

The importance of compassionate communication in care

My Voice Matters

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My Voice Matters is ensuring the voice of people with diverse lived experiences and backgrounds are heard.

We are proud to be able to give the opportunity for seldom heard voices to be heard by providers and wider organisations in their own words.

Purpose of the Report

This briefing has been co-written by the widow and family members of Cliff, a retired firefighter with more than 30 years' service in saving lives, and our Development Officer.

Cliff had a late stage cancer diagnosis in November 2022 and died in December 2022.

The family's concern in sharing their very personal story is to highlight the very real and long lasting impact on the patient and their family when difficult and negative experiences of care and treatment are compounded by communications lacking in compassion. Their hope is that their story will help to ensure that others do not have to go through similar experiences.

The details shared, have been captured through letters and conversations and are the personal accounts of events which ended with the death of a loved one.

About Healthwatch Bath and North East Somerset

Healthwatch Bath and North East Somerset (Healthwatch) are the county's independent champion for people who use health and social care services. We're here to make sure that those running services, put people at the heart of care. As an independent statutory body, we have the power to make sure that NHS leaders and other decision makers listen to your feedback and use it to improve standards of care.

We are here to listen and understand the needs, experiences and concerns of people who use health and social care services and to speak out on their behalf. We focus on ensuring that people's worries and concerns about current services are addressed. We are totally independent and can provide you with impartial and independent signposting advice. We are part of a network of 150 local Healthwatch across England and cover the whole of Bath and North East Somerset.

My Story

On Monday 31 October 2022 Cliff was admitted to the Medical Assessment Unit at the Royal United Hospitals (RUH) as an emergency from his GP.

Cliff had Bilirubin in his urine and the doctor suspected that he had Hepatitis or an infectious disease as we had just returned from a holiday in Egypt.

Although Cliff was feeling unwell, he was strong, he could walk normally and he carried his own bags into the hospital.

The following summarises what happened once Cliff was admitted to hospital, until his discharge in December. It includes our experiences of delays and mistakes in Cliff's treatment, as well as our feelings about the lack of kindness and compassion shown by some of the key people responsible for Cliff's care. This impacted greatly on Cliff at the time.

My family and I are still living with the effects over 18 months after his death.

My purpose in sharing this very personal story is to try and help ensure that others do not suffer from the same experiences as we did.

Summary of treatment timeline

This is set out in the family's own words – including some words of Cliff as recorded by his widow, and their daughters.

Monday 31 October – Cliff had lots of blood tests to see what was happening within the body

Tuesday 1 November – Cliff had an ultrasound scan on his liver and lungs and this showed that he had cancer in his lungs. The cancer in his lungs had metastasized into his liver but they could not find the primary cancer at this point. We were told that Cliff was booked to have a CT scan to find out more about origin of his cancer and potential treatment on Wednesday 2 November in the late afternoon. Cliff also received IV antibiotics on this day.

Wednesday 2 November – Cliff was moved to the Haygarth Ward (gastro-enterology) at RUH. The ward smelt of faeces and vomit. The CT scan did not take place that afternoon 'as there had been an emergency accident' and we were told it would be

carried out the next day (Thursday) instead, and there would also be an MDT (multidisciplinary team meeting) on the same day where they would look at the CT scan and decide the best option of treatment for Cliff.

Obviously, we were extremely worried about Cliff, so my daughter looked into paying for a CT scan privately. We asked the Medical Nurse Practitioner (MNP) about doing this but she reassured us that the CT scan would be done on Thursday. She also confirmed to us, when asked, that she would wait until family were with Cliff to give the results of the CT scan.

Thursday 3 November - the CT scan was delayed again due to more emergencies

Friday 4 November - Cliff finally had the CT scan late Friday afternoon.

Cliff's health was deteriorating very quickly. He was extremely jaundiced and in lots of pain. He was now extremely unwell.

To add to Cliff's distress, two people had passed away in the bay in which Cliff was staying on Haygarth ward. One person opposite his bed and the other next to his bed. He had to hear them struggling and making gurgling noises throughout his time there. This was very upsetting. Because of this, Cliff's mental health was at his lowest and he wanted to get away from what he had to endure and he wanted to go home.



