

**THE
PEOPLE
BEHIND
CANCER
CARE**

**WE ARE
MACMILLAN.
CANCER SUPPORT**

Patient and staff stories

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INTRODUCTION

Every person diagnosed with cancer should have a consistent, positive care experience and be treated with dignity and respect throughout their cancer journey.

Poor patient experience can impact on a person's health¹, be related to poor recovery², and is often associated with negative emotions resulting from a lack of support once treatment has been completed. This can include patients feeling unsupported to cope with the side effects of treatment and concerns about reoccurrence³.

In contrast to this, people with cancer associate a 'good' patient experience with feeling supported, respected and meaningfully involved in decisions about their care, from diagnosis onwards⁴. Macmillan believes that a positive experience is one that recognises that cancer affects the patient's whole life, including the lives of people close to them. Cancer patients are more likely to consider the quality of their care experience favourably if a number of factors are met. They must receive well-communicated information, be spoken to sensitively, feel they are being heard and involved in decisions, and be supported with the consequences of treatment⁵.

Research is beginning to indicate that these relational aspects of care may be what patients value the most. Findings indicate that 'the quality of technical care is often taken for granted, while patients and relatives comment more often on aspects of experiences and care mediated through interpersonal relationships between staff, patients and relatives⁶.'

The majority of people with cancer receive good, compassionate care from the NHS. However, as the Francis Inquiry Report into Mid Staffordshire NHS Trust⁷ highlighted, there are still too many people reporting a poor experience.

To make sure cancer patients receive a positive experience, and are treated with the highest levels of dignity and respect, we believe NHS staff need to be supported to deliver the best possible care. They also need to be treated with dignity and respect within their workplace.

There is a growing body of evidence that shows the links between delivering good care and staff feeling supported and engaged. Patients receive a better quality of care at NHS organisations where staff are strongly committed to their work and involved in decision-making^{8,9}. However, a strong link has also been found between whether NHS staff report harassment, bullying or abuse from other staff, and whether patients report poor care¹⁰. Not one of the trusts whose staff reported high levels of discrimination in the NHS staff survey reported high levels of positive patient experiences in the cancer patient experience survey. By contrast, over half of the trusts with the lowest levels of discrimination were in the top 20% for patient experience¹¹.

In the NHS, patients are cared for and staff work in the same environment. Their roles in this environment may be different but they are bound together so closely that every contact counts. This contact happens not just between staff and patients, but also among staff who should treat each other as peers in providing care. When this happens the healthcare culture is one where care can be on an equal footing with providing treatment.

ABOUT THIS REPORT

This report presents stories from 10 patients about a range of their experiences of relational care at different points of their cancer journey.

It also features a series of stories that have been broken down into quotes from healthcare staff who care for people living with cancer. These quotes provide personal insight into the good and bad aspects of working in NHS trusts and how these experiences can determine the quality of care provided.

The report's emphasis on stories and personal insight is deliberate. Capturing rich, qualitative insight through stories brings to life the importance of an agenda that at times can be difficult to quantify. That's because the importance of human interactions rests at its very heart. Bringing together stories from the two seemingly distinct, 'opposing' sides of patients and professionals also highlights that the divide is more imagined than real. Staff and patients alike recognise that quality of care is not solely measured by clinical outcomes.

We hope this report can be used to capture the hearts and minds of NHS staff and services too often inundated with data and action plans on how to improve the delivery of care. These plans often bury the 'human face' of the impact of good and bad experiences under a flood of numbers and statistics.

The report includes information on how Macmillan is supporting the NHS to ensure all cancer patients are treated with the highest levels of dignity and respect. It demonstrates what to do so that staff are supported to deliver this too. The common theme for these solutions is that relationships – between different members of staff, as well as patients and staff – form the foundations of improving patient and staff experience.

Patient and staff views are presented in their own words as much as possible.

We are grateful to all the patients and staff who told their stories.



PATIENT STORIES

For most people, being treated with dignity and compassion is just as important as getting the best medical treatment.

When people with cancer talk about their stories, certain themes are often repeated:

- their involvement in decisions about their care, and whether they were empowered to make informed choices and provide feedback on their care experience
- the quality of the communication between themselves and staff, whether they feel respected and well informed
- Coordinated/integrated care – whether they are supported as they move between different care settings

The following 10 stories from patients show how the relationships, interactions and conversations between patients and staff can make a difference for better or worse. All staff names have been changed to protect anonymity.



John's story

John was 61 when he was diagnosed with prostate cancer in 2010. Some of the themes John's story touches on include: good-quality communication and information; caring and compassion from nurses; and being treated as an individual.

For John, throughout his diagnosis and treatment, having a nurse that he had a rapport with and he knew he could trust was extremely important to him. There were two particular nurses John felt played a crucial role in his wellbeing throughout his treatment.

'Although Sarah had been in the background just hovering and making sure we were okay when we went in to see the consultant [for the results of the tests], I was with my wife. Unbeknown to me, my wife said the whole time Sarah was watching me like a hawk. I guess that was to see what the reaction was.

'When the consultant told me I had cancer, the next 15 to 20 minutes were a complete blur. But again my wife said Sarah was watching me all the time. When we went out [of the consultant's office], Sarah took us to a side room.

I was very angry with her. I don't know why it seems to be the norm that you've gotta be angry at somebody. But she completely understood.'

Sarah took John and his wife through what the consultant had said and explained clearly what the next steps would be. 'She went through the whole process and explained to us what it would mean. She told me the facts. I do need to know the facts – I don't want anything dressed up. I wanted to know exactly what the score was. She went through all the tests we'd got to go through and that it would take time and it was a worrying time for us.

'She said, "You can always give me a call if you need any reassurance", which I did from time to time. The most important pillar of the journey, if you like, was having her for help and reassurance.

To have someone there who you can relate to and you can talk to certainly helped me on my journey.'

After his final test to check the operation had been successful, John was invited by his oncologist to take part in a trial. This involved radiotherapy and hormone treatment which might reduce the chance of the cancer returning. The trial was clearly explained by Helen in the first instance.

'At that point Sarah explained there was a trial going on and I fitted the criteria. We were given paperwork and we went back for another chat with the research nurse, Joy, and we agreed to go ahead with it. There was no rush, never any pressure. Although, there were some doubts in my mind at first – did I want to go on a trial to become a medical lab rat? I sat down and thought what have I got to lose?

'We had the paperwork and had time to think about it. The side effects were explained to us and nothing was held back. Joy was always there and I was told to give her a call whenever I wanted to. When I went for my radiotherapy, I'd always see her and she'd ask me how I was, so again she was my point of contact.'

The most important thing for John was the feeling that both of the nurses truly cared about his welfare and recovery. Also, that he was never ignored by them or made to feel that they didn't have time to speak to him. 'They cared – you didn't feel you were talking to a robot. You didn't feel if you told them something it was going to be ignored. They genuinely cared.'

John's only negative experiences were when either of the nurses he'd built a rapport with were not there. On one occasion, during the trial, John had a radiotherapy session and was told to drink a litre of water. Because of his weak bladder, he was worried he would need the toilet. When John explained this to the radiologist and asked if the session could be as quick as possible the radiologist replied 'I hope you're not going to pee on the floor.' The radiologist's response left John feeling embarrassed. However, John relayed this experience to Pat who took his upset seriously and said she would feedback his poor experience.

'It's nice to have someone to talk to face to face who's probably dealt with it a hundred times and seen it all before. These are the two main people that got me through the journey.'

'She said, "You can always give me a call if you need any reassurance", which I did from time to time. The most important pillar of the journey, if you like, was having her for help and reassurance. To have someone there who you can relate to and you can talk to certainly helped me on my journey.'

Lyn's story



Lyn was 42 when she was diagnosed with grade three aggressive carcinoma in 2009. Her story highlights the effect uncoordinated care, lack of emotional support and lack of compassion can have on a patient.

When she found a lump on her breast, Lyn made an appointment with her GP who referred her for a mammogram. It took longer than two weeks to get an appointment due to her referral getting lost. After the mammogram Lyn met with her consultant and was diagnosed with grade three aggressive carcinoma.

Lyn needed two operations and, for both, she described the medical care as excellent, but there was a lack of emotional support that adversely affected Lyn's wellbeing. Similarly, Lyn didn't feel supported by the breast cancer nurse, who did not return her calls or provide support when Lyn needed it. Lyn felt that it was the district nurses that provided her with the emotional support she needed. 'My only support that got me through the poor days, the chemo, the operation, everything, were my district nurses.'

Two weeks after her diagnosis, Lyn was due to have an operation to remove the lump and was very anxious about the operation. The operation was scheduled for first thing in the morning. Lyn doesn't drive and had no one who could give her a lift to the hospital to arrive for 7am.

'When I was given the date, the surgeon I saw said, "It's not a problem – you can come in the night before surgery so you're settled and relaxed ready for treatment first thing the next morning." The letter came and said that I had to go in the day before the procedure and that I'd go from there up to the ward to get booked in.'

Lyn followed the letter's instructions and went to the ward ready to stay overnight. 'The nurses' station was full. There were so many faces – I'll never forget it. I leant over and said to one of them, "I've come to be booked in for surgery in the morning." The sister who was in charge of the ward said, "It's not hospital procedure [to stay overnight], go away and come back in the morning."

