

Inspiring Doctors. Episode 3: Rachel Clarke

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Martin McKee

Welcome to Inspiring Doctors, a podcast series brought to you by the British Medical Association. I'm Martin McKee, a professor of public health and the president of the BMA. In this series, I'm joined by people who I see as role models. They've successfully taken their medical knowledge to a wider audience in creative ways. So, what inspired their work? What lessons have they learned? And what advice do they have for young doctors who may want to follow in their footsteps?

There is something magical about the confluence of medicine and communication. My interviewees are only some of the role models who do this work. But they are all people who have inspired me. I hope that our conversations will in turn inspire you.

My guest today is Rachel Clarke. Rachel is a palliative care doctor and author of three *Sunday Times* bestselling books about her experiences of working in the NHS as a junior doctor, in hospice care, and most recently in the COVID-19 pandemic.

Rachel has been described by *The Guardian* as one of 'the very best doctor writers to emerge within a rich new scene'. Alongside her work in palliative care, Rachel writes for *The Guardian*, *The New York Times*, *The New Statesman*, and the *BMJ*, among other publications, as well as making regular television and radio appearances, and most recently at the Hay Festival.

Indeed, Rachel's first career before medicine was as a television journalist and a documentary maker, reporting on conflicts such as the Gulf War and the Second Congo War. She left journalism to pursue a medical degree in 2003 and at the age of 29, following in the footsteps of her father who was a GP, she began working as a junior doctor in 2009. She was the driving force and a public face of the junior doctor strikes in 2016. Welcome, Rachel.

Rachel Clarke

Thank you very much, Martin.

Martin

Now, your career trajectory, starting out as a television journalist, is really quite an unusual one in medicine. But you come from a medical family. You've got four generations of doctors, including your father, who was a general practitioner like mine was, and a great inspiration to you. So, it's perhaps no surprise that you then did decide to retrain as a doctor.

You once said in an interview with *The Observer* in 2020 that 'the heart of good journalism and the heart of good medicine is in some way the same. They are both fundamentally about relationships with people and listening to and respecting people's stories.'

So, the human story is the heart of journalism and equally in medicine, in every conceivable way, the human story matters. Could you tell us more about what you mean by that, the importance of stories in medicine? What have you taken with you from your career as a television journalist into your medical practice?

Rachel

I think fundamentally, unlike physical objects in the world, which are governed by the laws of Newtonian mechanics, people are not apples that fall from the tree. You know, our bodies may be beholden to those physical laws, but our minds, our psychology, that's not how we understand a person. We understand a person through meaning, what matters to them, what is significant and important to them and their values, what we care about, what motivates us. Are we driven by kindness, ambition, avarice, generosity?

You know, we're all a compendium of different values and characteristics. And therefore, I believe very strongly that the way to understand a human being fundamentally is in terms of what is meaningful to them, in the way that they are trying to live their life. And in medicine, it is easy to forget just how important what matters to the patient is as the underlying defining question that every doctor should have in the forefront of their minds in every consultation. Because it simply doesn't matter what our own opinions are about whether chemotherapy 'x' or surgery 'y' is the best thing for this patient. We may have got that completely wrong if we don't understand what's important to them.

Patients are people first and foremost, and I think the very proactive, attentive listening to interviewees that is an essential part of journalism was also wonderful training for me as a doctor. Listening is an incredibly powerful tool in life, full stop.

Famously, William Osler once said, 'Just listen to your patient. They are telling you the diagnosis.' That is abundantly true, particularly if by 'diagnosis' we mean not just the fact that this patient has a liver abscess or an inflamed colon, but maybe part of that diagnosis is they are wracked with anxiety because they're afraid they may have cancer or they are feeling desperately anxious because they've left their young children at home and they haven't really been able to sort out someone to look after them.

So, I try and remember in each consultation, and I often say this to the patient, there is only one person in charge here, one person's the boss and it's you. My job is to understand what's important to you and then try to help and guide you in making the best decision for you. And I think that process of framing the consultation around a centre point, that is the patient, is a narrative exercise. We can't do that if we don't understand the patient's values, their own narrative, and what is important to them in their life.

So, in a sense, we almost have to read our patients in the same way that we read a book. A consultation should be an act of imaginative empathy. And that might sound very, sort of idealistic, but it should be at the heart of medicine.