" We were assured that if Cliff went home it would not delay his treatment, and that he would be having his ERCP* on Monday 7 November, and someone from the Gastro clinic would call over the weekend to confirm the time"



**(Endoscopic Retrograde Cholangiopancreatography (ERCP) a procedure that combines upper gastrointestinal (GI) endoscopy and x-rays to find and treat problems of the bile and pancreatic ducts)*

Cliff was given antibiotics and some paracetamol, but no strong pain relief. Because of this I called Cliff's GP and they prescribed Tramadol which I collected.

No phone call was received over the weekend.

Monday 7 November – I called and discovered that no referral had been made for the ERCP to take place that day. An appointment for the ERCP was then made for Friday 11 November. On the Wednesday and Thursday Cliff was extremely poorly and in lots of pain. I still do not understand why there was a delay.

Tuesday 8 November – Someone from cancer liaison arranged for St Peter's hospice and Macmillan to call. She said that this was not about end of life care but was for support to Cliff and to us. She also mentioned that for any treatment such as chemo etc, Cliff would need to be fit enough to receive this.

St Peters Hospice did call, but they repeatedly asked if Cliff had signed a Do Not Resuscitate (DNR). I said we were not expecting a call for that, we were expecting only support for Cliff as he had still not received a proper diagnosis yet. The lady apologised and the call was ended.

Friday 11 November



“We took Cliff into the clinic on Friday at 9am and he was prepped for the procedure but was then told it could not be carried out. On asking why I was told he could have had it on Monday if he had not discharged himself. **This was after we had checked specifically that taking him home over the weekend would not delay any treatment.**”



Cliff was extremely distressed, extremely ill and we were told to take him home.

Monday 14 November – Cliff was taken back into Haygarth Ward in a wheelchair for observations before his ERCP operation on Tuesday 15 November at 10am. He called me very distressed and worried and said that another patient had the same procedure the day before saying he was crying and screaming in agony as they are not put under anaesthetic. Cliff was extremely unnerved and frightened as to what was going to happen.

Tuesday 15 November – A procedure to put in a biliary bag was carried out, as Cliff was too uncomfortable to have stents put in.

Why was the procedure on the 11 November not carried out?

We eventually had a call from one of the consultant gastroenterologists who said that there had been no referral for Cliff's MDT meeting so no one from the Gastro ward knew about it.



“He told me that when Cliff went in on 11 November it was the wrong procedure that was booked. He only looked at the CT scan that morning to know this. He said he was extremely sorry and would be requesting an investigation and the outcome would not benefit Cliff but would benefit others”



I appreciated his call but why were we initially told the procedure could have been carried out on Monday 7 if Cliff hadn't discharged himself – which was not true in any event?

After the operation was eventually carried out on Tuesday 15 November, Cliff saw the doctor who performed the op and he said he was really pleased with the outcome. Cliff was still unwell on antibiotics but he looked better than the days before.

Friday 18 November – Cliff was told that he was 'nil by mouth' as he was having a scan. He did not have the scan, either due to a mix up, or a delay, which was not explained. Cliff did not eat until the evening meal. At this point Cliff was dehydrated and was told a drip was needed.

Saturday 19 November – another doctor advised Cliff he was severely dehydrated, and a drip was provided (based on the family's experience this hadn't been done the night before). Cliff had also lost a worrying amount of weight.

Sunday 20 November – the procedure for the bile bag to be reversed and a stent put in was cancelled due to a mix up of some sort re blood tests

'I spoke to a trainee sister. She said it was because someone had not taken the correct blood test that was needed for the procedure. Either the box was not ticked or the nurse forgot. My daughter spoke to the other consultant gastroenterologist who said the reason he did not have the procedure was because 'Cliff's blood was not right'.

Monday 21 November - Cliff's jaundice was improving. He was out of bed and sat in the chair. He looked a lot better and the procedure, to put stents into bile duct which could not be carried out on 15 November, was rebooked for Tuesday 22 November.

Tuesday 22 November - Cliff had 3 stents put in and the biliary bag removed. He looked so unwell and the jaundice was back. He was not put on antibiotics despite being so ill. Cliff did not have a consultant. Cliff still did not have a named oncologist, or consultant and saw different doctors every day

Thursday 24 November - Cliff had a high temperature, was not eating and was very unwell.