'So I said, "I'm not going anywhere – it's been arranged. I can't get here in the morning." Everyone was looking at me. I felt frightened, I felt belittled and I felt so uncomfortable standing there. They realised that I wasn't going to move so they put me in the furthest quiet relatives' area that they could find, away from the patients who could hear everything that was going on.'

The person in charge of admittance came to see Lyn, apologised for what had happened and reassured her that she had been allocated a bed for the night. However, Lyn felt that the fact she had stood up to the sister meant she was treated differently by the nurses.

'I felt all the nurses weren't particularly kind to me. When I came up from surgery, and I'd had one of my lymph nodes removed from under my arm, so my right arm was quite limited, they made me wriggle across from the theatre bed on to my own bed. They didn't help me. They told me that I would have to drink but they didn't fill up my glass for me. They just put a jug of water

and a cup there and drew the curtain and left me to get on with it.’ The next day Lyn was discharged from hospital and was very relieved to go home.

The surgery revealed that the cancer had spread and that Lyn needed a second operation. Lyn didn’t want a repeat of the experience so she checked if she could stay overnight when she received the letter. She was told to ring the ward the morning she was due to go into hospital to check there was a bed for her. She did this and the same sister answered the phone and said, “The only reason you were allowed to stay last time was because you were so rude. You will not be coming in the night before surgery. You will come in at seven in the morning.”

‘By then, I’d developed a migraine, I was violently sick, I shook and I didn’t know what to do with myself I was so upset. I couldn’t see how I’d get to the hospital at that time in the morning.’ The same person in charge of admittance apologised and confirmed that there was a bed for Lyn.

However the experience led to Lyn feeling very nervous of going into hospital. ‘I had to go in for a third operation a year later. The surgery didn’t worry me. I don’t like cannulas, I don’t like needles but none of that bothers me at all.

‘I felt all the nurses weren’t particularly kind to me. When I came up from surgery, and I’d had one of my lymph nodes removed from under my arm, so my right arm was quite limited, they made me wriggle across from the theatre bed on to my own bed. They didn’t help me.’

The majority of my worries were going on that ward with her. If I had to go to hospital now, even if it was a different ward, I’d be so fearful it would happen again.’

When she was first diagnosed, Lyn was assigned a breast cancer nurse who met her and explained everything that would happen. She also contacted Lyn a few days later to check she understood everything and said Lyn could contact her. But when Lyn tried to contact the nurse she was never available. Even Lyn’s district nurses tried to contact the breast cancer care nurse on Lyn’s behalf when she was really low.

‘I had a reaction to the chemo and the district nurses came to take my PICC line out and I was ready to give up. They phoned her and said, “This woman needs some support – you need to phone her.” The breast cancer care nurse phoned later that day to say “I understand you are not very well – I’ll see you next time you are in clinic,” and that was basically it.

‘The next time I went to the clinic I was angry. If she couldn’t phone me and support me when I needed her I didn’t want her anywhere near me. She said, “How are you?” I told her straight I needed her support when I was really poorly not when I’d picked up the week after chemo had gone out of my system. I don’t need her talking to me when everything is fine. You have your poor period where they should be phoning you or emailing you to say “How are things today?”. When you go back for your next lot of chemo it’s the best week in the world, you feel on top of the world. Her response was “But I’m busy, Lyn, I’m dealing with patients.” And my response was “What am I?”’

Lyn felt what would have helped her through her journey was if more of the medical professionals had viewed her as a person and supported her. ‘They should be thinking “That person has feelings,” and not just “Right, that body there’s got breast cancer,” “That body there’s got bowel cancer”. They need to think of the people as people and treat them as such. I think if you feel like you’re supported that spurs you on to recover.”

Dan's story



Dan was 32 when he was diagnosed with Hodgkin lymphoma in 2009. His story touches on the themes of meaningful involvement and respect for his preferences and needs and good-quality communication. However, it also includes poor experience at some of his transition points.

Dan had been working overseas and while in the UK on leave felt so poorly that he decided to see a doctor. The GP took his concerns seriously which instantly left him feeling relieved that someone else could also see something was wrong. The whole process of diagnosis was very quick and, within a couple of months, when Dan was back in the UK he began his treatment.

The x-ray was only a few days after the visit to the GP. 'The following Monday I was straight in for an x-ray to see if it was TB as that was what he thought it could have been. I went along and had the x-ray three days later and it would have been almost impossible to do it any quicker really. I was then phoned by my own GP and asked if I could come in that day. "There is no sign of TB but there is definitely something funny going on in the chest area." The fact that the radiographer picked this up meant the diagnosis was made quickly. My GP said that he would definitely not have picked this up from the x-ray and we would have gone on to do more tests.'

After the diagnosis of Hodgkin lymphoma Dan began chemotherapy at his local hospital.. 'The nurses at the oncology and haematology unit were absolutely outstanding. I can't imagine that any other place of treatment would have been any better. They were fantastic right from the word go. When I went in to do my consent they explained everything to me, they map out your treatment, every single thing.'

Dan's positive experience continued throughout his chemotherapy treatment. 'I was sat there for

six or seven hours at a time and I had to go every two weeks for eight months. I actually look forward to going. The new treatment room opened in time for my second treatment and it was bright and airy. And you were sat with other people, some of whom had the same thing as you so you could chat about what you'd been through. It was a lovely environment, full of friendly people that were really concerned about making you better.'

As well as the nice atmosphere, Dan also appreciated the advice the nursing staff gave him. 'They were full of practical advice and they talked to you from a completely different perspective, which was totally what you needed. For some people who need a bit more support they were definitely there to give that. For me, we used to talk about composting and all kinds of random stuff. They'd also talk about what was physically happening to you and how to cope with some of these things. I don't think I had a negative experience ever going there. Nothing was ever too much trouble no matter how busy they were. They always seemed to have time for everyone.'

Dan went to his treatment sessions focusing on the conversations he would have, rather than the treatment, which helped to support his general wellbeing. 'The nurses, I'd go to my chemotherapy thinking I wonder what we're going to talk about today. And I'd go home thinking wow that was really interesting in relation to composting or whatever it was. I'm going to try that when I get home. The paradigm comes away from the victimhood of being sick.'

That's a really important shift. I'd had such a positive experience that it generated so much energy in me.'

The fact that he felt he was consulted about his treatment and treated as an individual was particularly important to Dan. 'They would consult with you about things – whether you want it doing this way, or another way. I kind of felt that I was part of it. It was being treated like I was in the room, that I was a human being who could hear what they were saying and was capable of responding. The treatment was something that I owned. It wasn't something that just got done to me. It was, "Let's talk to Dan about what we're going to do about his treatment." That is the critical difference. It's just that whole manner because in other places that just didn't happen.'

Dan's only poor experience was at a different hospital where he went for a biopsy to confirm whether he had Hodgkin lymphoma. 'The biopsy was meant to be keyhole surgery, in and out in 20 minutes. The problem was I didn't have any lymph nodes that they could biopsy. So the only ones they could go to were the ones in my chest that the radiographer had spotted. They ended up accidentally cutting my windpipe internally while they were doing that so they had to 'unzip me' to close that.'

'There was then some confusion over the pathology report going back to the oncologist, which took six weeks. It was only after that he said yes it is Hodgkin's lymphoma.' This was the slowest aspect of the process and Dan described it as 'the only weak link in the chain.'



Patsy's story



Patsy is 61, and was diagnosed with stage four multiple myeloma in 2005. After an initial poor experience at A&E, Patsy's story highlights the positive effect meaningful involvement, compassion and respect for a patient's need can have.

Patsy had been complaining about severe leg pain at her GP's surgery for over a year. A locum advised her to go to A&E, who were very unwelcoming. 'I had to beg them for an x-ray. I couldn't walk and was crying – it had been like that so long.' Patsy was diagnosed with stage four multiple myeloma and had her leg operated on in 2005. She used a wheelchair but can now run up and down the stairs and is back to working for herself.

In contrast to her initial NHS experience, once Patsy received hospital care she experienced a 'fantastic service. From that point in they saved my life.'

Patsy received excellent care during her treatment from an orthopaedic surgeon and a haematology consultant. 'The orthopaedic surgeon and the haematology consultant together identified what I had. Because my bones were in a terrible state, I just wanted to know was I going to lose my arm, was I going to lose my leg? I'd had a long operation on my leg. The consultant wanted to give me all the detail and I didn't want it. As soon as he knew how I wanted to be communicated with he adapted. He said, "We'll get you up dancing again." For me the connection he made, the way he gave the information, he just did it beautifully.'

Patsy saw the haematology consultant all the way through her treatment from diagnosis for regular check-ups until he retired recently. 'During my stay in hospital, I was seeing him on a daily basis, maybe a couple of times a day. He came across as quite a shy person but he was so sweet and gentle – we had a great relationship. I felt so safe with him. He and the surgeon saved my life. He had a lovely way about him – he would laugh. It seemed everything was possible, which is an amazing thing.'

'I'd always come out of the appointments feeling upbeat. You felt very safe with him because of his knowledge, the way he would talk and respect his patients to the greatest degree. He was always positive, he always looked at what could be done and I always felt very safe because he explained whatever he was going to do very well.'

