

**ADULT CARE & HEALTH
COMMITTEE (JOINTLY
COMMISSIONED (SECTION 75)
BUSINESS)**

Agenda Item 9

Brighton & Hove City Council

Subject:	Sussex Integrated End of Life and Dementia Care Pathway		
Date of Meeting:	17 June 2013		
Report of:	Geraldine Hoban – Chief Operating Officer, Brighton & Hove CCG		
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Key Decision:	No		
Ward(s) affected:	All		

FOR GENERAL RELEASE

1. SUMMARY AND POLICY CONTEXT:

1.1 The Pan Sussex Integrated End of Life and Dementia Care Pathway has been developed through multi-agency and multi-disciplinary stakeholder group collaboration across Sussex as part of the End of Life Care in Dementia Regional Innovation Funded project for NHS Sussex. It is part of the Joint Dementia Plan for Brighton and Hove.

1.2 The pathway comprises six phases:

1. Recognising there is a problem (awareness)
2. Discovering that the condition is dementia (assessment, diagnosis & involving the person with dementia in planning for their future care including end of life)
3. Living well with dementia (maximising function & capacity and planning for the future to enhance wellbeing)
4. Getting the right help at the right time (accessing appropriate & timely support. Reviewing advance care plans)
5. Nearing the end of life, including the last days of life (palliative care & ensuing advance care plans are reviews and respected)
6. Care after death (supporting relatives & carers to maintain wellbeing)

The knowledge and skills required by health and social care practitioners in order to successfully deliver the integrated dementia care pathway are also identified as are the information needs of people with dementia, relatives and carers.

1.3 The Brighton and Hove Clinical Commissioning Group Strategy Group supports implementation of the pathway as agreed at the meeting on 8th January 2013

2. RECOMMENDATIONS:

- 2.1 That the revised pathway to be approved for implementation to enable health and social care providers to ensure that the needs of people with dementia are integrated into end of life care planning, service specifications and contractual agreements.

The pathway

3. RELEVANT BACKGROUND INFORMATION/CHRONOLOGY OF KEY EVENTS:

- 3.1 A *National Dementia Strategy* (NDS) (2009 updated in 2010) aims to **improve end of life care for people with dementia (Objective 12)**
- 3.2 The *End of Life Care Strategy 2008* key areas for improvement include:
- **identifying people approaching the end of life**
 - **advance care planning**
 - **rapid access to care**
 - **delivery of high quality services in all locations**
 - **involving and supporting carers**
 - **workforce development**
- All of these are included in the integrated pathway.**
- 3.3 The pathway supports the achievement of the following priorities as stated in *The NHS Outcomes Framework 2012/3* - **Domain 2: Enhancing quality of life for people with long term conditions** - **Domain 4: Ensuring that people with dementia have a positive experience of care** This supports the key priorities of acute hospital admission avoidance; reduced length of stay and enabling people to die in their preferred place of care.
- 3.4 **Local Context**
The implementation of the integrated end of life care and dementia care pathway is part of the Joint Dementia Plan approved at the Joint Commissioning Board in February 2012.

Dementia is one of the priorities of the shadow Health and Wellbeing Board and it is included in the Joint Health and Wellbeing Strategy which will be ratified once the board is formally constituted in April 2013.

3.5 **Adult Social Care Health Committee March 18th 2013**

This pathway was discussed on March 18th 2013 at the Adult Care & Health Committee and has now been revised, subsequent to its submission to the committee. In response to members concerns re consultation, we can now confirm that 2 members of the Older People's Council and one member of Pensioners Action were part of the LiNK Steering group (now B&H Health Watch).

Revisions have also been made to the pathway in section 5 of the summary and phase 5 of the full pathway the wording "Implement Liverpool Care Pathway (LCP)" has been removed in response to members concerns. After discussion it

was agreed that this level of detail is inappropriate in such a broad pathway, and discussion around the LPC should be solely a clinical discussion in consultation with family/significant others.

The end of life pathway is one component of the work of the Sussex-wide Dementia project, which has also included a wide range of training for health professionals and resulted in the production of 2500 “This is Me” bags. These bags are designed to improve person-centred care as well as providing information, to enable people to make choices about their future care. This resource includes “This is me”, a resource developed by the Alzheimer’s Society, Preferred Priorities for Care, and Planning for your future care: A Guide (Included in the appendix).