Communication about DNR

The MNP had asked Cliff to sign a Do Not Resuscitate (DNR) form. Cliff said no, he wanted to live. The consultant then took me to a room and asked me to sign a DNR on behalf of Cliff as his next of kin.

I said no as Cliff was compos mentis and I asked him why he had not asked Cliff? The doctor said Cliff was stubborn. I replied with "what he is stubborn because he wants to live?" He tried to backtrack and said he meant to say determined. I was shocked and disgusted that a professional man could show my husband no compassion. He was determined to get the DNR. He said he would come and see Cliff in five minutes

I hurried back to Cliff and tried to explain to him that the doctor / consultant was coming to ask him to sign the DNR if his organs failed and not that they thought he had no hope, but only if it came that Cliff had no quality of life bringing him back.



"Cliff said 'that's it, I've had it'. He felt they were experimenting on him and that he was in the house of horrors. So, when the doctor asked him again Cliff said 'yes'. That was it. Cliff rarely spoke after this. He was broken and gave up"



Friday 25 November - Cliff now had sepsis. He was extremely poorly and was given IV antibiotics. He was very depressed and low.

Saturday 26 November - Cliff was supposed to have a CT scan to check the stents. Again, this did not happen.

Sunday 27 November – Cliff had his CT scan. The doctor could see a mass but was not sure if it was the stent, cancer or an infection.

Monday 28 November – The doctor booked Cliff in for an MRI scan. Cliff went down to the scan sat in a wheelchair. He was waiting for 40 minutes very uncomfortable and in extreme pain. For them to then say sorry they could not give Cliff the MRI scan as he had metal stents in his body

Tuesday 29 November – Cliff was now extremely poorly. He was uncomfortable, not eating, not talking to anyone or his family. He has been broken down with no counselling, no compassion or kindness.

The MNP came to Cliff's bed and sat at the end with me. She said she was going to stop his antibiotics as they were not doing anything. Cliff put his head up and said that he was still fighting! She did not stop them for a few more days after we protested.

Wednesday 30 November – Cliff was seen by the palliative care team and oncology to ensure he could be kept comfortable at home.

Friday 2 December – Cliff was discharged home. An ambulance was meant to take Cliff home. After waiting all day and hours later the family decided they would take Cliff and did so as the ambulance was clearly not coming.

Tuesday 20 December – Cliff died at home having been cared for by me and his family with some support from District Nurses, the hospice and Marie Curie.

Our unanswered questions about Cliff's treatment

We were left with many questions about Cliff's treatment, and received conflicting information from different people involved about what did and didn't happen, why and when. This has left us feeling, even now, that we do not have full and accurate explanations about the stages of Cliff's treatment.

We know that Cliff was very sick, but feel that the delays, errors and mistakes prevented him from having the opportunity to fight the disease and potentially live a little longer to spend precious time with his family and friends.

Our other key issues and concerns

Conditions on the ward – noise from building works

From 15 November to Cliff's discharge on 2 December there was the sound of constant banging and drilling due to building works in the ward. That the building works were to bring improvements to the ward in the future, did not make it any easier, and it added considerably to the distress of Cliff and other patients on the ward.

Lack of compassion and kindness

Whilst initially being welcomed on to the ward we found that as time went on, the MNP became unapproachable and unkind towards us as his family and showed a lack of compassion towards Cliff. If you spoke to her she would put a flat hand towards your face which we found rude and extremely worrying for us as we had to liaise with her to find out what was happening. I was worried she was harming Cliff.

It felt like because we had questioned mistakes, instead of rectifying them, she instead decided to make our time on the ward worse than it needed to be.

I've included some examples here.

- She told Cliff that he had bile duct cancer without any family member present despite saying she would not do so.
- I wanted to go to the ward in the morning before his operation to give Cliff some reassurance and talk to the nurses before he had the op. I asked the nurse if I could see Cliff just for a few minutes before he had his operation at 10am as he was very upset and distressed at having it done. She said of course I could and was very nice. I walked passed the MNP and as I got to Cliff the nurse I had just spoken to told me I could only stay for a few minutes. As soon as that nurse walked away a male nurse approached me and said that I had to leave as the doctors will be doing their rounds. My husband could not look at me, he was very worried, very low and depressed and he was in a terrible state.
- After the operation Cliff could not tell me what the result was so I asked the MNP and she tutted at me like I was wasting her time and replied with "I have just told Cliff what happened, ask him". She said "do I have to say it again". I told her I was asking because he was so sleepy and not making sense so yes she does need to say it again. She became agitated and told me what happened. She finished with "that is it!" in a very angry manner.