Patsy also felt reassured by the consultant's reputation. 'I felt even safer because he was very intelligent. I knew about his research – he was up there with the pioneers of research on myeloma. There was a big safety element in knowing he was an expert. But also him as a person, he was really very to the point.' The consultant gave Patsy time. 'Feeling that you're being listened to is a big thing as well. Feeling that it's okay to say whatever you want to say is so, so important.'



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The surgeon consistently made Patsy feel like an individual too. 'I was in hospitals for at least a month and saw him daily, and I saw him afterwards too as I had two post-operative appointments. I had a six-hour operation on my leg. When I was wheeled down I was so scared. He made a joke. He made me feel so at ease just before he was going to operate. He made me feel like I was his only patient – he gave me that much personal attention.

'He made me feel as if I was really important, and also what was really important, he made me feel it was going to be alright. He never gave me false hope, but in a very frightening situation he made me feel that it was going to be okay.

He made me feel incredibly positive and he made me feel safe which is crucial.'

The surgeon was very approachable and developed a rapport with Patsy. 'He was there right from the start. He didn't come across as being from the higher echelons. This was a guy who was up there in the gods and made himself available on all levels. He was smiling. It was the way he talked to me, picking up on the way I wanted information. He respected me and used humour appropriately. We talked about dancing to Meatloaf.'

'They are trying to save lives, they are under constant pressure but he was still able to build that rapport which was important. It made me feel safe. There is a lot going on in your mind at that time. His communication with me gave me confidence that I was going to be able to do things.'

Patsy's husband was also involved in discussions. 'The two doctors both built rapport with us. My husband was involved in most of those discussions and was respected as well. We were guided by them. They made themselves available and gave us the information we needed.'



Roy's story

In 2006, when he was 55, Roy was diagnosed with testicular cancer. His story shows the impact that a lack of coordinated care, compassion, poor communication and not being listened to can have on a patient.

Roy visited his GP several times over an 18-month period about his symptoms but his GP did not take much notice of him. Eventually, and reluctantly, Roy's GP referred him for a scan that revealed he did have testicular cancer.

Soon after Roy's diagnosis, he was admitted to hospital for surgery. After the surgery Roy returned home but experienced swelling. 'I believe it was the following day that I started getting a swelling, which got worse and worse. My wife took me down to the hospital, and the staff there didn't really seem to know quite what to do. I certainly felt that I was being a bit of a nuisance and I was in the way. I finally saw someone and they said "Yeah, that'll stop," and sent me home.

'Then, over the next 24 hours the swelling got worse. That's the only time in my life I can honestly say I was totally terrified. I thought I

was bleeding to death. I know the blood was staying in my body but as a non-medical person when you are experiencing those sorts of things you don't know what's going on. We returned to the A&E department of the same hospital and again I was examined. This time, the doctor at A&E said I needn't worry too much because as the blood was remaining in my body I wasn't bleeding to death.'

Initially Roy was relieved because he was going to be treated. However this feeling did not last because as soon as he reached the ward he felt his problem was not taken seriously by the staff. 'I was kept in hospital over the weekend with a view to seeing the consultant urologist on the Monday morning. I was given the distinct impression that I was taking up bed space that could have been used for something else in that hospital ward. I was a nuisance and I was in the way.'

This experience has had a long-term psychological impact on Roy as he is now terrified of ever needing to have medical treatment at that hospital. 'It's left an ingrained imprint on me. We still have relatives who live in that area and when we go to visit them, if we should happen to go past the hospital, my mood changes completely. It's a real sinking feeling of blackness and depression. All the time that we're there I'm thinking be careful, don't have an accident, because the last thing I would want to do is return to that particular A&E department. Even now, all these years on, when we leave that area to head down here again I feel a sense of relief. The mental trauma that has left I think will stay with me forever.'

Once Roy had moved, and was being treated at a different hospital, he found out that the first hospital had missed the fact that his cancer had progressed from stage one to stage two. This led to him having a second CT scan. Roy has an ongoing concern about the possible long term-effects of this.

'Figures given as a generality for CT scans about the amount of radiation one gets indicate that it's equivalent to about 200 chest x-rays. There is a thought at the back of my mind that the radiation my body has experienced through the CT scans could actually cause a type of cancer which wouldn't otherwise have come about. The issue for me is that I've had one CT scan that I didn't need to have because of the incompetence of the staff at the first hospital.'

In contrast, Roy had a very positive experience at the second hospital where he received treatment. He viewed the nurses in the oncology unit at this hospital as fantastic. The nursing staff and

consultant always had time for him and gave the feel of being like a family. 'From that moment onwards it was all sunshine and smiles. Theirs was and is a vocation. They cared but they were also fantastically knowledgeable and skilled.'

Roy had an issue during one of his chemotherapy treatments where he was experiencing breathing difficulties and the staff were concerned. Although it was a weekend the staff dealt with the issue immediately and contacted the consultant. This contrasted with his experience at the first hospital and reinforced the feeling of being cared for. 'During one of the chemo sessions I started to get slight breathing problems. This was on a weekend and the staff on the ward weren't really quite sure whether to carry on. So they contacted my consultant at home and he knew my case and he said 'carry on'. They carried on and the problem with my breathing dissipated.'

Roy felt that being told he had been cured was a shock and additional support at this stage would have been helpful. 'That hit me like an express train in the same way as "You've got cancer" did in the first place. I was numb. I couldn't remember much else about that consultation – my brain just couldn't take this on board. I understand that that sort of treatment is expensive and that it has to have a line drawn under it at some stage. But I certainly did feel that when I was told that I'd been cured it was like falling off the edge of a cliff.'

Roy felt that it would have been useful to have counselling available at the end of his treatment. 'On reflection, I think it would have been better for me as an individual if I could have had some sort of follow up or counselling to help me get over the trauma of the whole thing.'

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Lindsay's story

In 2002, when she was 55, Lindsay discovered a lump in her breast. Her story touches on the themes of meaningful involvement, good-quality communication, and feeling like she was treated as a person rather than a set of symptoms.

During Lindsay's treatment she felt supported by all the medical staff, which was very important to her. 'It made the world of difference. Everyone made me feel special I suppose. It made me feel they wanted me to get better. They were rooting for me.'

From the beginning, Lindsay was supported by her breast cancer nurse. 'When I was diagnosed I walked out of the room straight in to the arms of a breast cancer nurse who had been at the hospital for nearly 25 years. That lady just looked at me and said "we will beat this together".' One of the times the breast cancer nurse supported Lindsay was when her arm was swollen after an operation.

'I came home with a drain. I came home on the Friday and my arm swelled right up. I didn't know that was going to happen. I was terrified, so on the Monday I rang [my breast cancer nurse]. She said, "That's quite normal. Come up here and I'll drain it for you".'

The medical professionals were keeping a close eye on Lindsay and tailored her treatment to her needs. One example of this was how the staff responded to Lindsay's bad reaction to the chemotherapy. 'I went through absolute hell. My body had obviously said that's it, I've had enough of this. I think I'd had number eight, this was number nine and I was due to have 12 cycles of chemotherapy at this point. I went to see the oncologist and I said to my husband, "I'm going to tell them I can't take 12. I just can't take it."

We walked in and the first thing she said was, "We've been discussing your case and we're going to stop at 10." Well, I threw my arms around her.' Lindsay valued the fact that the medical team were following her progress closely. "People are following you in the background. There's no doubt about it: everything you do is analysed and assessed by somebody. You're constantly being monitored which gives you a great feeling of security. I never, ever felt alone.'

Lindsay also valued the fact that all the medical staff were looking out for her welfare. 'I was trying to work, albeit part time. I remember phoning one of the nurses who was absolutely livid with me because my blood count was so bad. She said to me, "You ought to be at home because you're so prone to infection." It was a nice anger – she was desperately worried.'

Lindsay received a lot of support from both her breast cancer nurse at her local hospital and the nurse who supported her at the hospital where she had chemotherapy. The most important thing to Lindsay was the fact that both nurses could empathise with her situation. 'They had enormous empathy. It's not the sort of job that you can just drop somebody into. It really does need training and understanding. They were dedicated to making sure that people who had breast cancer had every opportunity to recover from it.'

From her first contact with the consultant and breast cancer nurse, overall Lindsay felt that they would support her through her treatment. 'I was in the best hands I could have been in. I had a private patient plan – I could've gone private. I chose not to because at that point I'd had the two meetings and seen the consultant who was going to do my op. And I'd seen the breast cancer nurse who I thought was phenomenal and I just said to my husband, "I'll stick here." I honestly felt they could pull me through it and they did.'

'When I was diagnosed I walked out of the room straight in to the arms of a breast cancer nurse who had been at the hospital for nearly 25 years. That lady just looked at me and said "we will beat this together".'



Debjani's story



Debjani is 62, and she was diagnosed with inflammatory breast cancer in 2007. Her story details her experience of poor communication and uncoordinated care, as well as feeling a lack of compassion towards her husband and herself.

While Debjani was undergoing chemotherapy, the oncologists explained that she would need a tube fitted to make it easier for the treatment to be administered. She was initially given the choice between a PICC line or a Hickman line. The PICC line is less invasive and can be inserted by a specialist nurse without any anaesthesia. 'I have a needle phobia so I said I'd have a PICC line. The nurse tried very hard but didn't succeed so I was left with no option. She made many attempts and I can't tell you how painful it was.'

