

Helen Jackson—the seventh interviewee in my [chain interview experiment](#)



Helen was introduced by my sixth interviewee, Maria Leaf. She said: I've chosen my friend Helen Jackson who is a nurse in Leeds. I think back to the time when I was growing up. She was the friend I sat next to and she would say, "Yes of course you can do drama—of course you can be an actress". And I admire her because of her commitment to the NHS, especially in the present climate. She has just powered on in the face of adversity."

I met up with Helen in the cafe at Waterstones in Leeds. She told me about her job as a cancer specialist nurse and about some remarkable experiences that shaped her approach to this work.

Tell me what you're doing at the moment, Helen

For the past few years I've been working as a clinical nurse specialist with malignant melanoma patients, and I love it. My role is varied and quite different from the usual sort of nursing. I act as a key worker in co-ordinating care but a big part of my work is in offering psychological and emotional support to patients and their families. I meet people from all walks of life and follow them through until they're discharged or they die. Until about five years ago we had no real treatment for patients who had developed Stage 4 melanoma and the survival rate was very poor. But recently we've been trialling immunotherapy which involves stimulating the body's immune system so that it attacks the cancer. It's given intravenously in the chemotherapy day unit and the side effects are different from chemotherapy. People don't lose their hair and whilst they might get a bit of sickness, we're finding that many patients are able to carry on working full-time during their treatment. Other cancer groups are starting to use it too but we're still on a learning curve. It makes melanoma an exciting area to work at the moment.

How did you get into nursing?

I always wanted to do it. If you'd asked me at five years old I would have said that I wanted to be a nurse. My mother was a physiotherapist, my grandad was a pharmacist, and four of my aunts were nurses or midwives. So I grew up hearing conversations about that kind of world and perhaps that sparked my interest. I think it's a personality thing too. Like Maria, I enjoyed drama and I did toy with the idea of that, but in the end I chose nursing.



Photo: Mtaylor848

I trained at Leeds General Infirmary in the days when they took a new cohort of about thirty-five trainees every three months. We had six weeks in the School of Health and then we started our first ward placement. People, now, would have a fit at what we did. We were certainly thrown in at the deep end. I was quite quickly exposed to seriously ill patients and assisting with things like cardiac arrests. You'd observe a procedure and then be told "Nurse Jackson, that lady over there needs catheterising. Off you go, I'll watch you." So you did it and your confidence grew. And sometimes funny things happened. One day I was working with another student nurse and we'd been told to get a patient ready to go down for a procedure. My colleague went to the linen cupboard to get a gown and went behind the curtains to dress the patient. I was talking to the staff nurse and then the curtains were pulled

back and there was this little elderly lady in a frilly bedsheet kind of thing. She obviously knew what she was wearing but hadn't had the heart to say anything. It was a shroud. Fortunately she did see the funny side.

What did you do after you qualified?

Not long after qualifying I went to work in Romania as part of a charity based in Constanta on the Black Sea. It was about eighteen months after the revolution and I was on a ward for children with AIDs. It was very challenging and I saw things that no-one would ever want to see but it was as much a rewarding experience as a devastating one. They'd already had some help from charities so the situation was vastly improved from what it had been. But compared to what you would see here it was still like watching a car crash.

Under Ceausescu's regime both abortion and contraception were illegal. He'd wanted people to have as many children as possible in order to create a massive workforce but the trouble was that people were completely impoverished and huge numbers of children were abandoned. It was devastating for parents to leave their children at the orphanages but they simply couldn't afford to look after them. The orphanages had very few facilities and would typically have just two members of staff. It was a constant cycle of changing and feeding, and babies were left propped up in cots with bottles. The children were malnourished and many had anaemia. They also had deficits because no one was talking to them or stimulating them. Children who aren't picked up or cuddled will eventually stop crying. Another problem was that paediatricians were quite desperate to keep children alive—if a child died, then they had their wages docked. This led to practices that you wouldn't even consider under normal circumstances. For example, the staff got the idea that if they gave children small infusions of blood then that would strengthen them. They'd get cheap blood from Africa and other places and give children between 10ml and 30ml each. One 450ml bag of blood goes quite a long way like that, and as they re-used syringes and needles, it resulted in a huge population of children with AIDS. At that time the country was closed to outside information but the doctor in charge of the hospital began to realise what was happening. She reported seeing large numbers of children with HIV and AIDS-related symptoms. The response from the Government was to ban her from talking about it or seeking help, and she was followed by the Securitate.

When the regime ended she could go to conferences and seek outside help but there was still no money for treatment. And the awful thing was that people were scared of these children.

When you got there what did you find?

Well by then, the children weren't just being left in their cots. There was a playroom with toys and a television and they were given meals. There were also some educational activities but the bathroom situation was dire. There were a couple of big toilets but these were no good for the little children so they had a row of potties. The kids all had chronic diarrhoea and the potties weren't emptied regularly. Once a week the children were washed— they were literally hosed down. We said that if we did nothing else then we wanted to provide a proper bathroom for them. We also built a playground on a bit of scrub grass. A lot of the children had joint problems because they'd been in cots for three years so they needed facilities where they could play and develop. My mum came over and did some



physiotherapy with them. It was nice but can you imagine if people did that here? In Romania, they were so desperate for help that anyone could have wandered in.

Another thing that we tried to do was to boost the confidence and morale of the nursing staff. There was a stigma to working with these children and people didn't feel it was anything to be proud of. The staff were all poor and they didn't understand why so much care was being lavished on children who were going to die anyway. In this country we understand the need to support people through terminal illness—to give care and pain relief. But that concept wasn't there for them.

