



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:	<i>'A Good Send-off'? Patients' and families' Experiences of End of Life Care Report Response, March 2021</i>
Date of Meeting:	23 March 2021
Report of:	Sarah Pearce, Head of Integration / Alex Mancey-Barratt, Clinical Lead, Brighton and Hove CCG / Laura Fernandez-Kayne, Manager, Community Services, Brighton and Hove CCG
Contact:	Sarah Peace
Email:	Sarah.Peace12@nhs.net
Wards Affected:	All

FOR GENERAL RELEASE

Executive Summary

In September 2020 Healthwatch Brighton and Hove published the 'A Good Send-off?' report on experiences of people receiving End of Life care. 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 relatively small sample of patients, many issues emerged.

The report suggested that End of Life care was not found to be a dignified and well-arranged experience for many, and the sensitivity and dignity of individual care planning that was expected was not always provided. Healthwatch's recommendations were accepted in full by the NHS with a pledge to improve the care pathway and correct elements of personal insensitivity and absence of coordinated planning that were found.

Following the initial report Brighton and Hove CCG reviewed the recommendations in conjunction with Brighton and Sussex Hospital Trust (BSUH), Brighton and Hove City Council (BHCC), and Healthwatch and developed a response plan.

Since the publication of the 'A Good Send-off?' report, the Brighton and Hove healthcare system has actively developed support around end of life patients, with a focus on improving personalised care planning and keeping people out of hospital. The impact of the Covid 19 pandemic both in terms of the immediate impact and potential longer-term implications and learning have been central to this ongoing development. These actions also help inform the 'dying well' element of Brighton & Hove Joint Health and Well-being strategy, with further engagement supporting the need to develop End of Life care.



An update on the response to these recommendations is now being presented to the Brighton and Hove Health and Well-being Board at their request.

There has been input into both this paper and the review of actions in response to the Healthwatch report from Brighton and Hove City Council and Brighton and Sussex Hospital Trust as well as Brighton and Hove CCG.

1. Decisions, recommendations and any options

1.1 That the Board notes the update from Brighton and Hove CCG on responding to the Healthwatch report 'A Good Send-off?'

2. Relevant information

2.1 Background

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. The 'A Good Send-off?' report then outlined ten recommendations to the NHS around improving local End of Life care. These recommendations were:

- Greater focus on patients at the end of their life to improve their experience and hospital performance.
- 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.
- Better information and active early involvement of patients in planning their care and routine inclusion of their families. Implementation of the NHS 'Let's Get You Home Policy' and practice.
- 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.
- A review of the practice of readmitting patients through the Emergency Department 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.
- Involving patients and families in training programs on End of Life.
- 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-19.
- Proactive involvement of GPs, and other primary care and community health services and a review of the communications systems between hospital and general practice.
- Improved coordination of the services that already exist including those in the voluntary and charitable sectors and chaplaincies.
- Rapid provision of resources and care where there are gaps to assure 'A Good Send-off'.

Brighton and Hove CCG are committed to ensuring the needs of people of all ages who are at the end of their lives, and those who are bereaved, are recognised, and that there are robust and appropriate systems are in place to take into account people's priorities, preferences and wishes.

Since the publication of the 'A Good Send-off?' report, the Brighton and Hove healthcare system has actively developed support around end of life patients, with a focus on improving personalised care planning and keeping people out of hospital, particularly via the use of the Recommended Summary Plan for Emergency Care and Treatment..

This updated actions has been reviewed by the CCG, in conjunction with BSUH, BHCC, and Healthwatch. We have also consulted with colleagues at the Martlets Hospice and with SCFT (Sussex Community Foundation Trust).

As part of wider Sussex CCG collaboration there are in place monthly meetings with CCG leads for EOL, clinical leads and providers, including both BSUH and local hospices. The impact of the Covid 19 pandemic both in terms of the immediate impact and potential longer term implications and learning have been, and will continue to be, central to these ongoing discussions. Opportunities for joint working and developments are being actively worked on together.

2.2 Recommended Summary Plan for Emergency Care and Treatment (ReSPECT)

A major improvement in local End of Life care has been the development and implementation of ReSPECT. This is a summary of personalised recommendations for a person's clinical care in a future emergency should they not have capacity to make or express choices. It is intended to respect both patient preferences and clinical judgement. Benefits of ReSPECT include putting patients at the centre of their care, ensuring that treatment plans are recorded and available at all times, preventing patients from dying in hospital when they would rather be at home, identifying ceilings of treatment including wishes around resuscitation and goals of care, and ensuring clear and co-ordinated communication of treatment plans to all services. It is, however, noted that ReSPECT does not replace existing care plans, rather complements and provides a summary and a focus on personalised care and admission avoidance.