The oncologist was reluctant to let Debjani have the Hickman line fitted under general anaesthetic. 'I had to plead with him and eventually he said okay. He wrote a letter to my GP to say he was referring me to have it under general anaesthetic because of my needle phobia.'

However, the oncologist forgot to refer her and so a junior oncologist, who seemed unsympathetic, advised her to have the Hickman line fitted under a local anaesthetic. 'She said, "You can delay the treatment for your aggressive cancer – it's up to you." So I felt I had no choice as my only sister had died of this. But I was terrified as I went to the pre-op.'

At the pre-op, Debjani met the radiologist who would be fitting the Hickman line. 'My husband and I were quite reassured. We were told it was only a 15-minute procedure. The radiologist was quite friendly to begin with.

She said with the Hickman line there are no guesses involved because it is done under ultrasound, so she can see exactly where it is going in. She said, "It's only the pre-op today but let me have a look. Oh yes, I know exactly where it's going in. It's very easy." So I believed all this.'

Debjani explained her needle phobia to the radiologist. 'She asked "could you make sure I don't have to wait too long, because the longer I wait the more frightened I get of the needle. [The radiologist] said 'if you can get here at 8 o'clock I'll make you the first patient because I start at 8.30am. Also, she gave me her phone number and said you have a week before the procedure, if you have any questions you can ring up.' As the operation neared Debjani sought reassurance. 'I got quite nervous so I thought I'd ring the radiologist and ask her advice. Every time I rang they said, "She's not there." I said, "Can I speak to someone else?" and they said, "She's the only one, leave your number and she'll ring you back," but she never did.'

On the day of the surgery, Debjani and her husband arrived at 8.00 am. 'There was no waiting room, only the corridor. They were doing building work and it was really awful. I was sitting on a flimsy trolley bed wearing a gown. On one side was a window and the only view was of a rubbish dump, on the other side was a male ward. On the left side was a toilet and there were drops of blood on the floor.'

Debjani was kept waiting all morning without any information. Eventually a nurse came and her asked if she could have the local anaesthetic in the corridor so she could hold her husband's hand. 'They said, "No, you can hold the nurse's hand. It's a sterilised atmosphere inside."'

Inserting the Hickman line was a very frightening experience for Debjani. 'They started putting the line in – it was so agonising. I only found out a year after, when I wrote a letter of complaint, that the radiologist had got the place wrong and punctured an artery. I could see the blood. I wasn't very sure what they were saying after that because it became bedlam. The nurse who was holding my hand let go of my hand and put a pillow over my face. To me at the time, I couldn't understand why, but I was in excruciating pain. And it felt for some strange reason like this nurse, who I didn't know, was trying to suffocate me to death.'

'They were talking among themselves, they were in a panic and they didn't say anything to me. For some strange reason the radiologist seemed to be crushing me to death, she seemed to be actually sitting on my chest. I couldn't believe it. I tried to speak but I couldn't because my whole face was covered. I wanted to scream but I couldn't. It was a nightmare. I couldn't make out what people were saying.'

Debjani's husband was left in the corridor without any information for two hours. 'We were told it would be 20 minutes but I'd been in there for two hours. He stopped passing nurses and asked, "Can you tell me what's happened?" and no one would tell him. A nurse said, "We ran into a spot of trouble but we're on top of it." That's all he was told.'

After two hours Debjani was wheeled out soaked in blood and in shock. 'I looked at my husband and couldn't speak. I was waiting thinking someone will come and clean me up. And then I got another shock, I had been told they would put the Hickman line in the right side of my chest. But what I saw were two holes in the right hand side of my chest that were dripping blood, but the tube itself was on the left side where the cancer was. I thought, "They've got it wrong.'"

A nurse emerged and told Debjani, 'One of my colleagues got exposed to your blood. I'd never seen this nurse before. She said, "We need to do a blood test." I couldn't speak. I was still in shock. I just stared at her. She said, "We need to test for HIV" and gave me a leaflet. My husband was trying to be helpful. He said, "Let them take blood from your Hickman line and then at least we will know it's working." And the nurse turned to him and said, "Will you stay out of this? This conversation is between your wife and me – it's got nothing to do with you.'" They were both very shocked and upset by this incident.'

Debjani paid to gain access to her medical notes a year later. 'That's when I realised she had punctured an artery. I had never been told. The notes also said, "Communication with the patient was good." I thought, "What nonsense.", so I wrote a complaint letter to the chief executive of the hospital.'

Eventually, medical staff agreed to meet Debjani and her husband on neutral ground at the local town hall. She was promised that she would not meet the radiologist and the nurses, but the same radiologist was present in spite of their undertaking. 'At the meeting was a doctor, radiologist, a senior matron – some people I'd never met. They told lies, they told such lies. The councillor's secretary took minutes, and so did someone from the hospital. I've got two different sets of notes. My husband said, "She was in there two hours and we weren't told the artery was punctured."

'The radiologist said, "This is a common side effect which was explained to you and is in the booklet." I still have the booklet and nowhere does it say that. I said, "No, I wasn't told any of this." The other lie the matron told was, "She was in there half an hour at the most" and she said, "We take meticulous records." My husband asked to look at their records. Then the matron said, "Oops, I misread it. Yes, almost two hours. I wasn't reading it correctly – my apologies." I eventually got a letter of apology from the chief executive.' Debjani also reported the case to the Care Quality Commission which has used the case in their training materials for inspectors.'

Graham's story

Graham is 44, and in 2007 he was diagnosed with cutaneous T-cell lymphoma mycosis fungoides. His story highlights a number of themes, including poor communication and a lack of involvement in care. However, it also highlights the benefits of a positive relationship with staff, in this case, his specialist nurse.

Graham had been concerned about generalised rashes on his skin for a number of years but the condition is commonly mistaken for eczema. In 2007, he found a very large lump in his groin. Several doctors told him it was just a lymph node draining an infection. He decided to go to a private dermatologist about the rashes for cosmetic reasons. But the dermatologist wanted to do a biopsy.

'It was a difficult diagnosis – she said I was very, very unlucky but it was T-cell lymphoma.' The dermatologist referred Graham to a private surgeon who advised him to get back into the NHS and wrote an urgent referral letter for him to see a specialist. 'I was seen within two weeks and my experience of the NHS became really very good. The hospital saved my life so I was very lucky.'

A specialist nurse in haematology was assigned as Graham's caseworker. She provided continuity throughout Graham's treatment. 'She was very important to me because she was my primary point of contact with the hospital and she was the one who was communicating things to me.' The specialist nurse had a few weeks' sick leave at an important time during Graham's treatment, which made him realise how invaluable her support was.

In her absence, no one kept Graham informed about decisions made about his treatment. 'I had originally been told I would have three months of treatment. At the end of the third cycle, the nurses were starting to write up the appointments for the fourth. No one had said anything to me about it coming to an end or

being extended. I just didn't know what was going on because my caseworker was off sick. I was sort of left hanging. Normally, my caseworker would be there and made it okay because I got that continuity and extra level of explanation. But without her presence I was bounced from one registrar to another. I wasn't really being told anything.'

The specialist nurse provided a vital link between Graham and the clinicians. 'She knew a huge amount about the treatment of my condition and she knew everything about the treatment I'd had. So she could explain things to the registrars and to me. When she was there it made the sessions with the registrars much more meaningful to me. When she was off sick it highlighted to me just what an outstanding job she was doing.'

The specialist nurse also reported back to Graham about the weekly mixed disciplinary team meetings where decisions were made about his treatment. 'I had no involvement in that at all. My caseworker would report back on what was decided and why. The 'why' is really important. It turned out later to be hugely important because the reason they had decided to extend the chemotherapy was not bad news. It was good news because I had been responding so well to it.

'It really brought home how much I'd been depending on the specialist nurse's support. You do need that emotional support. It's one thing the doctors getting rid of your tumours but when you're going through stuff like chemo you do need support as well.'

Graham felt safe and confident in the care he was receiving as a result of the specialist nurse. 'The hospital did such an amazing job and they saved my life and I'll be grateful for that forever. I realise the mixed disciplinary team was making really smart choices but that wasn't being communicated to me at all except through her.'

'So when she was there I felt safe. I was very well cared for all the time but I only really felt it when she was there. Doctors are like scientists – it's all about the cell count. That's why the role of the specialist nurse is so important because they can connect the patient to the process.'

The specialist nurse provided particular support around the time of Graham's biopsy. 'One specific moment was hugely important to me. I had to have a bone marrow biopsy as part of the staging process. It was all a little bit daunting. When I was diagnosed and told this is my caseworker, being a macho guy I thought, "I don't need a caseworker. I don't need someone to hold my hand." I didn't say that but I thought that. I thought this is all a bit silly and unnecessary for me. But when I was being prepared for the procedure she popped by to say hello and see how I was doing. I can't tell you how important that was for me – it was a massively big deal. I think it just told me that everything was joined up and it made me feel so much more positive.'

'Those little extra things made all the difference and made me realise that I hugely valued having her and her function, joining up all these disparate parts of the hospital. It made me understand her role in a way I hadn't when I was first diagnosed, both emotionally and practically.'

'The specialist nurse struck an important balance between friendliness and professionalism. 'Her judgement in so many ways was just spot on. She established rapport with me really quickly. She started being quite comforting in the first session, but I don't think comforting was what I was ready for. So she quite quickly became more practical and professional. And then just turning up at the biopsy, it reassured me because it was just so incredibly well organised and thoughtful. I think the fact she'd been so thoughtful immediately made me respect her professionally, but also emotionally appreciate her presence.'