- On another occasion when Cliff had not eaten (for a period) he was asked if he wanted anything to eat, and he said 'just tea and biscuits', but they did NOT get him it.

The way Cliff was treated in getting him to sign the DNR form was really distressing for him, and for me

I am overwhelmed on a daily basis that the consultant called my husband stubborn, when he did not want to sign the DNR. It makes me physically sick that he took away any hope. It was cruel and unkind. He made Cliff feel there was no hope.

Why was counselling or other support not provided ?

After the procedure on 15 November I told the lady doctor that Cliff was very low and depressed. She told me I was not allowed to say depressed as he had not been diagnosed. I replied that he had been diagnosed with cancer and still not offered any counselling. A correction that certainly wasn't needed at that time. She said she would organise some counselling.

Earlier St Peter's Hospice had called but they kept asking about a DNR form and the call ended. (see 8 November)

No referral to Macmillan was made and no pastoral support offered.

When someone has had a devastating cancer diagnosis 'out of the blue' isn't there a real benefit in making sure that some sort of emotional support is provided for the person themselves and their family regardless of any clinical diagnosis of mental health needs?

Lack of communication with the family

I visited PALS every day since 11 November and later wrote to the Chief Executive to try and find out what was happening, why were mistakes being made and who was responsible. I was told on a number of occasions that someone would call me back and this rarely happened. We eventually had a meeting with senior nurse and staff members:

'All were apologetic and promises were made to make things right. ... It was promised that the team would talk to 'the MNP about [her manner of communication with Cliff and ourselves]. The plan was for me to then be updated every day with a phone call to have progress reports on what was happening with Cliff. I had one call. That was it, no one called again.'

On-going Impact on me as a result of how Cliff was treated

Whilst there were nurses, doctors and other staff who treated Cliff with the kindness and compassion he should have been able to expect the overall experience of Cliff and my family was that the hospital did not take proper care for him, or care about him and his emotional wellbeing.



"Cliff was in hospital for 23 days. He received no treatment for 15 days and suffered multiple delays in treatments and scans because of mistakes made. Not one mistake, not two but mistake after mistake after mistake! There were non existent referrals made and promises made to us that were not kept. Cliff was starved and left severely dehydrated which was made worse by your hospital and again another mistake. He deteriorated day by day because of this, in your care. The people who are meant to help him, not make him worse. Cliff did not see an oncologist until two days before he left hospital and only seen the consultant, [...] when we put in a complaint to the Chief Executive. He only then seen the [consultant] when he wanted him to sign the DNR after Cliff already told the [MNP] that he did not want to, he wanted to live. After Cliff was pushed into signing the DNR he said, "that's it, I am a gonner". He did not speak much after then, he shut down and gave up. He knew he had no chance of survival at your hospital. It haunts me every day and it is the cruellest thing I have ever experienced but Cliff was the person going through it. He was traumatised, frightened, very low/depressed and he had no hope. He told me he felt like he was being experimented on and said he was in the house of horrors.



Voicing our experiences to help others

The following comments have been provided by a Cognitive Behavioural Therapist who has been supporting Cliff's widow since February 2024.

"I have been working with Cliff's widow, initially in relation to anxiety following a car accident, but it quickly became very apparent to both of us that the more pressing issue was how she was coping with the death of her husband, Cliff. Our sessions have allowed time and space to process not only the loss of Cliff but her experience of the care provided during his final few weeks.

Cliff's widow showed many signs of complex grief which can be caused by various factors, in her case the sudden loss of a loved one, a lack of sufficient support, traumatic experiences and unresolved conflict.

Writing and publishing their story has been an important part of her journey, allowing her to express her thoughts and feelings and voice her experience in the hope it may help others in the future. "

Development Officer feedback

The Development Officer listened to the family's story and as there were a number of generic issues highlighted in the case decided, with Cliff's widow's permission, to make follow up enquiries with the hospital.

