

Borders NHS Board



LIVING AND DYING WELL: AN ACTION PLAN FOR PALLIATIVE AND END OF LIFE CARE: PROGRESS REPORT

1 Aim

- 1.1 To update members on the work of Borders Palliative Care Network (BPCN) and to provide progress updates around the delivery plan *“Living & Dying Well – A National Action Plan for Palliative and End of Life Care in Scotland”* and the next steps for aspects of future development.

2 Background

- 2.1 In September 2008, the Scottish Government launched *“Living & Dying Well – A National Action Plan for Palliative and End of Life Care in Scotland”*. This plan takes full account of the key messages of the August 2008 Audit Scotland review of Palliative Care Services in Scotland and aims to ensure that all patients can access good quality and comprehensive palliative care in all care settings across Scotland.
- 2.2 In light of this, the Cabinet Secretary has asked Board Chairs to ensure that palliative and end of life care is given prominence in the development of Board strategies.
- 2.3 Borders Palliative Care Network (BPCN) was established in 2001, a forerunner to the formal Managed Clinical Network structures which were introduced nationally for a range of specific conditions. The BPCN conforms to this standard structure in that it has a multi-disciplinary and interagency membership and engages with individuals and carers in all fora. A work plan was established which has been updated in line with current policy.
- 2.4 At the NHS Borders Board October 2008 Strategy & Performance Committee, it was agreed that the Borders Palliative Care Network should prepare a draft delivery plan to meet the actions outlined in the Scottish Government document. At the end of March 2009, the NHS Borders Board approved this draft delivery plan which outlined how the actions would be carried out locally. This has been submitted to the Scottish Government and was approved as a model delivery plan.
- 2.5 The Strategy and Performance Committee also discussed the challenges being experienced in local specialist in-patient palliative care. In recognition of this, the Committee:
- approved action to produce a business case to improve specialist palliative care and the patient environment at the Borders General Hospital.

- approved that in the development of the business case, account should be taken of the Board's revenue and capital position, and therefore funding sources and opportunities should be clearly identified, which may include fundraising.

3 Summary

3.1 The attached paper outlines progress and key achievements within NHS Borders against "*Living & Dying Well*" Delivery Plan. The paper also summarises progress with strategy development re improving the environment and care for specialist in-patient palliative care.

4 Recommendation

4.1 The Board is asked to:

- **Note** the update and progress within NHS Borders against "*Living & Dying Well*" Delivery Plan
- **Note** the progress update of the scoping work regarding specialist in-patient palliative care facilities
- **Note** the links across the work of Integrated Health Strategy

Policy/Strategy Implications	<i>"Living & Dying Well – A National Action Plan for Palliative and End of Life Care in Scotland"</i> is a national delivery plan against which Health Boards are measured.
Consultation	This work has been developed through the BPCN, with consultation through the Board Executive Team and the Clinical Executive.
Consultation with Professional Committees	See Above
Risk Assessment	Progress towards achieving certain elements within the delivery plan are monitored on a regular basis through the BPCN.
Compliance with Board Policy requirements on Equality and Diversity	Not applicable at this stage, as implementation progresses Lead Directors and Managers will ensure compliance.
Resource/Staffing Implications	Responsibility for achieving these objectives falls within the remit of a lead Director and lead Manager and the resources they have been allocated. Current and future resource issues have been identified within the attached paper.

Approved by

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PROGRESS REPORT

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3 Living & Dying Well – A National Action Plan for Palliative and End of Life Care in Scotland

3.1 The table below highlights the main areas of progress and achievement against the actions set out in the national delivery plan, since the plan was presented to the Strategy & performance Committee earlier this year.