Graham also appreciated the specialist nurse's support towards the end of his fourth cycle of chemotherapy, as she arranged for him to see the consultant. 'I had to wait a long time in Outpatients' – a couple of hours. She appeared a couple of times to reassure me. She knew it would be important for me to hear it from the consultant himself rather than the registrar. It was the correct judgement call – it was worth the wait. It was really good judgement on her part, to have the opportunity to discuss it with the consultant himself. So that was an example of building rapport and understanding what was important to me.'

Graham is also very grateful to the doctors working on his case. 'It was a very positive outcome. I had a complete response to the chemotherapy. I'm here seven years later. I think the mixed disciplinary team made so many good calls. In so many ways I'm so lucky and so grateful for what they did. So many brilliant judgement calls that they made mean my life is so much better today that it might otherwise have been.'

'So when she was there I felt safe. I was very well cared for all the time but I only really felt it when she was there. Doctors are like scientists – it's all about the cell count. That's why the role of the specialist nurse is so important because they can connect the patient to the process.'

Vivek's story



Vivek is 32 and was diagnosed with a rare brain tumour. His story touches on the themes of coordinated care, meaningful involvement and good-quality communication.

Vivek was eventually diagnosed with a rare brain tumour. He had reported a range of symptoms to his GP's surgery over three or four years from 2006 to 2009. 'My pituitary gland didn't work so my skin colour was very pale, and I had patches in my beard that just wouldn't grow. I got a lot of headaches and also problems with my vision. There were lots and lots of other things. I just remember going all the time and being told there's nothing we can do.'

He was sent for several blood tests which came back all clear. Vivek thinks the GPs should have been more concerned about his range of symptoms and perhaps should have sent him for a CT scan at an earlier stage. Eventually he developed a blind spot and only had 50% vision in one of his eyes. He went to the optician, who sent him to a specialist eye hospital, which referred him to the local hospital for a CT scan.

Once at the hospital, Vivek received excellent care. 'My surgeon said mine was a very rare case. I had doctors around me all the time. It was all good. After the eye hospital sent me to the hospital for the scan I was kept in overnight and the next day I saw the neurosurgeon. Two or three days later I had surgery. That was very quick and efficient and went very well.'

'Everyone who I had to deal with was so nice and professional. I love the NHS. I love the fact that we have this service. When it's dealing with something very serious like this it's amazing. They deal with you so quickly and efficiently.'

Vivek felt the neurosurgeon struck the right balance between getting to know him and respecting his privacy. 'The neurosurgeon was one of the best in the country and specialises in these rare tumours like I have. She was very helpful. I saw her at least once a day, maybe twice before she operated. I am fairly independent but she was reassuring. I was happy just to let them do their job. I wasn't upset or angry. I was fine with everything.'

He felt more confident in the treatment as the neurosurgeon was renowned in her field. 'She was very professional. When I found out she was known across the country I was pleased I'd got the best person on hand. I felt well informed. They did tell me a lot of things but I'm not too fussed about knowing everything. She did explain exactly what they were going to do, exactly where the tubes were going to go. But in the end I thought you know what? I don't need to know all the details and I'm happy with that. The neurosurgeon definitely took the time to explain everything.'

'Everyone who I had to deal with was so nice and professional. I love the NHS. I love the fact that we have this service. When it's dealing with something very serious like this it's amazing. They deal with you so quickly and efficiently.'

The neurosurgeon visited Vivek several times after his surgery. Vivek tried to stay calm throughout his treatment and felt the doctors appreciated this. 'It's just so important to have an objective view. It means you don't get too angry or upset – you just see it as a process. The neurosurgeons have to do their job. You have to go through this so you might as well deal with it and come out the other side and then try and get back to normal life. Everyone I had to deal with realised I was quite calm and just wanted to get it done.' Vivek now runs a Macmillan support group to help other patients maintain this sense of objectivity about their treatment.



Danny's story



Danny is 57. In 2011, he was diagnosed with colorectal cancer in the sigmoid colon. Danny's story centres around the themes of good-quality communication, good support by staff, and confidence and trust in the staff treating him.

Danny received high-quality care from a clinical nurse specialist working in a team focused on colorectal patients. The team worked across two hospitals. 'Once I was aware of the system and that there was a team phone number and voicemail, everything went absolutely wonderfully from there. I would always have someone call me within a day without fail, no matter what it was. I developed quite a good relationship with the whole team, so that was extremely good practice I believe.'

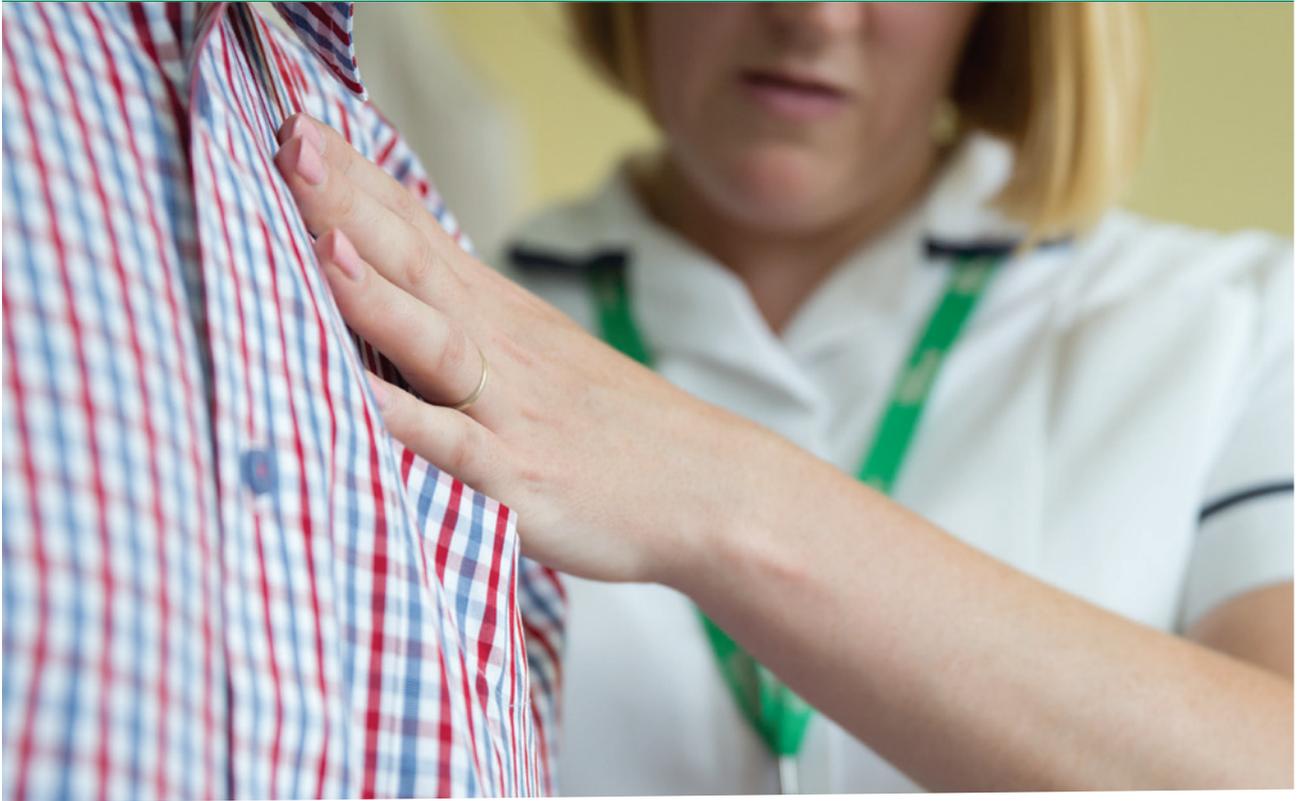
The clinical nurse specialist provided invaluable support in between Danny's hospital visits. 'The lead clinical nurse specialist stood out in my first couple of meetings with the surgeon. They had a habit of talking in very medical terms and she would keep an eye on my face and realise I was lost at the first sentence. She was able to tell the consultants in no uncertain terms to slow up and explain it better. She would then explain it in layman's terms. She would give the surgeon an example of what words to use.'

Danny felt more confident and able to ask questions as a result. 'Because of this interplay between the clinical nurse specialist and the surgeon, I felt that it wasn't a done deal, just because the surgeon or consultant had said so. It wasn't like that. It felt like there was a very healthy dialogue, so that gave me a lot of confidence.' Danny felt the clinic nurse specialists team provided a consistent and reliable source of support. This was particularly after the first set of tests and clinical consultation, and again after his chemotherapy.

'The clinical nurse specialists were very important and good at that stage. I could ring them up and leave a voicemail and without fail they would call me back the next day.' Danny also appreciated the clinical nurse specialists picking up on his concern about potential side effects or any risks. 'I felt they had a radar beam on you – the slightest twitch they would pick up, and that gave me a lot of confidence.'

Danny also found his consultant oncologist to be very approachable and willing to provide information. 'He was very good and very patient – very helpful in trying to ensure I got an appointment as early as possible. He was extremely good. I think he realised from the way I was asking the questions that I was digging into the statistical methods. I apologised and he said, "No need – I now know how I need to say things to you." He was very good about the research failings and the data and honest with me about how much they had to guess. His being so honest and open about it actually gave me a lot of confidence that what he was saying was the absolute truth.'