ReSPECT is now embedded across Brighton and Hove, and information is shared electronically with primary care, ambulance services, and hospices. Centrally the patient retains a hard copy of the most up to date version of the plan so this is available when needed and can be taken with the patient into hospital, clinics etc. as appropriate. The aim of this includes; increased shared decision-making for end of life patients, enabling more people to die at home if that is their preference, and reducing unwanted / unwarranted conveyance from care homes to hospital. Next steps is to develop an electronic interface between primary and secondary care and including any revisions to the ReSPECT process plan as part of discharge planning.

Frailty and End of Life locally commissioned services are also now in place, which support the implementation of personalised care plans for all frailer people and encourages discussion around ReSPECT at an earlier stage.

There have been a variety of educational and training events around ReSPECT, with webinars undertaken in April 2020 and December 2020 and another planned for April 2021. There is now a ReSPECT page on the CCG website, which is accessible to patients and to system partners/providers. This contains information about the ReSPECT process and how it supports patient care. Further Communications packs are being developed including videos and the ReSPECT information leaflets will be available in various languages. The aim of these will be to support the involvement of patients, carers and families and system partners in the use of ReSPECT in practice and in training and education around ReSPECT and its place in End of Life care.

2.3 A&E

There is a focus on admission avoidance for end of life patients, and palliative care consultants are working with primary care to encourage GPs to have conversations directly with staff at the hospital, the benefits of this are better information sharing and understanding of care needs. Part of this work is also to reassure GPs that they are able to give good End of Life care in the hospital if this is what the patient needs.

The CCG have also commissioned step-up beds as part of winter planning and to support admission avoidance. Other Brighton and Hove out-of-hospital services supporting admission avoidance have also seen an increase in end of life patients being referred to their service, enabling more personalised care and a more positive experience for patients.

In addition, the CCG working across Sussex has set-up a mutual aid pathway across Sussex hospices, where in instances of reduced capacity in a local hospice, patients can be conveyed to an out of area hospice rather than hospital. This has increased admission avoidance and the further focus on personalised care for end of life patients.

2.4 Fast-track domiciliary care

The CCG's Continuing Healthcare Team are working to review the way that fast-track domiciliary care packages are provided. This will reduce waiting for care packages in the community and ensure consistency and quality of care delivered.

2.5 Dying Matters Week

In 2020, a Dying Matters week of events and education was planned but had to be cancelled due to Covid-19 restrictions. Similar events are being planned for April 2021, to take place on-line, and will reference the recommendations made in the 'A Good Send-off?' report. This will encourage the sharing of information and learning across the health and social care system as well as with patients, families and carers. This year's Dying Matters focus will be '**a good place to die**'. It is noted that BHCC are involved in arranging local events within Dying Matters week.

2.6 Future Commissioning Intentions

One of the areas that Brighton and Hove CCG would explore the implementation of a centralised End of Life Care coordination Hub (ECHO), which has been successfully piloted in part of West Sussex. This service coordinates End of Life care across all local services and acts as a single point of access for help and advice for patients and families. This aspiration is also a priority for other areas of Sussex and is currently being explored at Sussex ICS level.

Another positive step is that BSUH palliative care teams have developed a case for the extension of specialist palliative care cover to seven days a week in the hospital. This also aligns with work carried out in West Sussex with Western Sussex Hospitals Foundation Trust, and will enable further support and care to end of life patients in BSUH hospitals, particularly at weekends, ensuring a more positive experience of End of Life care and discharge.

Finally, NHSE have developed a regional Palliative and End of Life Network, which will provide an opportunity to bring together expertise and learning across areas. This is still at an early stage.

2.7 Conclusion and Next Steps

The CCG has welcomed this Healthwatch report, and has progressed with actions against the recommendations made, over the past six months. Although the need to

support the local Covid-19 response has taken a priority across the local health and social care partnership, this has led to a further highlighting of the need for more personalised and joined-up End of Life care.

The CCG will continue to regularly review this actions, and work together with BSUH and Healthwatch, with a further update to the Health and Well-being Board if requested.

3. Important considerations and implications

Legal: There are no legal implications to raise in relation to this report which is the Board to note.

Lawyer consulted: Elizabeth Culbert Date: 12 March 2021

Finance: The seven-day palliative care business case from BSUH would require funding decisions, and at present funding is expected to be contained within BSUH's Aligned Incentive Contract funding allocation. Discussions have taken place with the CCG's contracting team in respect of the governance around this proposed service.

Finance Officer consulted: N/A(Sophie Warburton) Date: 12 March 2021

Supporting documents and information

Appendix A: The '*A Good Send-off?*' Report can be found [here](#).

