Although a formal committee of Brighton & Hove City Council, the Health & Wellbeing Board has a remit which includes matters relating to the Clinical Commissioning Group (CCG), the Local Safeguarding Board for Children and Adults and Healthwatch.

Title: "A good end-off", End of Life Care Report

Date of Meeting:

Report of: Health watch Brighton

Contact: David Liley, Chief Officer, Healthwatch Brighton and Hove
Tel: 07931755343

Email: david@healthwatchbrightonandhove.co.uk

Wards Affected: All

FOR GENERAL RELEASE

Executive Summary

"A good send-off" is presented to advise Board members about experiences of 15 people with an end of life prognosis discharged from the Oncology Ward of the Royal Sussex County Hospital between November 2019 and January 2020. At the request of Healthwatch England and the NHS this report was withheld from public release by local Healthwatch over the period of the initial response to COVID-19. The people in this report were not affected by COVID-19 at the time the case studies were gathered. They have now all passed away but are survived by their families and friends who were also impacted by the end of life care process.

The report aims to:

1. *Inform the Health and Wellbeing Strategy, "Dying Well" and "Aging Well"*
2. *Advise service providers across the health and care system about ways in which the patient experience might be improved in hospital discharge and end of life care*

3. Provide a basis for a City wide and system wide action plan to improve people's experience of end of life care *The report's recommendations most affect people undergoing end of life care, their families, and friends.*
Glossary of Terms BSUH = Brighton and Sussex University Hospitals Trust RSCH = Royal Sussex County Hospital CCG = NHS Clinical Commissioning Group, Brighton and Hove EoLC = End of Life Care

1. Decisions, recommendations and any options

1.1 That the Board request that the recommendations of the report are delivered through the Brighton and Hove Joint Health and Wellbeing Strategy, by all the relevant partners to the strategy. Particularly Dying Well and Ageing Well.

1.2 That the Board request partners to the JHWS to devise and implement an action plan to address the recommendations of the report. That action plan should include service users and their families as equal partners in service re-design and co-production of improved end of life care services.

1.3 That the Board refer this report to the Health Overview and Scrutiny Committee with a request that they monitor the progress of implementation of the report's recommendations and report back to the HWB on progress in 12 months time

2. Relevant information

Healthwatch talked to 15 patients on the Oncology Ward at the Royal Sussex County Hospital about their discharge from hospital between November 2019 and January 2020 and followed up with them once discharged. Though it was a small sample of patients, many issues emerged.

1. **Patients had been 'stranded' in hospital and regularly readmitted.**
   All the people we spoke to had been in hospital longer than one week ('stranded') or longer than 3 weeks ('super stranded') and all had been in hospital numerous times before, with most being readmitted through the Emergency Department (ED). Discharge planning was usually complex because of volatile clinical conditions and variable care in the community and family support at home. This report suggests that focusing resources to support oncology patients around the hospital discharge process would both improve their end of life experiences and assist the hospital to improve key performance targets. (BSUH data for 2018 shows that out of 1662 deaths, one third had been

in hospital 1- 5 times in the previous year. Over 400 people had had 6+ admissions. Presentation at Brighton and Hove Dying Well Conference Nov 2019)

2. **Patients fared better when they had support from specialist services for their End of Life Care such as the Hospital Discharge Team, the hospital Palliative Care Team and Martlets Hospice.**
   Complex discharge plans led by specialist discharge staff were largely successful. Routine ward-based discharge planning, not involving specialist support, was more likely to flounder or fail. Families repeatedly said they had not been involved early in planning for discharge as outlined in the hospital's 'Let's Get You Home' policy. Proper application of this policy could improve patients' experiences and assist families.

3. **Consideration needs to be made around the appropriateness of terminally ill patients having the same pathway as other patients in ED.**
   Extremely ill patients experienced multiple changes in their care in the week after their discharge, often with readmissions to hospital though the Emergency Department. This was a poor experience for patients and their families, with patients waiting many hours in ED. (Frail older people in ED for 10 hours have a 40% increased chance of dying in 10 days. Brighton and Hove Clinical Commissioning Group, CCG, A&E Delivery Board data.)

4. **Questions were raised around how NHS staff, patients and families understand the role of a hospice.**
   Three people who were considered for a home discharge were eventually admitted to a hospice, two very shortly after going home.

5. **There was confusion for families about what services were available in the community and how they could be accessed.**
   There was little coordination, and uncertainty for families about what they could expect from the NHS. No one had any contact from their GP in the week after their discharge. If GPs are unable to do home visits, then patients and families need other arrangements such as a peripatetic GP or clinician to be appointed.