These related to:

- The protocol for requesting a DNR form
- The protocol for referring someone diagnosed with cancer for support such as counselling?

The hospital had responded to the family's complaint, including saying that they would be providing training workshops for staff, and the Development Officer queried who these would be for and how user experiences would be used.

The Development Officer also asked if anything has changed as a result of the family sharing their experience, and whether the new Dyson Cancer Centre would impact on any of the issues raised.

Response by the hospital to our enquiries

A short summary of their response is included below:

The hospital responded that with regard to training in the completion of ReSPECT forms, (DNR) this forms part of the medical mandatory training programme, and that they have undertaken intensive work with all multidisciplinary teams over the past year to raise awareness, as the forms are increasingly being used.

The Patient Experience training programme is developed with deep consideration to the feedback received from patients and their families through complaints and concerns and this very much includes the feedback received in this case – in particular including returning telephone calls and providing updates to relatives, with the patient's consent, if requested, and in how to have compassionate communications.

The Family Liaison Facilitator team is now fully recruited, including a lead facilitator. The team will work across the organisation maintaining communication with families, providing updates and supporting families to speak with clinical staff.

The Dyson Cancer Centre has helped bring staff together into one place, which will help promote team working and care for our patients. The centre itself has a Macmillan wellbeing hub to enable private conversations with patients, patient counselling and support. It is our hope that it will improve the care of our future cancer patients

Recommendations

These recommendations are intended for hospitals and health providers across the Bath and North East Somerset, Swindon and Wiltshire Integrated Care Board (BSW ICB) area in general, rather than being directed at any specific hospital or ward. They focus on patient experience, and the expectation as set out in a Shared Commitment to Quality that patient experience is given equal weighting alongside patient safety and clinical effectiveness.

- Patients and their families being able to and have the time to ask questions about treatments and procedures should be welcomed and accepted as part of providing a positive patient experience and good healthcare practice

- Medical practitioners should explain conditions, treatments, procedures and decisions in a clear way and check back that they have been understood
- Medical practitioners should have compassionate conversations early on, especially where diagnoses of terminal conditions are being shared
- Medical practitioners and other hospital support services should ensure that information about the range of emotional support available is readily accessible and on offer for patients and their families, especially where patients are facing stressful conditions and terminal diagnoses regardless of 'clinical' need for formal mental health support
- Practitioners should give enough time to explain about 'DNR' processes and what this means and allow enough time for patients and their families to understand and ask questions about DNR and to consider their response. They should not feel rushed into making quick decisions if they need more time.

Next steps

The My Voice Matters report will be shared by Healthwatch Bath & North East Somerset with Healthwatch Swindon and Wiltshire and with the Integrated Care Board for the area.

The report may also be used to inform future work planned by Healthwatch across the BSW area into the provision of end of life and palliative care.

The report will be made available for the Royal United Hospitals and other hospitals within the BSW area to inform their ongoing training programme especially where this relates to patient experience.

Appendix – Resources for cancer support

Macmillan cancer support and wellbeing hub at the Royal United Hospitals for anyone affected by cancer

[Cancer Information and Support Centre | Royal United Hospitals Bath \(ruh.nhs.uk\)](https://www.ruh.nhs.uk/cancer-information-and-support-centre)

For online and other information and support

[Cancer information and support | Macmillan Cancer Support](https://www.mcmillan.org.uk/cancer-information-and-support)

Marie Curie – information and support at the end of life

[Marie Curie | The UK's leading end of life charity](https://www.mariecurie.org.uk)

POhWER – NHS complaints advocacy

[South West | POhWER](https://www.pohwer.org.uk)

We Get It – dealing with cancer together with support, resources and social events

[We Get It](https://www.wegotit.org.uk)

We hear You – cancer counselling through We Hear You

[We Hear You \(WHY\) | What We Do](https://www.whywehear.org.uk)

For additional resources please visit:

[Cancer Support Groups available Locally and Nationally | Healthwatch Bathnes](https://www.healthwatchbathnes.org.uk/cancer-support-groups)

Reference

A shared commitment to quality

[nqb-refreshed-shared-commitment-to-quality.pdf \(england.nhs.uk\)](https://www.england.nhs.uk/nqb-refreshed-shared-commitment-to-quality.pdf)

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