

“A good send-off?”

**Patients’ and families’
experiences of End of Life Care**





This report has been delayed in publication by the COVID 19 response. Healthwatch pays tribute to the magnificent work of the NHS and key workers who have put themselves in harm's way to benefit and protect us all.

The study was undertaken before COVID 19 hit our City and the challenges of End of Life Care have been thrown into even sharper focus by the impact of the virus. In this report, many discharges did not work for the patient and since writing, the criteria and processes for discharge have changed and will make End of Life Care support even more important. As the NHS enters a period of restoration and recovery, there are lessons in this report for reforming and improving the service.

This report is therefore offered in a spirit of mutual learning and for the 15 people and their families who shared their End of Life Care experiences with us, most of whom have now died.

**David Liley, Chief Officer,
Healthwatch Brighton and Hove
September 2020**



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**“A Good Send-off?”
Patients’ and Families’ Experiences
of End of Life Care- for discussion**

**Response to Healthwatch Brighton and Hove’s report into experiences
of End of Life Care by patients and their families**



We would like to thank Healthwatch for this report and recognise the sensitivity and importance of the discussions held with patients and their loved ones at such a difficult time.

We welcome this report and accept that all of the recommendations are appropriate and reasonable.

We 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 in place to take into account people's priorities, preferences and wishes

The Covid-19 pandemic has accelerated roll out of the ReSPECT tool, with it becoming a much more inclusive and responsive form of care planning summary than DNACPR alone. This means that there have been great improvements in the developing and sharing of End of Life care plans, supported by a number of ongoing educational events including a webinar planned for GPs next month.

We have drawn out some of the recommendations in the report and provided responses with additional information, which we feel are relevant and provide a full picture of the service provision:

In order to consolidate this learning and to further address your recommendations, the CCG End of Life GP lead and the End of Life lead consultant within BSUH will be meeting with the BSUH Chief Nurse later this month to build on the good examples of sharing of practice that are already happening.

The recommendation that the CCG GP membership undertake follow up in patients’ homes is a reasonable expectation and is usually a standard event. Even in the current circumstances of reduced home visiting, these visits can still occur and our GPs have access to the Roving GP service (with a lot of expertise in End of Life care and planning) if the patient’s own GP is unable to visit.

We entirely agree with the recommendation that a pathway for (re)admission of End of Life care should avoid hospital Emergency Departments as far as possible, and we have seen the better outcomes that can be achieved by a call from primary care to the hospital End of Life team to explain the situation before the person arrives. The CCG is actively using Healthwatch’s previous work on “Evaluation of Brighton and Hove’s Equipment and Adaptations service” (April 2017) to support the rapid provision of resources and care. Satisfaction levels for the overall service were very high with





positive feedback on the various aspects of the service including assessment, the suitability of equipment selected, and delivery and installation. We plan to revisit this report within the coming weeks with NRS and include focus on the new discharge feedback from your report with them.

The CCG's Continuing Healthcare Team are in the process of setting up an agreement with Martlet's Care to manage Fast Track domiciliary care packages. This will help ensure all have access to specialised service and speed up discharge from hospital and are progressing to set this up by winter.

Again, we would like to thank Healthwatch for this valuable insight and would welcome the opportunity for a continued dialogue in order to ensure the best quality of care and support at the end of life.

Lola Banjoko, Managing Director, Brighton and Hove, NHS, Clinical Commissioning Group, 3 September 2020



We welcome this report and its findings and appreciate the sensitive work Healthwatch has carried out to understand more about the experiences of patients and their loved ones at such a difficult time.

We are committed to providing the very best possible end of life care for our patients and to supporting their families and carers through their bereavement. This report highlights the challenges we face in doing so and particularly the need for communities and health partners to work together to ensure that every person's wishes are respected and acted upon as they approach the end of their life.

We have reviewed the report and delivered an action plan based upon its conclusions and recommendations.

In particular, we agree entirely that an acute hospital is not the place where people wish to spend their final days. Unfortunately, the sad reality is still that 40% of all deaths in the UK occur in hospital. We are committed to working with our community partners to do all we can to reduce that figure locally, focusing primarily on reducing delays in discharging patients to other, more appropriate settings and developing governance structures to provide assurance that this is happening.