To put in context discussions about Advance Care Planning (ACP) good practice is rooted in being guided by an individual’s preference and wishes. In summary, the key points about advance care planning from the good practices guide are set out below:

- No one is obliged to carry out advance care planning
- You may wish to discuss your wishes with your carers, partner or relatives
- Include anything that is important to you no matter how trivial it seems
- If you wish to refuse a specific treatment, consider making an advance decision to refuse treatment
- It is recommended that anything you have written down should be signed and dated
- It is recommended you seek the advice of an experienced healthcare professional if making an advance decision to refuse treatment
- If you make an advance decision that refuses treatment that is life sustaining it must be in writing, signed, dated and witnessed and use a specific form of words
- If you have named someone to speak for you or have a Lasting Power of Attorney, remember to write down their name in your advance care planning documents
- If your wishes are in writing or if you have a Lasting Power of Attorney, keep a copy of the documentation safe and provide copies to those who need to know your wishes e.g. nurse, doctor carer or family member.
- **Remember you can change your mind at any time.**

We would always recommend, and are committed to furthering practitioners skills in discussing end of life care. A recent study (Baker et al., 2012) found that advance care plan drawn up in primary care could help reduce unplanned hospital admissions by 52% as more was understood about the person’s wishes: ‘This means that when patients expressed a wish not to be hospitalised it was possible for this to be followed’ (Alzheimer’s Society 2012).

4. COMMUNITY ENGAGEMENT AND CONSULTATION

4.1 The Sussex Integrated End of Life and Dementia Care Pathway has been developed through multi-agency and multi-disciplinary stakeholder group collaboration across Sussex. In Brighton and Hove the following organisations were involved in either the stakeholder group or in consultation:

- Brighton and Hove PCT/CCG
- Brighton and Hove City Council – Adult Social Care
- Brighton and Sussex University Hospital Trust
- Sussex Partnership Foundation NHS Trust
- Sussex Community Trust
- The Martlets Hospice
- The Alzheimer’s Society
- The Carers Centre
- The Mediation Centre
- People with dementia, their relatives and carers
- South Coast Ambulance Service
- South East Health (Out of Hours Service)
- Nursing Homes, Residential Care Homes and Domiciliary Care Providers via provider forums
- LiNK Steering group(now B&H Health Watch) 2 member of this group sit on the Older People’s council and 1 on Pensioners Action

5. FINANCIAL & OTHER IMPLICATIONS:

Financial Implications:

5.1 The pathway has been analysed by commissioners and no financial implications were identified as all key actions for practitioners to implement were either already within existing plans and budgets or identified as highlighting best practice.

*Finance Officer Consulted: :Debra Crisp & Michelle Herrington
Date: 04/06/13*

Legal Implications:

5.2 All actions within the pathway and related to implementation are identified as highlighting best practice and flow from the National and Local policy and Guidance described in the body of this Report and are within the current responsibilities of statutory organisations and as described in the Joint Dementia Plan.

As identified in the body of this report consultation has been undertaken with a wide range of interested and potentially affected persons.

In implementing the plan regard must always be paid to individuals’ Human Rights enshrined in the Human Rights Act 1998

Lawyer Consulted:

Sandra O’Brien

Date: 04/06/13

Equalities Implications:

- 5.3 This was carried out as part of the Joint Dementia Plan

Sustainability Implications:

- 5.4 This would be included in the existing work as described in the Joint Dementia Plan

Crime & Disorder Implications:

- 5.5 Nil.

Risk and Opportunity Management Implications:

- 5.6 The drive to increase the number of people being cared for and dying in their preferred place of care may increase demand for hospice at home and domiciliary care.

Public Health Implications:

- 5.7 The number of people with dementia who currently have an advance care plan in place early in their condition is limited. This limits the level of forward planning to ensure appropriate and adequate services and support are in the persons' preferred place of care and death. This leads to a higher incidence of unplanned hospital admission and medical intervention as well as earlier admission to residential or nursing home care.

Corporate / Citywide Implications:

- 5.8 Not applicable

6. EVALUATION OF ANY ALTERNATIVE OPTION(S):

- 6.1 The development of an integrate end of life and dementia care pathway was identified as a need in response to both the National Dementia Strategy and the End of Life Care Strategy and reflects the identified needs and consultation locally.

7. REASONS FOR REPORT RECOMMENDATIONS

- 7.1 To ensure the pathway is successfully implemented across Brighton and Hove and fulfil the requirements as described in the Joint Dementia Plan.

SUPPORTING DOCUMENTATION

Appendices:

1. The Sussex End of Life and Dementia Care Pathway
2. The Brighton and Hove Stakeholder Group – terms of reference and members, now
3. Additional information on original consultation process

Documents in Members' Rooms

1. None

Background Documents

1. None