6. **Interviews with families and patients demonstrated the need for improvement in how they are informed and involved in treatment choices and care at end of their life.**
   When people were not supported by a specialist team there was no evidence of Advanced Care Planning (NHS, 2018). Patients and families did not know about the ReSPECT policy and there was confusion about Do Not Resuscitate (DNR) consent (EOL Care Lead, 2018-2020).

7. **More routine information is needed to access the support that is available.**
   Support for patients and families thinking about options and preparing for end of life is available: the Chaplaincies (NHS Brighton and Sussex University Hospital , 2020), MacMillan (Macmillan, 2020), Martlets Hospice (Martlets, 2020), Doula (Mills, 2020), Death Cafes (Ketuhridaya, 2019). Most people, however, do not

seem to be geared into or signposted to this support unless they are managed by the specialist teams.

8. **Quality standards and agreed policies and practices need to be in place to support 'a good death'.**
All those involved in End of Life Care need to establish a shared understanding of what 'a good death' looks like, including actively involving patients and families, by engaging with them. There are pockets of excellent care which can inform this. This report was written immediately prior to the Covid-19 outbreak therefore systems have changed and some policies and practices, essential in the emergency, may address issues raised in this report. The pandemic has highlighted the need to improve discussions and practice around End of Life Care. A debate was planned for the Brighton and Hove 'Dying Matters' week in May 2020 but this was cancelled due to Covid. An opportunity should be found to reinstate this later in 2020/21.

Recommendations from Healthwatch

1. Greater focus on patients at the end of their life to improve their experience and hospital performance.

2. Increased or improved use of specialist support teams both on End of Life Care and Discharge Planning and a recognition that most discharges of people with terminal care are complex *for the patient and family*.

3. Better information and active early involvement of patients in planning their care and routine inclusion of their families.

Implementation of the 'Let's Get You Home Policy' and practice.

4. Reconsideration of the quality of care that can be given in the Discharge Lounge for patients who are terminally ill and will not be dis- charged in a short time.

5. A review of the practice of readmitting patients through ED within days of hospital discharge and a consideration of a patient fast track continuity plan (rather than the admission being regarded as a new episode of care) to avoid this if their condition deteriorates.

6. Involving patients and families in training programs on End of Life.

7. Open and sensitive discussion of End of Life Care planning and a consideration of revisiting the agenda that would have been addressed in Dying Matters week which was postponed because of Covid.

8. Proactive involvement of GPs, and other primary care and community health services and a review of the communications systems between hospital and general practice.

9. Improved coordination of the services that already exist including those in the voluntary and charitable sectors and chaplaincies.

10. Rapid provision of resources and care where there are gaps to assure 'A Good Send-off'.

Healthwatch would like to thank the hospital staff for being supportive and other staff in the BSUH and members of other organisations who have helped us in this study.

3. Important considerations and implications

3.1 Financial implications: The report suggests that most of its recommendations can be implemented by care providers implementing existing policies and procedures. It is likely therefore that changes to improve care should be achieved within existing resources.

3.2 Equalities considerations: People with protected characteristics and suffering social disadvantage are likely to require and benefit from personalised, enhanced or specialist end of life care. Implementing existing policies and best practice for end of life care and ensuring personalised care will contribute to tackling health inequalities in Brighton and Hove.

3.3 Health and social care implications: The report suggests that for some people, experiencing end of life care, the health and care system does not operate in the co-ordinated and integrated way that might be expected – hospital discharge as '…..an event not a process'. Devising and implementing a joint action plan to address the findings and recommendations of this report will require health and care commissioners and providers to work jointly and in collaboration with service users and their families.

Legal:

There are no legal implications arising from this report

Lawyer consulted: Elizabeth Culbert Date:29/10/2020

Finance:

Please refer to Paragraph 3.1 above. If it is envisaged there may be any financial implications for BHCC and/or providers BHCC Commission these will be referred to at the meeting.

Finance Officer consulted: David Ellis Date:30/10/2020

Equalities:

Please refer to Paragraph 3.2 above

Sustainability:

Please refer to Paragraph 3.2 above.

Health, social care, children's services and public health:

Please refer to Paragraph 3.3 above

Supporting documents and information

Appendix1: Full copy of the 'A good send-off' report see: https://www.healthwatchbrightonandhove.co.uk/report/2020-09-28/%E2%80%9C-good-send-%E2%80%9D-patients%E2%80%99-and-families%E2%80%99-experiences-end-life-care

And….: https://www.healthwatchbrightonandhove.co.uk/sites/healthwatchbrightonandhove.co.uk/files/A%20good%20send%20off%20-%20end%20of%20life%20care%20FINAL%20%281%29.pdf

Appendix 2:
Appendix 3: