Patient Engagement at Mount Vernon Cancer Centre

11 October 2018

Introduction

Who we are

Healthwatch Hillingdon is an independent health and social care watchdog. We are here to help our residents get the best out of their health and care services; and give them a voice to influence and challenge how health and care services are provided throughout Hillingdon.

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Background Information

In June 2018, the inpatient services that were being provided by East and North Hertfordshire NHS Trust, in The Michael Sobell Hospice, were relocated to the nearby Mount Vernon Cancer Centre.

This interim measure remains in place whilst the NHS and other partners consider the options for palliative care provision, for the north of Hillingdon and the surrounding area.

As a result of this change, Healthwatch Hillingdon approached East and North Hertfordshire Trust and asked if they could speak to the patients on these wards, to see how the change may have affected patient experience.

We would like to sincerely thanks the patients and their family who spoke to us, and East and North Hertfordshire Trust for giving us the opportunity to visit wards 10 and 11.

Mount Vernon Cancer Centre

The Centre is a highly specialised cancer centre providing technical treatments and patient care in non-surgical oncology. The Centre has specialist cancer consultants, who are supported by a team of doctors in their outpatient clinics and on the wards. Nurses deliver chemotherapy treatments and radiographers deliver radiotherapy treatments all supported by teams of physicists, administration staff and engineers.

Hospice Care

The aim of hospice care is to improve the lives of people who have an incurable illness.

Hospices provide care for people from the point at which their illness is diagnosed as terminal to the end of their life, however long that may be.

That doesn't mean hospice care needs to be continuous. People sometimes like to take a break from hospice care if their condition has become stable and they are feeling well.

Hospice care places a high value on dignity, respect and the wishes of the person who is ill. It aims to look after all their medical, emotional, social, practical, psychological, and spiritual needs, and the needs of the person's family and carers. Looking after all these aspects is often referred to as "holistic care".

Care also extends to those who are close to the patient, as well as into the bereavement period after the patient has died. **(NHS.UK)**

Engagement

Our Aim

To gather the experience of palliative and cancer patient care on the hospital ward setting, and how this may differ from hospice care.

Our Methodology

We visited Wards 10 and 11 of the Mount Vernon Cancer Centre and spoke to some of the current patients. We asked them three questions as part of that conversation, to gain an understanding of the care being received by these patients.

The questions were:

1. What are the positive things about your care?
2. What could be done to improve the service?
3. If there was one thing that would improve care for you personally, what would it be?

Our Visit

The Deputy Head of Nursing met us at the start of our visit giving us the context and background of how wards 10 and 11 became the place of care for the re-location of patients from the Michael Sobel hospice.

They explained how initially all the staff had transferred across with the patients but over time many had left. She explained how the building of Michael Sobel House was in terrible disrepair with some patients having to be regularly moved when it rained as the ceilings leaked in several places despite repeated repairs. They advised that none of the patients who had moved from the hospice were currently on wards 10 and 11.

On the day we visited, the Ward Sister showed us to patients who were able to speak with us. There were 25 inpatients but due to treatments taking place and those with confusion, we were able to speak with 8 patients. We also spoke to the family of an end of life patient.

Our conversations

Patient 1 - age 87 from L.B. Hillingdon. Very bright and articulate. A palliative care patient in ward 10 for 2 weeks to date. Patient 1 was on the open ward.

Response to questions:

(1) "Everyone is very helpful, they are marvellous, even the cleaners are all kind and friendly"

(2) "I can't think of anything that would improve the care, the food is good even.

(3) "My own TV would be good. There is a sitting room with a big TV, but I would like to have my own one like they have in Hillingdon [hospital]. I would like an ice cream parlour"

During the conversation they explained how they had been a teaching assistant for many years at a school after they had raised their own family. They seemed happy and contented. When asked about their pain they explained that their condition was being managed very well on the ward and they were happy. Patient 1 was expecting to go home in the next day or so.

Patient 2 - age 47 from Hertfordshire. Despite high doses of morphine they were articulate and engaging but clearly very unwell. Patient 2 is a palliative care patient with oesophageal, liver and lung cancer and is hoping to go to the Peace Hospice in the next day or two. They were in a side room where they had been for a week.

Response to questions:

(1) "The staff are lovely, the care is great"

(2) "The wi-fi is terrible here, that's the only thing I would change"

(3) "I would like to look out on gardens and a better view"

During our conversation Patient 2 told us that they had been in the Peace Hospice before. When I asked what the difference was between the hospice and ward 10 they said they were much the same, although the hospice probably had a greater breakfast choice, not that they wanted to eat anything now. They told us they had three children under 14. Their spouse didn't drive so the family hadn't been to see them for some time, but they explained that was partly their wish as they didn't want the family to see them so thin and poorly. They did say that the family were coming tomorrow as they 'selfishly' wanted to see them.

They told us they had been a tree surgeon and when asked told us their favourite tree was a cypress tree, as they are ‘majestic’. They said they had tried to interest their children in trees, but they only liked food related interests. They told us about their career in the military and their cancer journey and how now they just wanted to go to the hospice to die. We asked why they wanted to go to the hospice again. They just said that they thought it would be more relaxing. We asked how it would be more relaxing and they just laughed and said all they do is just lie on the bed, so it probably couldn’t be any more relaxing, but thought it might give more individualised care. They couldn’t say what form this would take.

They said they were very happy with the care received on ward 10, and that their pain was managed well, but they were just very tired. They thanked us for our time.

Patient 3 - age 69 from L.B. Hillingdon. A palliative care patient on the open ward with primary stomach cancer. Patient 3 had been there for 3 days.

Patient 3 has had cancer for 10 years but explained to us that they had been given 2 months to live now.

Response to questions:

(1) “They look after you very well, you don’t want for anything, you don’t have to worry about anything. If you want anything, they are there. The staff here are wonderful. I was in Hillingdon [hospital] and had terrible diarrhoea and sickness and they couldn’t stop it for days, and then I came here, and they fixed it in a day”

(2) “The day centre needs a lot of improvement, they give you a Caesar salad or a sandwich, I want something hot, so I take a cuppa soup when I have to go there. They were going to have a BBQ, but it got cancelled, which is such a shame. It used to be so good there, my Mum died there, and they used to give them sherry when they wanted it. Here is good, although they seem to have stopped the hot drinks at 8/9pm and you need a hot drink to go to sleep, so that could be improved”

(3) “Individual TVs would be good as there’s nothing to do, and fans, they need more fans”

Patient 3 was due to go home. They were happy and said their condition and pain had been managed well. They couldn’t speak more highly of the staff.

Patient 4 - age 47, a palliative care patient from Harrow with a brain tumour. They had been in a side room for 4 weeks. When we interviewed them, they were with their spouse who had been taking care of the home and their two children.

Response to questions:

(1) “The pain is managed well here. They are all very nice and I am pleased with the care”

(2) “Sometimes the bell rings late at night, other patients and I can hear it and it goes on for a long time, that’s annoying”

(3) “I have a TV in my side room but it’s not working”

Patient 4 was pleased with the care they had received but was anxious and so we didn’t stay with them long. They were excited and apprehensive about going home. They were looking forward to their own bed.

Patient 5 - aged 55 non-palliative. Patient 5 is from Maidstone and is on ward 11 for treatment for their vulva cancer. They were diagnosed with cancer in August 2017 and has since had radiotherapy.

(1) “Everyone is so lovely, they couldn’t be kinder. The food is good.”

(2) “I can’t think of anything”

(3) “Oh, they should maybe have a rule on the use of mobile phones as last night a lady down the end was on their phone talking loudly for 2 hours which got on all our nerves.”

Patient 5 chatted about how they had been a few times to their GP when they had discovered a pea shaped lump in their vulva. It had been dismissed as a harmless cyst without any investigation. The tumour has now broken out and the cancer is in their lymph nodes. They feel angry that precious time has been wasted. They now want to make it to their 21-year-old daughter’s wedding in 2020. They said they would be happy, if necessary, to come back to the Mount Vernon Cancer Centre, as the care has been excellent.

Patient 6 - aged 52 from L.B. Hillingdon Harefield on ward 10.

Patient 6 has been in for 4 days. They have throat, jaw, chest and lung cancer and has been living with cancer for 6-8 years. They were hoping to go home today or tomorrow. In the last day a large swelling has appeared on their left jaw.

Response to questions:

(1) “I can’t find any fault with this place, they are all great. They do anything they can to make it better for you. They manage my pain well, I only ever get slight pain. I’m on morphine and paracetamol and it works”

(2) “I need to take my machine home with us [nebulizer] but I’ve been told they aren’t free any more and I have to pay for it, I’m not happy about that”

(3) “Personal TVs would be good. A machine was bleeping last night that drove us mad and the orderly was down the end asleep! So, they didn’t do anything about it.”

Patient 6 seemed very contented. They said they felt well, and well cared for. They were happy reading and doing their puzzles. They said the food looked good, but they couldn't eat now anyway. They said they would recommend the hospital to anyone.

Patient 7 - age 80 from Sussex. Patient 7 has been living with prostate cancer for 12 years and was on ward 11 for Brachy treatment. They had been in the hospital for 3 days.

Response to questions:

(1) "Conditions here are marvellous, the care is great. Everyone is very professional, kind and just how you would want them to be."

(2) "The plug sockets are up high so can be difficult to reach"

(3) "Can't think of anything that would be better, it's been great"

Patient 7 seemed very well, very articulate and was full of praise for the care they had received.

Patient 8 - age 49 palliative care/end of life from Hertfordshire.
Patient 8 was heavily sedated in a side room when we approached a family member who was sat with them. Almost immediately the rest of the family came into the room to maintain their round the clock vigil. They explained that the care had been excellent. They had been in the room since last Sunday (5 days).

Response to questions:

(1) "The care has been excellent. The staff are all really kind"

(2) "Patient 8 keeps slipping down the bed and I [patient's brother] have to keep putting my arm as a barrier so that they can push their feet against it to move into a more comfortable position."

(3) "It's lovely here but we want a homelier environment for him, somewhere where they can get personalised care".

Patient 8's sister-in-law explained that they had been told by a hospice that they could give them drugs that a hospital couldn't give them and therefore they were going to move Patient 8 into the Peace Hospice in Watford, as soon as a bed was free.

Post engagement review

After speaking with the patients, we met again with the Deputy Head of Nursing at the Centre to discuss the areas patients and their families had raised.

It was explained that it is a myth that hospices can give different drugs from a hospital.

They said they hadn't met a patient yet that was opting to die on ward 10 or 11. All patients were given an explanation about their options and each patient is asked about their preferred place of death. Around 60% say home, 20% a hospice and 20% a nursing home.

Supplementary care was available. Referrals are made to the Lynda Jackson Macmillan Centre, for support with pre-bereavement and phycological counselling, and therapists attend patients for Reiki, relaxation techniques and other complimentary therapies.

We asked about hot drinks at night. This was a surprise, as it is normal practice for nurses to give patients their medication, settle them in bed and provide give them a drink.

We discussed the issue raised by Patient 6 about their 'machine' and the Deputy Head of Nursing said they would get back to us.

[The day after our visit they contacted us to advise that the machine referenced by Patient 6 was a nebuliser, which patients do have to pay for themselves. However, the Head and Neck Cancer Macmillan Team had used their charity funds to pay for Patient 6's nebuliser and their nurse specialist was organising this for them.]

The Deputy Head of Nursing also thought it was a good idea to have sponge filled supports available for patients to help them to push themselves up on their beds.

They also said how anxious the staff were, to have their dedication and commitment questioned, amidst all the politics and bad press that they unjustifiably seemed to be getting, following the closure of the hospice.

Summary

Our researcher found the Mount Vernon Cancer Centre environment to be clean, spacious, respectful, and bright. All the patients they spoke to were happy on the ward. Patients were very pleased with the management of their symptoms, they were comfortable, and were receiving excellent care - that was being delivered with kindness and empathy.

When asked about how their experience could be improved, patients mainly gave personal reasons, such as wanting garden views, a hot drink before bed, the use of individual TVs and a desire for an ice cream parlour. None of the points raised by patients related to their treatment, or care.

Patients also mentioned some areas relating to the care environment. These included, wi-fi connectivity, a TV not working, and more fans required. There was also a specific reference by 3 patients of being disturbed at night, by ringing bells, bleeping machines, and other distractions.

Most of these issues require individual attention. Healthwatch Hillingdon would however ask the Trust to consider what action could be taken to address the reduction of noise at night. As a possible solution, we refer the Trust to the NHS quality improvement projects that have already achieved positive outcomes with this issue. https://improvement.nhs.uk/resources/reducing-noise-at-night-on-a-hospital-ward/

Conclusion

Experience of palliative and cancer patient care on the hospital ward setting

Our engagement and the conversations we have had has fully assured Healthwatch Hillingdon that the patients on ward 10 and 11 are receiving excellent, empathetic care and that the medical, and emotional needs of the patients we interviewed are being met.

How this may differ from hospice care.

During our research, we met 1 patient and family members of a patient who had chosen to go to the Peace Hospice to live out the last days of their life. These individuals said that for them the ward setting is not as homely as a hospice, and that they believe the care they would receive in a hospice would be more personalised.

We have seen every effort taken by the Cancer Centre to make patients as comfortable as possible, but this is a hospital setting and the ward configuration makes it difficult to make it completely homely.

Healthwatch Hillingdon feel that there is an opportunity to be explored, that would offer patients a more personalised service. The Michael Sobell Hospice Charity is committed to supporting patients in the inpatient unit during the relocation to its temporary setting. The Trust could look at working in collaboration with the Charity, to provide tailored, personal, support to patients; which could offer things like ice cream, foam cushions, and ear-plugs for sleeping.

This in itself does not make Mount Vernon Cancer Centre a hospice setting, but it would enhance the current excellent patient experience we have been told about, by providing inpatients, at a difficult time, with a more holistic service, whilst efforts are being made to fully restore inpatient hospice care in the north of the borough.