Martin

I think that's so important. Much of my work takes place outside the United Kingdom, and one of the things that I find to be very important when you're having a conversation with someone is to be constantly testing the language that's used to see if you're actually using words in the same way. So often we use words, but we attribute completely different meanings to them. And when you watch these conversations, people are just talking past one another. So, you must have found that too, particularly in your work overseas.

Rachel

Absolutely, and in this country as well. I mean, it's fascinating how we can be using nominally the same language, but actually the potential for misunderstanding is so pronounced in a medical consultation.

I remember vividly as a medical student being taught this by an incredible consultant haematologist, who was one of my great mentors as I learned medicine, because he was exceptionally good at communicating with patients. And one day he told a group of us students a story about how he had laboured and laboured with a patient and the patient's wife, to communicate the fact that he had a diagnosis of blood cancer or a form of leukaemia.

And he put all his effort into communicating this without jargon and without technical terms. And he was feeling quite smug with himself at the end and thinking, this has gone terribly, terribly well. Well done me, I've done such a great job. And just as they were leaving the consulting room, the wife of the patient turned to him and said, 'Thank you so much for explaining everything so superbly, Dr Littlewood. We're just so glad it's not cancer.'

Martin

But it is whenever doctors do have that ability to really engage with the patient. One of my role models, a consultant I worked for in Northern Ireland, where we had a tremendous burden of respiratory disease, he knew everything about the different jobs that people did in the shipyards, in the linen industry, because what you got really related to which bit of the factory in which you work. And I think that ability to go beyond just looking at the results and so on, but to engage with the patients to find out what the reality of their lived experience was.

But I wonder if we're going in the wrong direction, because as we listen to media reports of scientific advances, one sometimes feels that humans are being reduced to a combination of DNA, RNA and proteins, for example. And at the same time, the decision-making process, the diagnostic process, the conversation looks as if it may be going towards artificial intelligence. And it's not quite clear that a machine will have the same empathy that you will have. So, are you worried that we're moving away from all of that?

Rachel

I absolutely am Martin. And my great fear for the future of medicine is a world in which human relationships, human touch, a clinician giving you their time and attention and energy becomes something that is no longer universal in healthcare in this country, it's actually something that is the preserve of the rich, those who are rich enough to pay for it.

We already have a two-tier system where, for example, an NHS GP appointment will be 10 minutes if you're lucky. I have oncology colleagues who have 10 minutes in an outpatient clinic to break the news to a patient that they have a diagnosis of cancer, or their cancer is now terminal. 10 minutes. And of course, if you are lucky enough to be able to pay for a private GP or secondary care consultation, you may have half an hour, an hour to have that conversation.

And I think the idea of machines, artificial intelligence, replacing doctors is always dressed up in very positive terms, 'this will free up the human beings to provide patients with the human touch. The thing that no computer can do.' To which I always think, aha, will it? I'm just not sure that's part of the business plan of the big American hedge funds that are behind these initiatives. And it's a great concern.

Martin

You know, it's interesting, we're just finishing a systematic review where we're looking at the issue of trust in artificial intelligence and this phenomenon of explainable AI. That's where the machine tells you how it came to the decision, because the challenge is that either the clinicians don't trust it enough, so they don't use it, or they trust it too much and then they defer to it when their judgment would tell them otherwise. And often they're right.

So, there are a lot of things that we need to work out and all of that. It does make me think, again, going back to your father because presumably, he was a GP in a time when there was that continuity of care, as there was with my parents who were general practitioners, and they knew everything about their patients. They saw them and they knew their families, they knew where they worked and so on.

Rachel

Yeah, completely. So Dad was a sort of old-school family GP who would know three, even four generations of the same family. He had some patients who he saw from a bump inside their mothers to being an adult middle-aged individual. He spent that much time in his practice. And he was loved by his patients because he was sometimes the one constant in turbulent, traumatic lives. And so he had this incredible trust with his patients, and I think he really cared about them, in a very simple human sense. And they knew that.

There's a wonderful book about this, which I would sort of press into the hands of every young doctor and medical student, which is by a journalist called Polly Morland, and it's called *A Fortunate Woman*. And it is her description of a female GP in a very rural practice and the kind of traditional, relationship-centred medicine she strives to practice, even when COVID-19 ravages the country. And it's pretty much everything about what matters in medicine in that book. It's wonderful.