'The oncologist would always take the trouble to try and explain. I preferred them being open and honest with me about how uncertain they were. They said, "If that doesn't work we can try this." They gave me confidence that whatever they tried, if it didn't work, there were other options.' The consultant oncologist treated Danny as an individual, using his first name and stopping to say 'hello' when collecting other patients.



The surgeon who operated on Danny also treated him with respect. 'I always felt the surgeon took a personal interest in my case, and was making excuses to come in and see me. Even though he was off for the bank holiday, he still popped in to see me, even after he'd handed me over to another doctor. He popped into the ward, I was at the far end and he made a beeline for me, just to see how I was progressing.'

'The oncologist would always take the trouble to try and explain. I preferred them being open and honest with me about how uncertain they were. They said, "If that doesn't work we can try this." They gave me confidence that whatever they tried, if it didn't work, there were other options.'

The surgeon took the time to get to know Danny and check on him on a daily basis during his hospital stay. 'It was most important to me that the surgeon was really listening to what I was saying. He wasn't just repeating platitudes. He always came back with an explanation. I didn't feel he was reading off a script – he was saying something to me personally. He had that kind of communication skill that made it personal. He would joke with me that he hoped I would break his record and be out of hospital in two days, not four as it happened to be. It made me feel more confident about getting better. He wasn't just treating me as a number.'

The surgeon developed a rapport with Danny, treating him as an individual. 'During the very first meeting I had with the surgeon we digressed into cultural discussions, so right from the word go we hit it off. He always took the trouble to explain the details of what was going to happen, what the chances were and so forth.'

The surgeon struck an important balance between professionalism and friendliness. 'I got to know his character and it was a bit of fun for me. A bit of lightheartedness is very important when you're not well.' The surgeon also took the initiative to phone Danny's wife to update her while he was recovering in hospital, which Danny felt was important and appreciated.

THE LINK BETWEEN PATIENT AND STAFF EXPERIENCE

It's important to remember how inextricably linked the treatment of hospital staff is to good patient experience.

Macmillan's analysis¹² of two national datasets shows that in trusts scoring highly on a range of staff survey measures, experiences reported by cancer patients are also higher. And, conversely, where staff report more negative views of their workplace, the experiences of cancer patients also tend to be more negative.

We still don't fully understand some of the links between staff and patients' experiences. Our own research suggests that the underlying reasons for the relationships are likely to be complex and affected by multiple variables. For example, explaining the link between health and safety training and overall patient experiences, or why the availability of hand-washing materials is linked to patients' experiences.

However, we can start to see explanations for some of our findings.

In trusts where cancer patients were more negative on a range of aspects of their experiences, staff were more likely to report having suffered discrimination, or violence or harassment from colleagues. It's easy to imagine how these extreme examples of breakdowns in team and management culture could have a tangible impact on the care these teams provide patients. Conversely, we found a link between trusts where staff reported that they felt valued by colleagues and higher overall experience of cancer patients.

In the next section, staff talk about how empowering it is to have a culture where they are listened to and can talk openly to their colleagues. Hearing from patients in the previous section, this is also the type of environment they want – one where they are listened to and involved in decisions.

We also found that in trusts where staff were more likely to recommend their trust as a place to work or receive treatment, cancer patient experience was also more positive. This was perhaps the most intuitive link. Clearly, staff are aware of the quality of care they are providing and this is what drives and motivates them.

Coupled with what we hear from staff and patients, and research¹³ from the National Institute for Health Research, we know supporting and empowering staff leads to better patient care.

LISTENING TO STAFF STORIES

As demonstrated in the previous section, there are strong links between patient and staff experience. Staff experience can be seen as an indicator of good patient experience as well as a warning sign for poor patient experience.

This is why for good patient experience it's integral that we also listen to staff stories. We talked to cancer care staff across a number of NHS trust hospitals about their

working environment, relationships with their colleagues, communication between each other, and their wellbeing.





University Hospitals
Coventry and Warwickshire
NHS Trust



EMPOWERING AND VALUING STAFF

Staff talked about the value of openness among themselves and the empowering feeling of being able to discuss issues with senior staff. Part of this empowerment is the ability of all staff to raise issues. For this to be effective, there is a need to feel these can – and will – be acted on.

Among the staff we talked to, we found they felt generally positive about their ability to openly discuss issues, voice their opinions and be frank. The communication channels were either via team meetings and or speaking to a senior colleague.

‘Within our team people can definitely voice their opinions. We have lots of debate. It’s not very heated – we’re all very professional. I was operations yesterday and I had lots of issues. So I’ve asked for a team meeting on Friday as we need to get our act together in this respect. I can raise it and we’ll debate it tomorrow’.

Consultant nurse

‘That hasn’t always been the case to my knowledge over the years. People were afraid to speak up or whistleblow or whatever. And now, while we don’t positively encourage it, we don’t deter people from saying what they really feel they need to say and it will get dealt with. Things get reported and discussed and talked about and that improves morale because people feel they’re being listened to.’

Matron

However, this was not always the case. Empowerment was sometimes seen to be an issue, particularly when focusing on certain roles.

'I don't think nurses are empowered to get anything done. In the past five years nurses have been and are so miserable. They've lost any kind of drive. And even newly qualified nurses, only in the job 18 months, are already quitting because it is miserable. On the frontline it is hard work and nobody thanks you. They might think you've done a really good job but that never comes down.'

Emergency practitioner

'One of the barriers among the nursing team may be that it might be quite hierarchical, so some people may not feel empowered to do a few things. That's a possibility and I'm not 100% certain about that. To be fair to the way the system has developed, I think it's very safe and it's a very good system as far as the patients are concerned. Sometimes the nurses might feel they're being held back a little bit but not without good reason. It's obvious that it's better to be safe than sorry. In (location removed), there's a lack of initiative generally. I think people have been over stretched over such a long period that they've become apathetic.'

Medic

Research also shows that localised management and workplace relationships are factors in staff experiences¹⁴. Perceptions of management were found to differ significantly across trusts. The reoccurring theme from staff at one trust was a sense of not being valued and a lack of support from higher management.

'I'm very valued within my team, I think. I feel valued by my direct line manager and the cancer staff teams, the ward staff and people like that. The head of our department doesn't value us quite so much. Maybe that's something to do with her management style. It makes you a bit less enthusiastic. But I'm lucky in that my direct line manager is very supportive, so.'

Healthcare practitioner

'I haven't had a thank you from anybody. Patients, yes, and you do it for them because they need that help. But you don't expect them to give you that reinforcement and well done for doing your job because they shouldn't have to. They should just be poorly and you look after them and they get better and go home and that's your reward. But if a manager was saying, "Well done for that, thank you so much for helping out today, I know you've done a good job, it was really difficult." It's not like a pay rise or anything – it just makes you feel like someone has noticed what you've done.'

Practitioner

Staff at another trust also expressed strong views that management did not have an understanding of the issues faced by clinical staff.

'Ideally what I'd like is a therapy manager to come and spend time with me on my ward to see what it's like. They're only exposed to the area they're working in and I don't think they realise that. I felt like I was banging my head against a brick wall because I went to him for support and it was more like, well, you need to manage your time. It was like I wasn't really being listened to. It was frustrating because I'd worked with him previously and he knew that time management was probably one of my better attributes. My line manager is very good and very supportive. I don't know if things will ever change, unfortunately. It's all about money at the end of the day.'

Occupational therapist



However, in contrast, other staff were overall positive in their views of management. This could be explained by a number of factors being in place. Firstly, the style of management being visible and joining in the workload with other staff. And, secondly, an awareness by management of the pressures on staff and a consideration of their wellbeing.

‘Although (name removed) may not be clinical, she is always in and out so people see her. She’ll come in and do the tea round, put some chemo up. So she’s always around and people can see that I think that benefits patients and staff. You feel like you’ve got that support as staff but also the patients know that they can just ask or she’s there. She’s on the end of the phone. Visibility is a big one.’

Specialist practitioner

‘If you’re not feeling very well or you’ve got stresses at home or bereavements, things are taken into account here which is really good.’

Staff nurse

‘Everybody has bad days but, again, it’s the kind of management that you can go in and say, look, I’m not feeling great today, or this has happened. Or go to our seniors and say, I don’t think that I could possibly deal with this patient today. Or I might just need to do a bit of admin today. Could I be put on this duty? Could I be put on that?’

Nurse



HOW MACMILLAN SUPPORTS EMPOWERING STAFF

The Macmillan Values Based Standard®

No matter where they sit in an organisation people can act as leaders. Frontline professionals and patients can often be best placed to say what is needed, and what should happen to get there. Healthcare professionals and patients need to be empowered to lead improvements in experiences of care. The Macmillan Value Based Standard® is a quality improvement framework for improving staff and patient experience. This is not a project – it is a way of working which focuses on continuous improvement, with the aim of creating behavioural and cultural change within organisations.

Macmillan worked with 300 healthcare professionals, patients and carers to translate human rights principles such as dignity and respect into practical, observable behaviours. The Standard is founded on eight behaviours that patients and their carers said matter the most, and that resonated with what matters to health professionals in their roles

Although originally developed for cancer care, some organisations across health and social care have been using it to improve the experience of all patients.