Table 1 – NHS Borders Key Achievements to date

Relevant National Objective/Action	NHS Borders Progress to Date
<p>The progress within NHS Borders to date contributes against the delivery of actions 1, 2 & 5 set out in the national Delivery Plan, these are as follows:</p> <ul style="list-style-type: none"> ▪ NHS Boards, through palliative care networks and CHPs, should ensure that recognised tools/triggers to support the identification of palliative and end of life care needs of patients diagnosed with a progressive, life-limiting or incurable condition and the needs of their carers are used across all care settings by 2010. ▪ NHS Boards, through palliative care networks and CHPs, should ensure that patients identified with palliative and end of life care needs are appropriately assessed and reviewed in all care settings using recognised tools currently available. ▪ NHS Boards and CHPs should take steps to ensure that patients with any condition who have been assessed as having palliative or end of life care needs are included in primary care palliative care registers, are supported by a multi-disciplinary team, and have their care and that of their carers co-ordinated by a named health or social care professional. 	<p>Two part time palliative care education coordinators were appointed on a fixed term basis to provide education and promote the use of the End of Life Care Pathway in hospital wards, community hospitals, care homes, and primary care as well as syringe driver training, palliative care for carers and for newly qualified staff. Work is ongoing to secure recurring resources to support this work.</p> <p>24 out of 25 GP practices have engaged with the Palliative Care Scottish Enhanced Service which requires identification of patients with palliative care needs, development of anticipatory care plans, development of anticipatory care plans, out of hours handover information and the use of an end of life care pathway. Returns have been submitted for November 2008 – March 2009 and these will be analysed by BPCN. The one practice not engaged has been visited and has a palliative care register and actively assesses and seeks to meet the needs of these patients. See also non-malignant palliative care below.</p> <p>Implementation of agreed guidelines (SIGN 106, Lothian & Borders Palliative Care Guidelines), local protocols (Prescription of Opioids using a Sliding Scale, NHS Borders Joint Prescribing Formulary), and local assessment tools (Borders Pain Assessment Tool and Pain Chart).</p> <p>Under the auspices of the Borders Palliative Care Network, we have established a Non-Malignant Palliative Care Group which is developing guidelines and processes to support people with long term conditions who are moving towards an end of life phase. Non malignant palliative care spans most long term conditions and all five Borders MCNs. The Group is focussing initially on respiratory conditions and CHD, with those two MCNs taking a lead in developing guidance</p>

for staff around defining when someone is moving into a palliative care phase of their pathway, the application of the End of Life (Liverpool) Care Pathway, development of specific anticipatory care plans and the development of training & education about managing very difficult conversations and appropriate communication with these patients and their carers. Review of the DNAR policy is being taken forward with the aim of incorporating guidelines relevant to primary care and community settings. A list of patients with end stage cardiac and respiratory MCNs and practices have been notified of their own patients on this list to ensure they are on the practice's palliative care register. The non-malignant group during July is engaging with mental health and medicine for the elderly to broaden the remit to frail elderly and patients with dementia.

As part of the Non-Malignant Palliative Care work, Stow & Lauder Health have developed and are piloting an Anticipatory Social Care Plan which is an interagency approach to anticipatory care to try and prevent hospital admission for social care reasons. It comprises a patient/carer register, multidisciplinary assessment of patient and carer requirements and seeks to anticipate requirements should a family carer become temporarily unable to look after a patient requiring a high level of care or should a patient become temporarily bed bound due to an episode of illness treatable at home. It incorporates a handover sheet detailing relevant information for out-of-hours services. This will be evaluated by the LTC Collaborative national team with the intention of rolling it out across Borders.

An audit on referrals has recently been carried out to determine the service demand for non-malignant palliative care. Out of 243 referrals audited 28 were non-malignant (13%). The care at home service (care funded by the palliative care budget for patients felt to be in the last 6 months of life) is also currently being evaluated and during 2008/09 a total of 201 referrals were made to the service, 16 of these were non-malignant (8%). The BPCN recognises the inequity of this situation and is proposing a prospective audit to try and establish the reasons for this which will include a redesign of the current assessment tool. It will also be necessary to try and establish future need in