Martin

I look forward to reading that.

Being a palliative care doctor, you're surrounded by death and dying on a daily basis, and many people will see that as a depressing career choice. But in your TEDx talk called *Pink gin and lemonade*, you stressed that palliative medicine is a specialty that gives you creative licence to bring joy to patients' lives in imaginative ways. As the title of your talk suggests, in one case that involved pink gin and lemonade for one of your patients, and in another, sneaking the cherished prize-winning bull of another patient, a farmer, into the hospice garden. So, could you tell us more about why you chose to specialise in palliative medicine?

Rachel

Yes. So, for me, I always wanted to work with patients who had very, very grave and serious things wrong with them. I think in part because I went into medicine later in life, I gave up a career to become a doctor. But also, I learned very quickly as a medical student that within the whole collective of patients, there was something of a hierarchy, and some patients were definitely at the bottom of the heap, and palliative care patients were most certainly in that category on the bottom.

I describe in one of my books this horrific experience where I was on a surgical ward round as a medical student, and the consultant surgeon told a patient that they had cancer and their cancer was inoperable. And as we turned away from the patient's bedside, he glanced at his junior doctor and said in the most dismissive way, 'Send her to the palliative dustbin.'

And I was so disgusted by that. I couldn't believe a doctor could treat a human life with such contempt. And I realised that these patients were no longer interesting to certain doctors because we didn't any longer have the capacity to save their lives. But to me, they were still human beings and in fact, they needed us even more than maybe other patients, precisely because they knew they were dying.

And in palliative medicine, I think more than any other specialty, the focus is enabling patients to live as fully and as richly as possible on their own terms. Whatever time remains to them, whether it is weeks, days, even hours sometimes.

That means it's a very creative form of medicine because sometimes the best thing you can do is put up a syringe driver with the right doses of morphine. But sometimes it is literally smuggling a bull into the hospital premises without telling anyone in the hospital because, you know, it was best they didn't know that a tractor and a trailer and a bull were passing all of the hospital car parks. Or providing a patient with their drink of choice, or maybe getting them to sit at the riverbank where every Saturday for the last 30 years they've gone fishing, and although they can't fish now, they can sit there and relive that experience.

Or even once, I remember some years ago I cared for a very young man who was dying, and his mates were all going to Ibiza for a bit of a rave and a massive drinking weekend, and he had a syringe driver. He said to me, 'I know you're going to think this is crazy, but I want to go. You're going to stop me, aren't you?' And I said, 'No, let's talk about the risks. Let's see what you think about them.'

And sure enough, with his syringe driver on the aeroplane slung over his shoulder, he set off and had a wonderful time, you know, in Ibiza, watching his mates one last time as they all got absolutely hammered and he had a few sips alongside. And that opportunity as a doctor to practise 'hard medicine', the difficult matter of physical diagnosis and treatment. But also on the other hand, practising a very human form of medicine where you are using all your powers of empathy and creativity to think: this patient has told me what matters to them, how can I help them enact it, even though they're frail and in their last days of life? I adore that. I absolutely love it.

Martin

But what you're also telling us is that these experiences are so rewarding for you, too. And we always remember individual patients. One of mine was an elderly woman who had secondaries from lung cancer, non-smoker, but had secondaries in her spine when I was a house officer in orthopaedics, and I had been reading up on palliative care. We didn't really have a palliative care service, but I was able to alleviate her pain and she had a peaceful and relatively pain-free death.

And you still remember that. Well, I mean, I'm thinking back to 1979 now, so it's a very long time ago. But that's what gives you that sort of buzz in medicine, the satisfaction, the sense that you're doing something. But sticking with this hierarchy of patients, because hospice care is largely outside the NHS, it's provided by Marie Curie and by local charities and by others. Doesn't that tell us everything?

Rachel

It's a national scandal. I mean, the cliché about the NHS is that from its inception in a wonderful moment in 1948, it would provide a cradle-to-grave National Health Service for everybody according to their medical needs. And that's absolute rubbish because today, over two thirds of palliative care in Britain is funded by charities, not by the NHS. And that's not just hospice care, that is care where staff are going into patients' own homes, and it's also often care of hospital inpatients, which is actually provided by teams that are funded by charitable donations.

