted in the current level and range of provision for palliative or end of life care in the Borough, based upon the local Strategy.

9.2 This is characterised by a consistent focus on individual needs, wishes and preferences and personalised care planning. The involvement of families and carers has been a key consideration with services having been positively reviewed by the CCG and externally assessed by the CQC and bench marked against national data. In line with the Government's response to the outcomes of the recent independent review, there has been a continued focus on the

priority development of collaborative and integrated services which is guided by the district wide end of life care clinical steering group.

9.3 In acknowledging these strengths, there is also a willingness to develop services, further, particularly for those with a non cancer diagnosis and in access to services. The Service is committed to further improvements in personalised care planning and extending choice, again, in line with the Government's response to the independent review..

10.0 Resource Implications

10.1 There are no resource implications arising from considering this report.

11.0 Appendices And Background Papers

11.1 There are no appendices to this report. Background papers used in the compilation of this report are available to view by contacting Karen Sadler, People Directorate, Barnsley MBC, PO Box 639, Barnsley S70 9GG, telephone (01226) 773836 or e-mail karensadler@barnsley.gov.uk