To find out more, visit learnzone.org.uk

These eight behaviours are:

- 1. Naming:** 'I am the expert on me.'
- 2. Private communication:** 'My business is my business.'
- 3. Communicating with more sensitivity:** 'I'm more than my condition.'
- 4. Clinical treatment and decision-making:** 'I'd like to understand what will happen to me.'
- 5. Acknowledge me if I'm in urgent need of support:** 'I'd like not to be ignored.'
- 6. Control over my personal space and environment:** 'I'd like to feel comfortable.'
- 7. Managing on my own:** 'I don't want to feel alone in this.'
- 8. Getting care right:** 'My concerns can be acted upon.'

STAFF WELLBEING

Staff talked about pressures they felt and how it impacted upon their wellbeing. Support from their team was important, and good workplace relationships and communication were key, with workload recognised as an impeding factor.

Workplace relationships were recognised by clinical and non-clinical staff across the trusts as an essential requirement to enable effective working. Across the interviews, the clear finding was that staff valued good working relationships with their peers.

'It's very important that the patients see that we're a team and that we're willing to help each other, because that makes them more valuable.'

Sister

'Staff relationships are a big thing because if you can't help each other then it would be a really hard place to work. If you see that someone is struggling and you can't offer any help? Because there's an awful amount of time where you need to say, "Please could you do this for me? I'm just busy for two minutes – please could you do this?". But knowing that someone would equally do that back for you.'

Healthcare assistant

'If you haven't got the support there then staff morale is going to wane. If you're not being given the opportunities to use – I don't know whether that sounds right, use your job, or fulfil your job in the way that you want to.'

Nurse

A number of staff talked about communication with consultants. In the first of the following quotes, the staff member recognises the importance to the patient of establishing a relationship with the consultant. However, the second quote demonstrates that this staff member felt that the communication between some consultants and administrative staff was less than optimal. They considered that it focused mainly on consultants' lack of understanding of the staff's role in assisting with the patient's care:

'It's really important to strike up a relationship with the consultants, from both ends of the scale. Having a relationship with the consultants as a staff nurse is brilliant because when you're with the patient and talking through their care, they presume that you all know each other. Wherever you work everybody presumes, oh, you know Dr So and So, and it's nice to be able to say, oh yes. And if they're in the building or they walk by you can talk about or go to them with a problem. It's really nice rather than to have to say to one of the sisters, "I've got a problem. Could you tell the consultant?" And again it's nice that if you've got a problem you can go to the secretaries, reception staff or healthcare assistants.

'Everybody is in the loop really. And I know in some places it's very segregated – the nurses do this, the consultants do that and you don't cross paths. But we really do here and quite a few of the consultants are friends as well. You do build up a good relationship.'

Staff nurse

'Getting patients treated within the timeframe is critical for the patient. Some consultants are fine, they're there and they're available to listen to you, but some are very dismissive. If you're looking at changing any aspects, even the slightest things like changing the way you put your list together for discussion, your patient cases, they get disgruntled about it'.

Administrator

Another aspect of consultant/team communication was the perceived division in the role between consultant and nurse in the context of breaking news to patients. It was viewed that the structure in which bad news was communicated to the patient/family was variable. There was a need for consistency within the team – consultant and nurse – as to how conversations with patients are managed at times of bad news and distress and their subsequent journey.

'It's been quite interesting to understand the dynamics between the clinician and the nurse and whose role and responsibility it all is. I think it varies. It's dependent on the ability of the clinician to be consistent in their approach to delivering bad news, and also consistent in their response to patients who express distress. Because the nurses then know what input they need to give. But it's this knowledge that this is the way we work. I consistently deliver the bad news in this way and you consistently mop up the effects, as it were.

'I suppose along with that is a trust and a mutual respect of each other's roles and responsibilities within that site-specific team. I see that to varying degrees within the organisation. I think we've got some clinical nurse specialists who don't necessarily class themselves as a cancer clinical nurse specialist. In some of the tumour sites the clinical nurse specialists to me are more like advanced practitioners so they scope or do certain interventions. I think the emphasis on what we would purely call the psychological is quite variable, really. And that is something we want to address in the organisation.'

Manager

There were some sentiments expressed by clinical staff about the impact their work had on their own wellbeing. When explored more deeply, stress and strain were often seen to be framed around perceptions of heavy workload and insufficient staffing, but the emotional nature of the work also played a part.

'Regarding working hours, it does put a lot of strain on you when you have to see lots of patients in a day. Although nobody seems to let it affect their care, it's having one in, one out and trying to get their treatment delivered as quickly as you can. But that could affect your care – you could be rushing them along and you can't always answer questions and things. I know we always try to.'

Nurse

While the opposite accounts relate to the impact of workload on patient care, staff also discussed the impact their workloads have on them.

‘You have to carry on as normal. Go home and carry on with normal home life. You think if you put the extra hours in it might make the next day a little better but it doesn’t because something else comes upon you. And each day you’re getting new patients coming into the system, new patients referred in. It’s busy and if there was an opportunity to get out I would.’

Senior administrator

‘If you’ve been emotionally attached to a patient then sometimes it is really difficult to hear that they’re not very well or they’ve died. And sometimes you do need a bit of a debrief of that because you could end up taking that home and it nagging at you all the time. You need to sit and chat about things sometimes and I think we could be a bit better at that.’

Staff nurse

Staff across the trusts also talked about the implications of staffing levels and the impact on their ability to do their job effectively.

‘If you don’t have the staff to provide the service and people are doing potentially one or two roles they don’t have the time to build that rapport. They don’t have time to sit for the extra 10 minutes with someone’s relative to explain what’s happened with their scan result. Even an extra five minutes to make someone a cup of tea is what people remember.’

Healthcare practitioner



HOW MACMILLAN IS SUPPORTING WELLBEING

Schwartz Centre Rounds®

Dealing with emotionally challenging situations is an everyday occurrence for those working in cancer care. But the need to present a professional face doesn't always allow time and space to think about the impact of difficult conversations and decisions. Reflective practice is a key ingredient of any learning organisation. Having the time to reflect on the emotional impact of patient care can benefit healthcare professionals' wellbeing and emotional resources, in turn reinvigorating their ability to provide compassionate care for patients.

One way of providing a safe space for this reflection is through Schwartz Centre Rounds. These bring staff together from all disciplines for regular facilitated discussions about social and emotional issues they face in caring for patients and families. The Point of Care Foundation provides organisations with training and support in running the Rounds.

Action learning sets

Clinical supervision is a well-established approach to using reflective practice and shared experiences to support learning and development. Action learning sets take staff through a group-style supervision setting, which as the group becomes more established becomes self sufficient, and staff facilitate themselves.

Action learning allows staff to develop their own skills in resolving individual workplace issues. It is usually carried out using a set format – participants present issues while other group members explore these and enable individuals to see what actions they can take to resolve them. The benefits of action learning sets extend beyond problem solving and sharing ideas, enhancing individuals' confidence and communication skills, as well as helping to develop self-awareness and leadership skills.

We've been working with cancer management teams in acute trusts to develop action learning sets. In one acute trust, approximately 60 staff have been supported through the group process, acting on the Care Quality Commission's recommendations to provide evidence of staff support. Despite the challenges of releasing staff to attend, these groups are now becoming self sustaining and embedded in clinical practice, with the continued support from Macmillan as needed.

TRAINING FOR STAFF

Learning and development is not only essential to enable staff to do their jobs to the best of their ability – it is also part of valuing and investing in them.

We found that staff's view about training contrasted between the trusts. Some clinical and non-clinical staff held positive views about management's encouraging attitude to staff training, access to training and the benefits of training to their work:

'Since day one I've been on an in-house training course and an in-house chemotherapy course. I'm also quite keen to go back to university after the chemotherapy course and do Masters courses. I've approached (name removed) and senior staff about that and they're really supportive and sorting things out like funding and study leave. That can all be taken into account. When I asked about doing my Masters it wasn't, "Oh, we'll have to see." It was, "Great – get the paperwork. Let's start the ball rolling."

Nurse

'Yes, I've done a lot of training since I've been here because I'm currently doing a Masters as well. I've always been given the time to do that, as well as the funding, which is brilliant. That's very important, particularly here. The training is quite focused and we've got a specific lead trainer and education nurse who makes sure that when she does the appraisals it's what you want to do, where possible.'

Healthcare practitioner

'We've always been supported to think about training. It's never been something that we've been told we couldn't do unless, obviously, it meant that the needs of the unit weren't going to be met.'

Healthcare assistant

In contrast, the views expressed by other, mainly clinical, staff reflected a more negative perspective. This included concerns about the quality of the training, along with access to and lack of cancer-based training generally.

'I'm worried about the NHS but in terms of our service I think we're alright. Some of the youngsters coming through, who are going to be our future leaders, are not getting the same level of education that perhaps we had when we were younger. That sort of traditional bit has gone, but the access to education to develop yourself – and therefore your care and skill – is lacking now. We have quite senior people who have no cancer qualification. It's not to say they're not good nurses. However, if you want to develop good, rounded individuals you need to give them some theory and understanding of disease process and the care and compassion path of cancer.'

