YASMINE

Female
Age 40-50
Refugee/Surgeon

Yasmine is a surgeon, who recognised her own symptoms during a lecture about a rare tumour. She was diagnosed abroad with a growth pressing on her optic nerve. She came to the UK three and a half years ago, fleeing domestic abuse, and told doctors immediately what she was living with. Yasmine has yet to receive the treatment she needs.

"As an asylum seeker, every time they move us from one place to another, I lose my specialist and I go on a waiting list from the beginning for six months or one year."

The pattern has repeated for three and a half years. New address, new GP, new referral, new waiting list. Meanwhile the tumour and pain have grown. At one point the Home Office moved to relocate her again, which would have meant losing a specialist she had already waited six months to see.

She needed a letter from the hospital confirming she was under their care. She was told to speak to the specialist's secretary so she went in person.

"I just mentioned the word report. She stood, hit the table. 'We're not giving anything for an asylum seeker here. Go out, you don't talk to me.'"
Yasmine notes that the woman who said this was not white either.

"We're both foreign. Why are you treating us like that?"

She left in tears. She then had no contact from the specialist for five months, not receiving any letters, until they called to ask why she was not attending appointments. At that point she did not know the NHS app existed. Nobody had told her.

Two weeks before this conversation, the Home Office wanted her to move to Wales. Accepting would have meant losing her neurology appointment; the first real offer of surgery in three and a half years. She refused, and submitted medical evidence explaining why. Her financial support was stopped.

"They say everything is paper, paper. But we provide everything, and they still don't want to look at it."

When asked about Macmillan, she said she knew about them but understood she was not entitled to a referral.
'No, I'm not allowed because I'm an asylum seeker. I'm not a refugee. I've been here for three years and a half now. I don't even have a proper report from the hospital that explains my case'

When asked if she has looked for any support, she said she had tried but no one listened or helped. Now she's given up on them, because it is such a struggle and even trying to have the conversation could affect her health

'I get nothing from anywhere, you know. So why should I bother myself? Why should I be crying and then crying affects my head and then I will end up in the hospital. And what else? Who will look after my kids? Nobody.'

Yasmine volunteers with a refugee charity, running a women's group every Friday for elderly women: Helping them to use the NHS app, taking them to appointments, interpreting and helping with forms. She works to help people navigate the gap between health and asylum systems. As much as possible she spends quality time with her two young children.
Yasmine is a doctor. She speaks English. She knows what her tumour is, where it sits, what the operation involves, she has even watched the procedure performed. None of it helps.

"I'm a surgeon. I've been there. I watched this operation before. I know how it's done. But I have no power here. I'm an asylum seeker."

MARGARET

Female
Age 70-80
Irish/White

Margaret was 77 when she began wetting herself and assumed it was a urinary infection. She booked an appointment, was sent for a scan within a fortnight, and was called back for a second one. She brought her granddaughter with her.

Nobody told her what they found.

"I received a second scan and at this time my granddaughter overheard the team discussing that there was cancer in the scan. My granddaughter told me what she had heard."

The staff had discussed the results with each other, in the room, without addressing her. Margaret felt her granddaughter was put in a difficult and unfair position; being left to deliver the news. In fact she was never formally told at all. It only became explicit when an operation was offered.

"I pride myself on speaking up for myself but felt dismissed due to my age... I never really got told it was cancer, only when they were going to offer me an operation."

Margaret felt the process was far too sudden, with little to no advice given. Instead she was given lots of leaflets, which only made the process more overwhelming. This led her to make a treatment decision she now regrets. She declined radiotherapy because "I didn't want nuclear particles in my body". Even though she was not happy about chemotherapy, she assumed it was safer.

"The hospital gave me lots of flyers without explaining the treatments and the cycle of what was going to happen. As I felt completely overwhelmed, the leaflets were useless as I was unable to digest the information."

"*I could have been informed of the cancer diagnosis more clearly as a lot of the information went over my head because I was just distressed by my symptoms.*"

"When the cancer was found, if somebody had sat me down and discussed the treatment with me I would have possibly made a different decision."

She had five surgeries in total, and three bouts of sepsis. Her experiences with the hospital show how little was explained to her. As her family live outside London, it was not possible for them to be present throughout.
From one surgery she had a PEG inserted but did not know what it was. It later fell out at home and nobody could tell her what it had been for. She kept it.

After surgery she was discharged on a weekend, sent home on the bus and had to come back the following day:

"I was discharged on the weekend in my nightie but due to transport problems at the hospital I was sent home on the bus. The only medication I was given was for overnight so I had to return in the morning."