So, we live in this astonishing situation where the one certainty for every human being in this country is we will die. We know that there is a terrible burden of unnecessary, avoidable suffering around the end of life. And yet, whether or not you get basic palliative care depends on how many people ran the London Marathon and held a car boot sale this weekend and therefore got the donations in.

And I just think that is scandalous. And I think it's to do with the fact that in healthcare, to a significant extent, the resources follow who has the loudest voices. So, if you can mount an incredibly successful, seductive campaign and maybe get celebrities on board, then there's a really good chance you can promote your cause. I won't give examples of that because it's not fair and, you know, every patient, every illness is important.

But the fact is: dying isn't sexy. It's not seductive. It's something that's a taboo topic in this country. And often not just members of the public, but doctors and healthcare providers as well, feel intimidated by dying patients and anxious – they don't quite know how to relate to them. They almost see them as aliens, not quite people like you or me. Whereas the truth is, a dying person is literally you, Martin, or me, Rachel, a little bit further down the line.

Martin

Indeed, a very sobering thought. But it's not just this country; the situation in many other countries, the Project on Death in America and so on, is a reminder that across the world we have an enormous problem.

Rachel

Absolutely, yes.

Martin

You tell many patients' stories in your books, but of course, as a doctor, you have to avoid sharing information without their consent. Now, a lot of people who are going to be listening to this podcast are going to be looking to you and to my other guests as people that they will want to follow. So, just a bit of practical information for them. How do you handle the balance of telling stories that are or feel real while also keeping patients anonymous when they need to be?

Rachel

So, a really important question this, and I wrestled with this long and hard before I started writing, and I ended up coming down to a basic principle. For me, in order to preserve patients' and relatives' confidentiality, I needed to anonymise any individual to such an extent that not only would nobody else be able to recognise their story, but crucially, that individual themselves, or somebody who knew them would not be able to recognise them either.

And the only way to do that, I felt, was not necessarily simply just to change identifying details, gender, age, disease, etc. It was actually to write stories that were composites of different individuals, different situations, so that even the patient themselves could not read that story and recognise themselves.

And I think in order to do that honestly, you have to be upfront and open and candid about it. And so, in each of my three books, I have an author's note at the start where I explain that process very clearly, and the fact that these stories are composites. They have been formed and shaped, and I think it's really important to just be open about that.

The other thing that I prefer to do actually, when I'm writing, is to consider talking to a patient or a relative about whether or not they might like to be written about with their consent. And that would always be my first choice. But sometimes, for many different reasons, somebody obviously does not want to do that. And then you have to be absolutely committed to ensuring nobody can ever recognise themselves.

Martin

Because in some cases you might find patients who... they and their relatives might feel that they would like to be memorialised in a way, by being in the book. Has that ever happened?

Rachel

Very much so. I have written about a number of my patients, with their consent, and have then gone on to either show what I've written to them to ensure they are happy with it, or because the patient has died, I have then shown what I've written to family members.

And that can be an astonishing experience, because for relatives it's very precious to have this testament on paper to the person they loved so dearly. And if you have managed to do your job as a writer well, then hopefully you have given life to that individual through the writing. And I have relatives to whom I have spoken afterwards, and they have been absolutely thrilled to have a kind of literary memorial to the person they loved.

And the other thing that's extraordinary is, I found – especially if you're writing about palliative medicine – when a book is published, you as the author are deluged with letters from people who you have never met, for whom the book has struck a chord, either because they have been bereaved or perhaps because they have a terminal illness.

I think one of the types of letters that moves me above all is when somebody writes to me to say, I have terminal breast cancer, for example. And I was really scared to read your book, but I wanted to. And now I feel less frightened of dying. Now I feel I understand it better, and I feel a little bit more at peace with what's coming. And that means a lot to me.

Martin

So, it really brings up quite an interesting issue. As you know, I'm a public health doctor and I do a lot of epidemiology, so I'm dealing with numbers rather than people. But I've often talked about the need to put flesh on the bones of epidemiology, to understand the stories behind the statistics and the challenge of how we actually bring to life those numbers. You do it so very well, but I think it is a challenge for all doctors to try to make sure that they don't just see the statistics, and actually recognise that there are real people behind this.