It is important also to recognise that the conditions affecting many patients in the final phase of their life leave them vulnerable to requiring hospital readmission. Again, we agree that Accident & Emergency departments are not the right place for these patients to be for extended periods and we are working to minimise the time they wait for both assessment and treatment or admission.

Finally, we would like to thank Healthwatch once again for their work on the experiences of end of life patients and their loved ones, and for their support of our efforts to provide the best possible care for them.

Anne Middleton, Chief Nurse, Brighton and Sussex University Hospitals NHS Trust, 23 September 2020



Healthwatch: key findings

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 through 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.

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.

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 discharged 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'.

A good send-off? - Patients' and families' experiences of End of Life Care

Methodology

Healthwatch carried out an exploratory study on the Courtyard Ward (oncology/cancer) at the Royal Sussex County Hospital (RSCH) between November 2019 and January 2020. We talked to 15 people and their families in hospital who staff had identified as being ready for discharge. This was a discharge to their own home or sometimes to another community setting, for example a care home, nursing home or hospice. The focus of the study was to find out how the discharge had worked for the patients and families and to obtain feedback about what happened to them outside the hospital settings. Our research questions were: did discharge and support arrangements work for people and their families? how might that process be improved?

Most people were followed up at home. Three people died before they could be discharged. One patient had severe mental health problems and it was difficult to interview him. We were unable to contact three people. Two patients remained on the ward. One homeless man of 37 years had not been discharged as a place could not be found to manage his condition and he had been in hospital for 9 weeks. Some patients or their families were interviewed multiple times. Most patients had been in and out of hospital on numerous occasions before and during the study; the majority have since died. The interviews were carried out by trained Healthwatch volunteers.

The people we interviewed were extremely ill and were mostly in the last stages of their illness. Patients' conditions were rapidly changing and clinical care, support needs, personal and family situations were complex, for both practical and emotional aspects of care and support. Most of these people were leaving hospital facing the prospect of the end stage of their life, not recovery. Most people we interviewed, and most people generally, expressed a preference to die at home, but data shows only 25% achieved this (Brighton and Hove Clinical Commissioning Group, 2019-2030, p. 8). We were interested to find out why this was the case.

A major challenge in End of Life Care and support is how to make the last few weeks and days of a person's life as comfortable as possible with the best care, support, and comfort available to enable patients to have a 'good death'. One bereaved wife (of two days) described giving her husband a 'good send-off' with herself holding his hand, her children, and grandchildren around the bed and 'kind and considerate staff'. This positive memory enabled this wife to concentrate on a fulfilled and happy family life with him, and even in the presence of death to celebrate his life. This man was desperate to go home, but his health deteriorated and despite the fact he died in a hospital ward, he still had a good death.

What patients and families told Healthwatch

Discharge arrangements

‘Let’s Get you Home’

1.1 Brighton and Sussex University Hospital Trust (BSUH) has been part of an initiative called ‘Let’s Get you Home’ since 2018. The concept of this policy is that patients and families who are hospitalised should have a discussion shortly after their admission about the process of going home as soon as it is clinically appropriate (NHS, 2018). There are posters across the hospital outlining this approach. The evidence shows that being in hospital longer than necessary adversely affects patients: health can deteriorate, and they ‘decondition’ - become weaker (NHS, 2018). In this study, we saw little evidence that this discharge policy was embedded in practice. Patients and families said they had not been talked to at an early stage about discharge needs, even though most people had been in hospital a long time and often repeatedly over the previous months. One family member who was upset about the way her relative had been discharged asked us whether the hospital *had* a discharge policy.

1.2 The observation that this discharge policy is not being implemented has already been made in a report written in February 2019 by Healthwatch called “‘Let’s Get You Home’: Hospital Discharge for older people” (Kay & Liley, 2019).

1.3 Since doing this study, we understand that a systems discharge group has been sitting at the BSUH and a rolling program of mandatory training was about to take place, pre-COVID, involving all staff, not just in the hospital but in the community. This is welcomed, but Healthwatch suggests that views of patients and families must be fundamentally incorporated into this training. Our study shows that the views of different parties vary and that all aspects will need to be considered for ‘a good discharge’. It is also our understanding that a ‘Let’s Get You Home’ discharge booklet has now been printed and is available. The impact of COVID 19 on this aspect of hospital discharge is not clear and is an issue that Healthwatch are working on closely with the NHS (Liley, NHS Reset: What we have learned about hospital discharge amid the COVID-19 pandemic, 2020).

Changing discharge plans

1.4 Discharge appears to be viewed as an event in the hospital system not a process. Whatever changes are made in care plans, patients at the end of their life should not be summarily discharged from hospital without full consultation with the patient and family and plans made for their care at home. Families reported frequently changing discharge plans. We recognise this could be because of changing clinical needs, or limited options for discharge but for some people this was very disconcerting. A young woman with two small children had had a very comprehensive package of care set up, including equipment, and intensive social care arrangements. This involved the whole extended family being mobilised as a support team. The date of her discharge was delayed causing much family disruption and stress. Another patient and his family were assured categorically that discharge was not imminent. The relative visited the next day to find his bed empty: she was shocked and ‘feared the worst’. She searched around and found him in the discharge lounge, packed up at

short notice and ready for transport home. There was no time for planning and no time to mobilise family support, which created a sense of confusion surrounding already complex relationships. There are a lot of emotions going on with families when someone is at the end of their life and these changes, which to them seem unexplained, cause great anxiety.

The Discharge Lounge

1.5 Two extremely ill people sat for 4-6 hours in the discharge lounge where they felt uncomfortable (both were readmitted within days). There is pressure on wards to discharge patients before noon as new patients are waiting for admission. This means that often patients need to wait for their supply of medication to be sorted out, something that that could be arranged in advance. It is questionable whether moving around some patients who are very ill within the hospital is good patient care. The criteria for 'long term parking' some extremely ill people to the discharge lounge needs revisiting.

Revolving door

1.6 Some patients were discharged into a situation that immediately broke down and were readmitted to hospital within days, having to spend hours in the Emergency Department. One person had two failed discharges over a weekend and had at least seven different care contexts in less than a week. Another patient had six failed discharges in less than a week and was still in hospital (on a respiratory ward) awaiting a nursing home place during the latter period of this study.

Case study 1

D had blood in his urine a few days after discharge and paid carers phoned for an ambulance. They waited 2 hours. In RSCH Emergency Department (ED) he was assessed to be transferred to the Princess Royal Hospital in Haywards Heath. He was put in a side ward in ED, sitting uncomfortably in a chair. It took 9 hours to arrive at the PRH. D was paralysed from the waist down.

Case study 2

S was discharged from hospital to intermediate care where he became ill within days and was admitted to ED. He waited for hours and then spent time in the Acute Assessment Unit before being admitted to a respiratory ward, where he stayed over 30 days. He was very ill on his first discharge. He had been in 7 care settings in a month. Prior to this discharge he had been in hospital three times in 10 weeks, all admitted through the emergency department. S, at the time of interview, had a short time to live.

This was S's end of life journey.

Day 1 Discharged from the oncology ward to the discharge lounge for 3 hours. Transported to an Intermediate Care Home

Day 3 Referred by visiting GP back to the emergency department and was there for 7 hours; and reported by a relative to have been 'somewhere' in ED overnight

Day 4 Admitted to Acute Assessment Unit at the Royal Sussex County Hospital

Day 5 Admitted to a Respiratory Ward

Day 17 Still on the Respiratory Ward

Day 20 Case conference postponed

Day 23 Case conference was held and determined that S needed a nursing home place. This required approval for 'continuing care funding'

Day 34 S was hoping to be transferred to a nursing home 'in a couple of days', but was still in hospital the last time they were interviewed by the Healthwatch team. S and his family had been interviewed several times by our volunteers.

Support at home in the community

2.1 We found that the care packages that were provided at home with the involvement of the specialist hospital discharge teams were carefully planned and worked well for people.

2.2 What the hospital might consider a “straightforward” or “simple” discharge (small pieces of equipment, rails, small amounts of care support), did not go so well. Equipment was sometimes slow in arriving, leaving people feeling unsafe or unable to move from one place to another.

Case study 3

A week after discharge N was still waiting for a hoist, without which she could not sit in a wheelchair, and the wheelchair had not been delivered. N was a younger woman with teenage children, she was paralysed from the waist down.

2.3 Not everyone knew who to contact in an emergency. B however, had been given a bright red sheet with direct numbers to contact. Clearly there is a system, but not everyone discharged is clear about it.

2.4 Two people we talked to had effectively got no fixed abode. Both were terminally ill with cancers. They were younger (30s and 40s). It was difficult to find an appropriate place for them to be discharged to as they did not fit into the profile for most nursing homes or Craven Vale but were not able to look after themselves. One person’s condition deteriorated during the study and he was admitted to Martlets Hospice, which was seen as appropriate by him and his family. The other person was still in a hospital ward - ‘super stranded’ after 3 months and needed specialist facilities but not hospice care. A suitable care setting was difficult to find.

2.5 None of the patients who were discharged home, without specialist team support, had been contacted by their GP. This was irrespective of their clinical need, or the volatility of their health, social or housing situation. We question why there appears to be no proactive contact by the GP practice or Community Health Care services: whether the system of discharge letters to GPs is working for these patients; whether appropriate flagging of the end of life nature and severity of people’s illness is clear. People who are discharged without the appropriate support often experience personal and family distress, and it means that extremely ill people suffer in silence trying ‘not to make a fuss or bother the doctors and nurses. The need for extra help is finite and could be provided at low additional cost.

Case study 4

The family felt that F could have been assessed before discharge and a lot of home support could have been in place in advance. The equipment that was provided was not suitable for a small house and therefore was dangerous. The family did not find any discharge plan when F came home, so did not know who to contact about problems. They were not provided with a list of F's medication and when paramedics arrived after he fell on arrival at home, they did not have all his details. The family had no idea how many carers and professionals would be coming to the house and when they would visit.

Anticipation of which discharges are risky and likely to fail needs to be part of the discharge process and information on risk and contingencies needs to be available for the families. F did want to go home, but his physical condition and family situation indicated that there was a high risk of home care failure. There was another severely disabled person at home, family care was not available, and a care package not already in place. F fell 4 hours after discharge and was readmitted to hospital through ED. He was discharged 3 days later and admitted to Martlets Hospice for palliative care within a few days of arriving home.

Some people we interviewed did not know what care services would be set up when they were discharged. The delay and uncertainty around having a package of care in place at home on discharge often seem to have contributed to further health breakdown and hospital readmission.

2.6 In at least one case, no one knew who to contact when they needed help - and had phoned 999 when they did have a health problem.

2.7 People told us that Community Nurses and District Nurses appeared to be the only health professionals available to support them at home. They attended to change wound dressings, and in one case the Palliative Care team assisted a patient by phone. However, they were not always in attendance. The links and relationships between community nurses, specialist nurses and how they relate to their GP surgery was not clear to families. There seemed to be a 'remote' approach to supporting people by phone and apart from families and paid carers, people at the very end of their life were not routinely seen at home by other professionals.

Case study 5

At 10 am K arrived home to an empty home, except for the cat. “They just dumped me at home, all food had ‘gone off’ in the fridge”. K rang carers who arrived at 1.45pm. A food parcel arrived later in day but until then K had no food. ‘I was exhausted, just struggling to keep alive’. K required a small care package to be reinstated and medications from the GP. The surgery never made contact. K was admitted to a hospice a short time later and died.

2.8 Paid home carers were the most present people in people’s homes and were highly commended. N said, “They are amazing, helpful, jolly, friendly and lovely”. Nevertheless, it was not always clear what home care agency was providing the service and what duties they were expected to perform.

2.9 Most patients and their carers understood medication management, though in one case, the family told us a person was sent home without adequate pain management.

2.10 Nutrition was an issue for some patients. One person who had oesophageal problems was discharged home without any dietary advice and the family did not know what he could eat. The same person was subsequently admitted to the Royal Sussex County Hospital Emergency Department, where he spent 6 hours without a drink and having no voice was unable to call out. No one checked on him or offered him a cup of water.

Support for the family

3.1 Most patients had daily visits in hospital from their family, but support often fell mainly on one member of the family. Healthwatch found that our follow up gave the main carer a chance to talk and they appreciated our concern and interest for their challenges and issues.

3.2 Some family members were fully engaged in care planning and the discharge arrangements, but others where there appeared to be comparable needs felt they were not adequately consulted about the person coming home or did not have the complexity of *their own* situation taken into account. In End of Life Care the abilities and capabilities of families will always need to be considered and support for the patient or the family may need to be enhanced.

3.3 Examples include a patient in his late 70s discharged home on a Friday to his older wife who was bent double with spinal disease and his daughter who was returning back to paid work on the Monday, with no care package or equipment in place on discharge, and not provided over a weekend.

3.4 Hospital discharge, with an End of Life prognosis, may need different psychological, practical, and emotional support. This should be considered routinely as part of the discharge process. Discharge is not just sending people from one place to another. For many, it is a major life changing event.

3.5 Some patients need a different or adapted approach to D2A and other discharge processes. The current model is to discharge people home and do most of the assessment after the person returns home: 'Discharge to Assess' or D2A (Department of Health , p. 2). Although this is appropriate for many patients, it is questionable with some of these extremely ill patients whether this works. The patient and family need most of the care and support package to be in place on the patient's return, not afterwards, to give them confidence they can manage. Until it can be guaranteed that home services can be put in place as soon as someone returns home, discharge of people who are in the last few days or weeks of their life should be classified as complex, unless otherwise indicated and services put in place in advance with levels of assurance to families that this will happen.

3.6 Some families had already experienced what they considered a 'failed' discharge and they were understandably more concerned about having the patient back home again. This gives a greater impetus to getting it right the first time. In three cases, the patient returned to hospital in days, one person was back in hospital on the same day as being discharged. This patient entered back through the ED, creating distress for the patient and family and pressure on ambulance and hospital services.

3.7 There was little evidence of people's spiritual or emotional needs being addressed, even though there are chaplaincy services available in the hospital.

Choices at the End of Life

4.1 Several patients and families told us the prognosis was not made clear to them. Most patients appeared to follow the 'doctor's advice' rather than making any active choice in treatment options. It is possible that discussions had taken place, but in a way that patients found it difficult to absorb. Difficult information needs to be repeated, sometimes backed up with written information as well as having consistent messages from all staff. Only one patient talked openly about being at the end of his life with only a short time left.

4.2 Many patients had unrealistic and over-optimistic expectations about their prognosis and of what they could do and manage if discharged home. This sometimes differed from the expectations of the families that would be looking after them. One man who was very ill and had serious mobility problems thought he would be out of hospital and driving his car shortly afterwards, even though he could only walk a few

feet with a stick. Another who thought he would be driving days after his discharge, died within days of our interview.

4.3 The lack of clarity in the language and meaning of ‘terminal care’, ‘end of life care’ and ‘palliative care’ seems to be getting in the way of people’s understanding of their condition, their prognosis and what care and support they need and can expect and whether they need to pay for it.

4.4 For example, one man had been designated ‘End of Life Care’ by clinicians, with a year to live but the family were not told. This designation not only affected the patient and family and their understanding of all of their lives but also whether they would have to pay for care. In fact, he was ‘fast tracked’ to NHS end of life care funding. It was only when he was ‘fast tracked’ for NHS continuing care funding that the person and their family had confirmation that he had little time to live.

4.5 There was confusion regarding ‘do not resuscitate’ - DNRs (Compassion in Dying. Supporting Your Choices, 2018). One patient was sent home with a DNR form that his family did not know he had signed even though they visited the hospital daily. They had not been involved in any way and were upset and shocked when it was the first thing they saw when his bag was unpacked. We did not see any evidence of ReSPECT forms (Resuscitation Council (UK), 2014), or of Advanced Care Plans being in place. Patients and families did not know what we were talking about when we asked about ReSPECT forms and advance care plans. Hospital notes may have included these forms but there was no evidence that patients and families had been informed or involved in drawing them up.