Senior nurse

'I've never had any training but I feel alright about it because you just do it. It's more a confidence thing to make decisions and it's always a responsive thing. There's never any, "Tomorrow is a new day, so what are you doing in the here and now?" That's the fault of the whole hospital, the whole system, in that we think only of the next 24 hours rather than the day after.'

Consultant nurse

'In-house training has definitely improved but it's releasing the staff to go on the training. That's another thing that we fall down on. Staff are off sick and we get called off or pulled back from our study days to work on the ward.'

Nurse

'The main thing would be communication. I know generally that everybody is good at it but we all fall down at times. Sometimes it can be because you're so busy that you've forgotten to pass on a message or anything like that. I think communication is a big factor. In-house training has definitely improved but it's releasing the staff to go on the training. That's another thing we fall down on. Staff are off sick and we get called off or pulled back from our study days to work on the ward.'

Therapy lead for oncology

HOW MACMILLAN IS SUPPORTING TRAINING

We provide a wide range of development opportunities for all Macmillan professionals. This is to support them when they first become a Macmillan professional and make sure they can maximise the impact of their role as they develop it further.

The opportunities include:

Courses and workshops

We provide courses at different levels across the UK to ensure professionals have the knowledge and skills they need for their roles. Examples include:

Measuring impact

Professionals need to be able to demonstrate the impact of their services for a wide range of stakeholders, including peers, commissioners and people living with cancer. This course supports them in evaluation methodology.

Cancer awareness

Many Macmillan professionals are in non-clinical roles but need a good understanding of cancer and its impact to best support people living with cancer. This course covers definitions of cancer, diagnosis and treatment, and long-term impact.

Motivational interviewing

Many people living with cancer would like to manage their own health and wellbeing more effectively, and will need to do so more in the future as the number of people with cancer continues to grow. This course enables professionals to develop the skills they need to support people to self manage.

Mindfulness

We designed this course to enable professionals to look after their own health and wellbeing.

Coaching

We now offer coaching to support professionals who face challenges at work and need more intensive support than a traditional course can provide. This is one of the largest coaching programmes in the UK.

Learning and development grants

We recognise that professionals may need additional support that we're unable to provide. We offer individual and group grants for this purpose.

Healthcare assistants' programme

There are currently 1.3m frontline, unregistered staff in the UK who deliver the bulk of care in hospitals, care homes and individuals' own homes. Healthcare assistants are often those with the most direct contact with patients. Our work implementing the Macmillan Values Based Standard has found that health care assistants have the least investment in their professional development.

Given an opportunity to reflect upon patient experience, they continuously demonstrate how well they can respond to patients' needs. But they have little time to reflect on their practice, how their behaviours impact on their patients, or how their work affects them personally. Without this, the role of a health care assistant can become extremely task focused.

We're developing and testing a new, innovative development programme to support healthcare assistants in all healthcare settings. Possibly the first of its kind, the programme is workplace based, person centred, and embeds Macmillan's Value Based Standard of compassion, dignity

and respect as a common thread. Healthcare assistants from a variety of roles will go through the programme. The modules, combined with workplace support and experiential learning, support many of the requirements outlined in the new Care Certificate

Modules include:

- You and your values
- Working with the person I am with
- Supporting your communication skills at work
- Difficult conversations and looking after myself
- How I make a difference at work
- Knowing how I contribute to safe, high-quality care.

The programme will be piloted and evaluated in 2015. Once its efficacy has been demonstrated, there is the potential for it to be rolled out nationally.



AFTERWORD

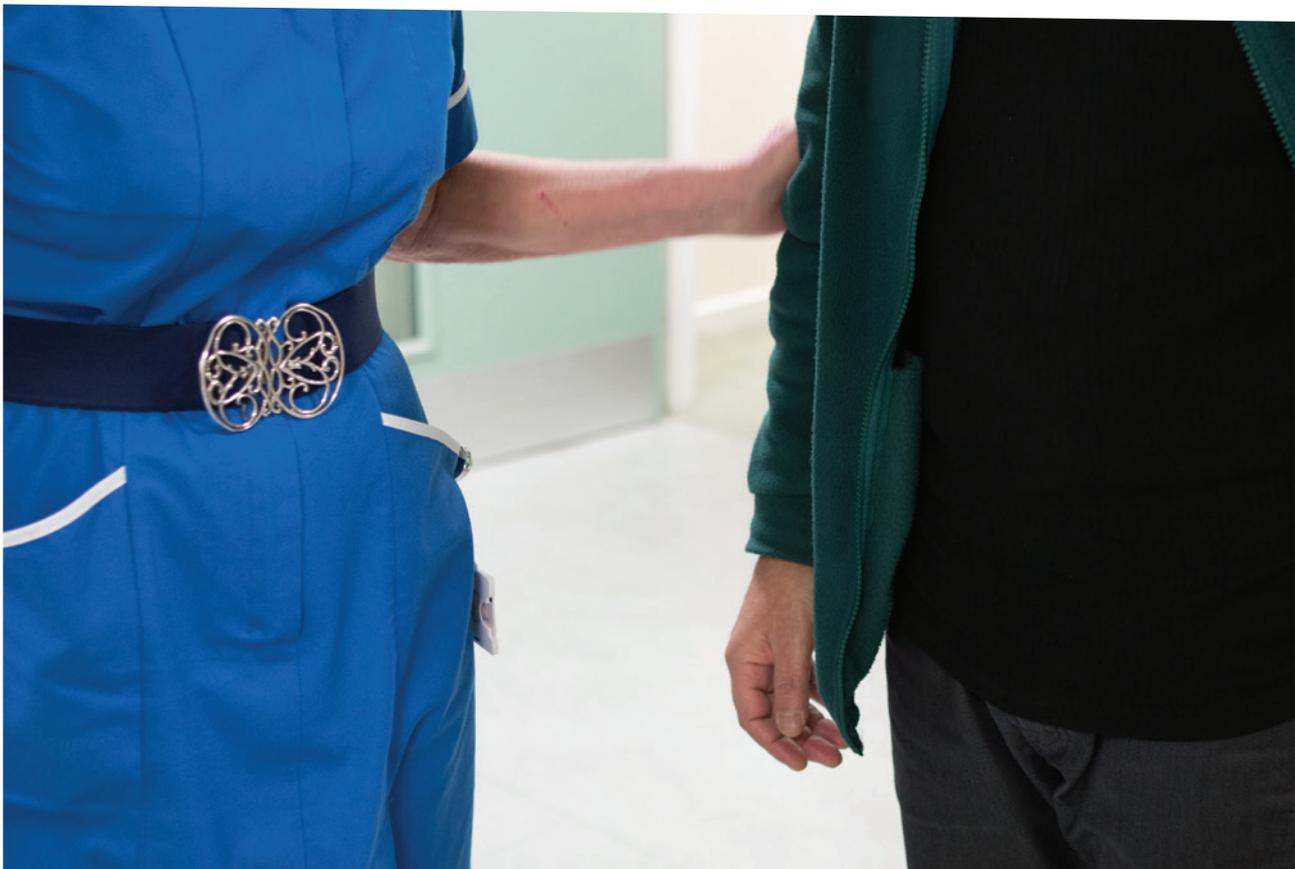
We're deeply grateful for the contributions of each patient and member of staff. Their openness and honesty is symbolic of the step that everyone in the NHS can take to move towards a learning culture rooted in the voices and experiences of staff and patients.

We want patients and staff to share their experiences, and use these to shape the relationships that are crucial to good cancer care. Too often, launching piecemeal, top-down solutions offers the immediacy of a quick win, but these solutions don't sustain over long periods. However, a culture of investing in relationships over time will.

People tell each other stories to feel safe, to learn and to strengthen relationships.

Patients are more than their conditions and staff more than their uniforms. They all have stories to tell and we should listen.

The Inclusion Department, Macmillan Cancer Support, 2015



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- ¹² Macmillan commissioned Picker Institute Europe to investigate the relationship between the results for the Cancer Patient Experience Survey (CPES) and the NHS Staff Survey. The data was from the 2011 CPES and the 2011 NHS Staff Survey. The full methods and analysis by Picker Institute Europe is shown in its report. The relationship between cancer patient experience and staff survey results. At a trust level, the analysis showed a number of correlations between different aspects of patient experience and staff survey key findings ie showing that positive patient experience was related to positive staff experience and vice versa. A limitation of the analysis is that staff survey results apply to those providing general patient care, not just those working with cancer patients. We assumed their experiences were representative of staff who work with cancer patients.
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When you have cancer, you don't just worry about what will happen to your body, you worry about what will happen to your life. How to talk to those close to you. What to do about work. How you'll cope with the extra costs.

At Macmillan, we know how a cancer diagnosis can affect everything. So when you need someone to turn to, we're here, because no one should face cancer alone. We can help you find answers to questions about your treatment and its effects. We can advise on work and benefits, and we're always here for emotional support when things get tough.

Right from the moment you're diagnosed, through your treatment and beyond, we're a constant source of support to help you feel more in control of your life.

We are millions of supporters, professionals, volunteers, campaigners and people affected by cancer. Together we make sure there's always someone here for you, to give you the support, energy and inspiration you need to help you feel more like you. We are all Macmillan.

For support, information or if you just want to chat, call us free on **0808 808 00 00** (Monday to Friday, 9am–8pm) or visit **[macmillan.org.uk](https://www.macmillan.org.uk)**