	<p>order that the cost of providing an equitable service to all patients dying at home, whatever the cause can be considered jointly by SBC and NHS Borders.</p> <p>The work of the Group aims to support people in the end-of-life phase of their long term conditions to remain at home wherever appropriate and in doing so will help to prevent avoidable hospital admission and attendances at A&E.</p>
<p>The progress within NHS Borders to date contributes against the delivery of actions 4 & 6 set out in the national Delivery Plan, these are as follows:</p> <ul style="list-style-type: none"> ▪ CHPs, palliative care networks, older peoples services and LTC teams in each NHS Board area should collaborate to ensure that timely, holistic and effective care planning is available for those with palliative and end of life care needs and is carried out in a manner which is person centred and responsive to the needs of the diversity of the population at appropriate stages of the patient journey. ▪ NHS Boards and CHPs should take steps, including the use of Patient Group Directions and Just in Case boxes where appropriate, to facilitate the use of anticipatory prescribing to enhance patient care and aid the prevention of unnecessary crises and unscheduled hospital admissions. 	<p>Anticipatory social care planning for people with non-malignant palliative care needs has been developed and trialled in one practice by the multi-disciplinary team. This is to be evaluated by the LTC Collaborative prior to roll-out across Borders.</p> <p>There is a proven history of robust joint inter agency working across Borders the LTC Strategy incorporates non-malignant Palliative Care and broader anticipatory care planning. The Chair of BPCN is a member of the LTC Steering Group and the LTC Manager also manages all MCNs including BPCN. Borders LTC Strategy is an inter agency strategy and reports to the CH&CP. A social work manager is an active member of the BPCN core group creating good interagency working and communication in the network. Development in NHS Borders of a pre-printed anticipatory prescribing chart for all patients at the end of life across all teams. This has now been incorporated in the updated Borders Palliative Care Kardex which also facilitates the prescription of opioids using the sliding scale protocol. The updated Kardex will be available from the printers in August and will be promoted across Borders. The sliding scale protocol for opioids allows trained nurses to make appropriate and timeous adjustments to a patient's medication regime in response to patient's pain without the delays inherent in waiting for a doctor to write out a fresh prescription.</p> <p>Palliative Care Drug boxes are available at Out of Hours hub and local health centres and should be left in a patient's house if it is anticipated that additional drugs may be required.</p>
<p>The progress within NHS Borders to date contributes against the delivery of action 7 set out</p>	<p>Borders Health in Hand (www.bordershealthinhand.scot.nhs.uk) has been</p>

<p>in the national Delivery Plan, these are as follows:</p> <ul style="list-style-type: none"> ▪ NHS Boards should work collaboratively with local authorities to produce service information directories for use by health and social care professionals and by patients and carers which outline how and when to access the services relevant to those with palliative and end of life care needs, including telemedicine and e-technology. These should be produced in a range of formats and communicated in different ways to ensure they are accessible and appropriate to the diverse needs of all groups. 	<p>established under the LTC Strategy. As part of its content this website houses information on end of life and palliative care including sign posting to both local and national supports.</p> <p>An inter agency telehealthcare project group has recently been established to take forward developments locally; palliative care will be part of this work.</p> <p>The BPCN is planning a comprehensive information section on the NHS Borders intranet which should be in place by the end of this year.</p> <p>The BPCN has produced a patient leaflet on “Help Required” for patients in the end stages of their illness. It details services available, both in and out of hours, provides contact information and encourages patients to contact the services when they have problems. It has recently been updated and is available on the web.</p>
<p>The progress within NHS Borders to date contributes against the delivery of action 8 set out in the national Delivery Plan, these are as follows:</p> <ul style="list-style-type: none"> ▪ NHS Boards should implement consistent DNAR and associated documentation such as the example developed by NHS Lothian across all care settings and provide education to support the effective and appropriate application of the documentation and procedures. NHS Boards should enter into discussion with the Scottish Ambulance Service regarding adoption of DNAR policies which are consistent with the SAS End of Life Care Plan. 	<p>To date the DNAR policy has largely focussed on secondary care. Review of this policy is being taken forward but also aims to incorporate guidelines relevant to primary & community settings. Alongside this work is further development of training & education for staff with regard to communication and managing difficult conversations associated with DNAR and end of life care. A member of the BPCN is working with the NHS Borders Resuscitation Team to take this issue forward, both in terms of finalising a policy and of implementation and education.</p>
<p>The progress within NHS Borders to date contributes against the delivery of actions 9 & 16 set out in the national Delivery Plan, these are as follows:</p> <ul style="list-style-type: none"> ▪ NHS Boards and their partners should ensure equitable, consistent and sustainable access to 24 hour community nursing and home care services to support patients and carers at the end of life where the care plan indicates a wish to be cared for at home and this is 	<p>There is a dedicated local out of hours phone number for patients nearing the end of life enabling direct access to a local nurse OOH. Patients/carers are given a leaflet detailing when and who to call. Each patient who has been given the leaflet will have had a handover sheet (developed by the BPCN) completed by the professional involved and sent to the OOHs hub. NHS 24 is aware of local arrangements for palliative care in the Borders and will pass any calls received back to the local hub. The service</p>