Did that change?

It started to. We did a lot of work with the staff. For example, a convoy came over with medical supplies and I asked for some nice things that we could give to the nurses. We made up a box for each of them with chocolate, coffee, soap—things to make them feel valued and that they couldn't afford to buy in the shops. There was also the problem that by coming in and doing things in the hospital, we were undermining them to a certain extent. It was like saying, "You haven't been doing your job well enough so other people are coming in to help you do it better." We wanted to avoid them feeling that.

There were many difficult things but one still really upsets me. It was not long after I got there, and a child came to the hospital from the orphanage. She was a little girl of about six although she looked much smaller, and she was skeletal and moribund. I went into one of the side rooms with another English nurse and found her there. It was clear that she was dying but she was all alone and grossly dehydrated. Her breathing was really laboured and she was very uncomfortable—I felt so angry. I went out of the room and collared one of the nurses who said, "Well she's dying. What can we do? There's no point." The staff couldn't understand why we were so upset but we gave her some fluids and some Calpol—they did at least have that. And we just sat with her and she died in our arms not very long afterwards. When she did die, one of the nurses came in to light a candle. They do that when someone dies and blow it out to let the spirit go. Then they literally bundle up the dead body in a sheet, tie it up at either end and swing it down the corridor to the mortuary. That was one of the most devastating things I saw and I think it has impacted very much on my feelings about how to support people at the end of their life. Here, I see some very upsetting things but however difficult it is, I don't see anything like that. There, life was cheap but hopefully my patients don't die in pain. You can't make it perfect every time because sometimes emergencies happen, but generally where you can, you try to make the end as supported and dignified as possible.



I also remember a little girl called Florentina who was three and a half. I liked her from the moment I saw her. She was very spirited and hilarious—a right little monkey. She used to run around and talk but then she got quite poorly with diarrhoea. She was in her cot and I asked if I could have some stuff to clean her up but they said, "She's already been changed today." And I said, "Yes, but she needs changing every ten minutes." So we cleaned her all up and gave her some sips of water because she was grossly

dehydrated. It was summer and about forty degrees. We gave her some mashed up food and she survived the whole process. After that she called me 'Mummy' and it was really hard to leave her when I came home. She was such a bright, lovely little thing and if she hadn't been born into that awful situation, she would have had lots to offer in life.

The hot water system in Romania was turned on and off by the Government so you would never know when you were going to get it. When I got back to England and was working in a hospital I remember turning on the taps, and being surprised that the water was warm, and also that there was so much in the drugs cupboards. In Romania we had very few basic medicines. Sometimes I think that if people could only see that then there would be a greater appreciation of what we do have. Some things are just too powerful to ever leave you.

Is there anything else that has affected the way you work today?

Well, my parents divorced when I was ten and that was quite a defining moment. We moved from a little village in Hampshire to a challenging inner city area of Leeds. My mum had to be very tough because she was pregnant when my dad left. The role of being supportive started early on—there are five of us and I'm the eldest—and I felt responsible for my siblings and also for my mum as I could see that she was very sad. My grandmother took us in and later when my mum bought a house she moved in with us. She was like a second mum and did lots for all of us—she was an amazing lady. She had cancer when I was nineteen and as my mum has no brothers or sisters, I was the only person there to help. My mum and I got to the hospital just a few minutes after she died. It was very early in the morning so when we came back home, the other kids were in bed. And I could see that my mum wouldn't be able to tell them. So I told the boys and then I told the girls. It was devastating but I did it.

That was my first experience of breaking bad news and I do it rather a lot now. I suppose it's been a pattern in my career—if ever relatives have needed to be phoned then nine times out of ten people say, "Helen will you do it?" and I think it's because I understand. It's a huge responsibility. People may not remember what you said or what you did but they'll remember how you made them feel at that moment. It's important to be really honest. But I think people also need to feel that you care about the person that was important to them. You need to make it personal and not as if you're reading it from a sheet. I always try to think that if this was my husband or brother or sister how would I like to be told. What would be the important things for me to hear? If any of my patients are dying in the hospital then I'll often go to see the family during that time or just after. Because I've known their relative for some time then I can talk to the family in a different way. Sometimes you don't have to say very much. It's just about holding someone and letting them talk about their relative. And being an anchor when everything has gone haywire.

What are the best and worst bits of your job?

Sometimes the worst and the best bits come together. It's an enormous privilege to look after people when they're facing challenges and are at their most vulnerable. You get to know your patients and whilst you treat them all the same, there will always be people that you particularly connect with. It's hugely rewarding to support people through a difficult process but when you watch them deteriorate and die it can be very hard. You have to remember that it's not your relative but equally as a human being it's impossible not to relate to that. Whatever level of professionalism you maintain at work you still feel it and to say that I never shed tears over my patients would be a lie. I absolutely do, and sometimes with them, but you learn ways of coping because otherwise you couldn't do it. The uniform is a kind of armour—you do your work and then you take it off. I get the bus to and from work and that forty-five minutes at the end of the day is like a psychic shower. I read a book or I think and then when I walk through the door at home, that's it. But the day I don't find my job a privilege is the day I think I should leave. I don't ever feel that I made the wrong decision. I still love what I do.

And who are you going to pass me onto, Helen, as the next link in the chain?

I'm passing you on to Liz Carrington who is a physiotherapist and friend of my Mum. Through her work in India she inspired me to look at volunteering myself and that's how I found myself in Romania.