She was fitted with a stoma bag but not taught how to change it, or any thought given to the fact she lives alone.

"After the operation I was given a stoma bag that was impossible for me to fit as it required two people, so I had to ask a neighbour to help fit it which was extremely embarrassing. I had to do it for a year. It took two weeks for a stoma nurse to show me how to fit the equipment and have a conversation on how it works."

In the meantime the bag leaked constantly. She was changing bedding repeatedly, and had to ask a neighbour she barely knew for help with something intensely private.

"At this stage she looked for support and found Macmillan through her own research and joined a group.

"When I attended the group, the Macmillan person spoke about what you could have before the operation ('would of, could of, should of'). I was very upset as it was like me having a hysterectomy and then being offered birth control."

Many of the attendees had stoma bags fitted but the material was all pre-surgery, including how to avoid needing a stoma at all.

"I was very angry as firstly I had to find the group myself, and the information I was given was absolutely useless. From the experience of the group I would not recommend someone to Macmillan."

Margaret felt totally lost and became suicidal during this period, remembering sitting on the floor and crying when the bed was wet.
The turning point came when, through her own research, Margaret found a company who made stoma bags she could fit without a second pair of hands. She feels this restored her dignity and she got her life back.

Margaret had advantages many patients don't: fluent English, good health literacy, a radiologist in the family, and a habit of speaking up for herself. She was still let down at nearly every stage with no one in her health journey giving her time or meaningful support outside of friends and family. And the one time she actively sought help actually made things worse.

DENISE

Female
Age 45-54 South East
Carer for a LGBTQ+ friend

Denise's friend was diagnosed in March 2026. He'd had kidney disease for years, so when his legs began swelling, everyone assumed the two were connected. A test came back with very high cancer markers. The hospital suspected testicular cancer. It was only when they scanned him that they found a 10kg growth on his stomach.

He needs aggressive radiotherapy. Because of the kidney disease, he can't have it, so his treatment will take longer.

Denise isn't family. She's a friend of forty years, and she is the only person he will accept help from.

He is gay, and not out. That fact shapes everything about how he is cared for.

"Because of sexuality everything is very secretive, so he doesn't want anyone to know about anything."

He goes to all his treatment alone. He wants Denise to come to the hospital occasionally, but not to be seen with him, partly because of incontinence caused by his condition, which he finds humiliating. He has refused every other offer of support. Denise describes him as very proud. She does his washing and brings him food. He won't let her into his home.

"I do everything for him; washing clothes, food, but he's refusing access to his home, so I have to leave it on the front porch."

She felt she was coerced emotionally to be listed as his next of kin. During a conversation with a nurse at his bedside, the nurse pointed out repeatedly that he had no next of kin. As he was there within earshot Denise felt like she had no choice but to offer, to which he said yes. She was given no guidance on what being next of kin or a carer involves.

She isn't given access to his notes. She sits in on consultations at his request; "he asked me to sit in with the consultation as he is very scared now", and afterwards works out what was actually said.

"Leaflets were given but not explained so I had to google the information to discuss with my friend."

"Overwhelmed with information with leaflets. I put together a folder for him to read at his own leisure. I am able to go through the information after the consultant at a slower pace but I use google to find out information as I am not given his notes so I need to speak to him after to get an understanding of the conversation."

Being present together helped, but only up to a point.

*"**We felt it was easier to ask questions as we were together but the information was brushed over and we were just given another leaflet for us to find out ourselves."***

Denise is also feeling pressure financially, emotionally and the increased time & energy burden of unpaid care. It takes two buses and a walk to reach the hospital, then an Uber home to her family, who have special needs of their own. Her friend cannot help financially and she has no entitlement.

"Transport issues and cost and a difficult place to get there. I need to take two buses and walk and then Uber back home to my family who have special needs."

She is managing her own health at the same time. Denise lives with a long-term health condition and mental health conditions. Her own lived experience includes domestic violence, abuse, foster care and financial hardship. She is doing all of this unpaid, alongside a family who need her.

When asked what would help her situation, her wishes are actually quite simple: “Travel care for carer/hospital patient and help with transport”

Every point of contact this patient has with the health system runs through one person. She not only helps him as a friend or with household chores, but also in helping to understand and decipher the leaflets and advice from Doctors. If Denise can no longer help, her friend's care journey is put at risk. Meanwhile nobody is asking how she is or what she needs.

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