<p>compatible with diverse and changing patient and carer needs.</p> <ul style="list-style-type: none"> ▪ NHS Boards should ensure that safe and effective processes, electronic or otherwise, are in place 24/7 to enable the transfer, to all relevant professionals and across sectoral and organisational boundaries of patient information as identified in the ePCS regarding any patient identified as having palliative and end of life care needs and who gives consent 	<p>was based on research of patient and carer needs and received an NHS Scotland “Evidence into Practice” award and was mentioned as a model of service in the Audit Scotland Palliative Care report. This has been in place locally for 5 years and has been favourably evaluated by patients and carers.</p> <p>There is excellent engagement from clinicians in providing handover information.</p>
<p>The progress within NHS Borders to date contributes against the delivery of action 10 set out in the national Delivery Plan, these are as follows:</p> <ul style="list-style-type: none"> ▪ NHS Boards should ensure that rapid access is available to appropriate equipment required for the care of those wishing to die at home from any advanced progressive condition. 	<p>The BPCN has long-established links with the Joint Equipment Store and has funded specific equipment. Satellite stores are now in operation for access to small items of equipment by nurses 7 days per week. However large items such as beds and hoists are not available at weekends and work is ongoing to address this.</p>

4 Improving the Patient Environment and Care

- 4.1 As previously outlined there are challenges being experienced in local in-patient palliative care provision. The BPCN review of local in patient palliative care provision had highlighted that the current model of in-patient specialist palliative care within a general acute ward at the Borders General Hospital poses significant challenges in respect of patient mix and continuity of care for patients.
- 4.2 In October 2008, NHS Borders Board discussed these challenges and acknowledged the opportunities to improve the patient environment and care consistent with “*Living & Dying Well*”. In particular, the Board considered the potential for improvements to be funded through a fundraising initiative. The Board requested a business case to identify the options for improving these services, and at the same time examine how these options could be delivered, highlighting where capital investment would be required and identifying the implications and risks attached to each option and approach (including fundraising).
- 4.3 It was recognised that in the current financial climate any additional revenue costs attached to capital spend would not be viable. It was therefore identified that there may be the potential for fundraising activity to support improvements in specialist in-patient palliative care. Based on work with estates colleagues, indicative costs of a modular build unit are around £1.5m.

- 4.4 Initial scoping work has now been completed to inform the business case and work is underway to test the feasibility of the fundraising for improvements. Part of this process has looked at current spend and outlined potential capital and revenue costs. The scoping work has also identified strengths and challenges in meeting care.
- 4.5 Since the Board considered this matter, two particular factors have become prominent:
- 4.5.1 the deterioration in the economic climate with a potential knock-on impact in fundraising
 - 4.5.2 the advancement of the Strategic Change Programme and the need to ensure strands of work are connected to this in a coherent way
- 4.6 These points do need to be taken into account in taking forward planning in respect of palliative care.
- 4.7 The Fundraising Committee has discussed the risks in progressing this as a scheme as well as a Palliative Care Fundraising appeal being an opportunity for a future major fundraising initiative. In line with good practice, it is important that a rigorous feasibility review is carried out to assess the risks and deliverability of a Fundraising appeal of around £1.5m. The feasibility review, which is being progressed, also needs to assess the risks associated with on-going revenue costs.

5 Summary

- 5.1 Progress against *“Living & Dying Well – A National Action Plan for Palliative and End of Life Care in Scotland”* has been good overall with patients in Borders receiving a very high standard of palliative care. The ongoing hard work and commitment of those working within palliative care services and Borders Palliative Care Network must be acknowledged in achieving this.
- 5.2 However, there remains some significant challenges to address if we are to sustain and develop the service to meet local needs and national policy requirements. Further work will be taken forward in assessing the feasibility of fundraising to support improvements in the in-patient environment.