Discussion and good practice points

The people we interviewed have the exact profile of high users of the NHS:

- They are admitted to the Emergency Department and wait over 4 hours.
- They are moved around the Emergency Department and often wait over 12 hours for a hospital bed.
- When they are admitted, they frequently stay on wards for long periods. They are the ‘stranded’ and ‘super-stranded’ patients: those who are in hospital for longer than a week or three weeks respectively.
- They are in and out of hospital over short periods of time.
- Their discharge is often delayed because of difficulties getting care packages together and the patient’s changing clinical condition.
- They are high users of the ambulance service and they are frequently admitted and readmitted through ED where the whole process starts all over again.

In the community, it is unclear to people who coordinates services. The apparent lack of GP involvement is concerning particularly if coordination cannot be done from GP surgeries, and home visits are not available. Most of the people we saw could either not walk, or not walk far.

We started this study with two questions:

“...what have been the experiences of people, and their families, when discharged from hospital towards the end of their life”? and

“... how can we improve the end of life care process when people are being discharged from hospital care”?

The proportion of people who die at home in Brighton and Hove is better than the average for England, with almost half of all deaths, 49% in 2017, happened within people’s usual place of residence, compared to 40% in 2006 (Brighton and Hove Health and Wellbeing Strategy 2019-30, p 8). Because personal circumstances are often complex and clinical conditions change, often rapidly, it is inevitable, and frequently appropriate, that people will die in hospital and other care settings, not their usual place of residence. In other instances, families may not be able to cope with the practical complexities of caring for a dying person without assured support.

Our study suggests that personal and family preferences and expectations should be taken into consideration as a central issue in the discharge plans for patients in the last few weeks of their life. Every family situation is unique, and often complex, even if the discharge arrangements seem routine, simple, and straightforward to NHS staff and other service providers. Discharge arranged through the hospital discharge team supported by specialists seems to provide better outcomes for people, even in the context of complex clinical and family needs.

The policy of partly assessing discharge needs in hospital and completed when the person goes home (Discharge to Assess - D2A) may not be appropriate for some terminally ill patients. For example, if they require equipment and adaptations to be in place on, or before discharge. Particularly if securing these supports is an uncertain process liable to delays.

Patients with terminal care needs, and their families, should not be left without clear advice about who to contact when concerns arise, and about what support might be expected. Those people who were under the care of specialist services, such as the BSUH Palliative Care Team or the Martlets Hospice were linked into care systems to support end of life and tended to have a better experience.

It should be clear who in a multi-disciplinary team has the responsibility to discuss with people and their family what sort of death they want, including Advance Care Planning and Do not Resuscitate preferences and expectations. These discussions should be held as early in the End of Life Care process as possible and should be open, frank and dignified. Planning end of life care needs to be an inclusive and empowering process, to involve informed conversations, with patients and families. The RESPECT policies appear not to be embedded in the hospital discharge process, and more work is required to understand how these policies improve patient experience, and their understanding of what options are available when they are dying. Consistent and thorough implementation of the “Let’s Get you Home” policy is needed.

The amount of churn and movement for patients in the last period of their life is concerning. If an objective of end of life care is to make people comfortable and pain free our study suggests that this objective is not being routinely achieved. People facing the end of their life need to be treated with dignity and, if possible, a sense of calm and peace. Families need to be assured that everything has been done for their relative at the end of their life: that is what **they** call 'A Good Send-off.

Report authors:

Fran McCabe, Chair, Healthwatch Brighton and Hove

Christine d’Cruz, Director, Healthwatch Brighton and Hove

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How to contact Healthwatch

Healthwatch Brighton and Hove:

Healthwatch Brighton and Hove
Community Base
113 Queens Road,
Brighton
BN1 3XG



Share your experiences of health and social care services with us:

- office@healthwatchbrightonandhove.co.uk
- 01273 234040
- @healthwatchbrightonandhove
- @HealthwatchBH
- healthwatchbh

Website: www.healthwatchbrightonandhove.co.uk