Rachel

Yes, I think that's a very good point. And it's difficult because the whole notion of informed consent – and it's terribly important for us as doctors to equip patients with the understanding that enables them to make informed consent – that, in large part does come down to statistics. We have to talk about relative risks, absolute risks. It involves numbers, of necessity.

But I think what I try to do when I'm having that type of conversation is attempt to reach out beyond the numbers and almost frame the statistics in terms of a human scenario, for example, that the patient may understand. So, for instance, if you're talking about palliative chemotherapy, there will be numbers that will tell a patient how many months of extra life they may get from that palliative chemotherapy.

And that may be helpful, they want more time with their families. But that's not enough. They may feel rotten while they have their extra months of life, and they may feel that having two months of good-quality life without nasty side effects from chemotherapy is actually a preferable option to having six months of life in and out of hospital feeling rotten.

So, the numbers are important, but trying to frame the discussion around what is important to the patient is the thing that matters. So, I may say, 'You've mentioned that the thing that you love more than anything is seeing your grandkids and you love them crawling all over you. You'd love to still be able to walk with them in the park. So maybe this is something to think about. You may have more time with your grandchildren, but you may not be well enough to do that with them.'

And suddenly those statistics, now, you have placed in a story – a scenario that makes sense to the patient, in terms of what matters to them. And I think that's a skill that I was not taught at medical school. I sort of learned that on the hoof and I wish we could all be taught how to do that.

Martin

And unless your patient is a professor of health economics, expressing those prospects as a QALY [quality-adjusted life year] or something like that isn't really going to help very much is it?

Rachel

You will obviously be that rather cantankerous patient Martin.

Martin

I hope not. I hope not. But if I am, I hope that you'll be able to look after me.

Now, you've written that following your father's death from cancer in 2017, you 'returned to work as a different doctor'. Could you tell us more about how your father's death changed you as a palliative care doctor?

Rachel

Yes, I loved my dad to bits. He was on a pedestal. From my earliest memories onwards, he was a real sort of hero figure in my life. And he was in his early 70s when he was diagnosed with cancer. So, in theory, I believed he had lived long enough to be very lucky. Some people die in the first hours of their life. He also had lived, in inverted commas, 'a good life'. He had had a wonderfully fulfilling career as a doctor. He loved his family, his wife, his children, his grandchildren. He had lots of friends. He was a happy man. He was sort of, on paper, everything that you hope a life will be.

And yet, that kind of theoretical 'well, I shouldn't be too upset because Dad has had a good life' mentality bore no relation to what I felt, which was this kind of screaming, shattering grief that Dad, who I loved so much, beyond belief, was going to die. And that kind of crippling, sort of overpowering grief and despair that Dad was going to die was like nothing I had ever experienced. Because at that stage of my life, no one I had loved as much as Dad had died. And I'm very lucky, that's still the case.

So, I realised that as a doctor, someone who thought I was quite good at doing the end-of-life stuff – it was my specialty, my profession, I sought to have very sensitive conversations with grieving relatives, dying patients every day at work – I'd naively assumed that I understood what it was like from their point of view. And actually, just the intensity of this horrible, traumatic grief that I felt made me realise that I just didn't get it at all.

And I came back after Dad died really humbled by that experience. I felt like I properly understood how little I really knew as a doctor, and how important it was to try to take that imaginative leap into someone else's shoes. You can assume you understand what life is like for another person, but you probably don't, and you need to be mindful of that.

The other thing that I came back with was this really acute awareness of the fact that all the way through life, life is loss. We lose things every day of our lives, whether it's another day of our life span or the keys, which I sometimes put in the fridge, you know, we are always losing things. We lose jobs, we lose people. We have to live with loss. And the ultimate loss, because

we are mortal creatures, is of this magnificent experience of living in the beautiful world around us.

And I think I realised that grief is exactly in proportion to how much something or someone is loved. The terrible burning anguish that I felt with Dad dying corresponded exactly to how much I loved him. And there was no palliating that suffering. That was a necessary price of loving somebody, if the moment you open your heart to someone and you love them, you are laying yourself bare to potential grief.

Understanding that and seeing that as something different to all the kinds of suffering that doctors *can* help with at the end of life – palliative care is very good at managing pain, breathlessness, all the symptoms that may be associated with dying – was very important to me as a practitioner. And I came away from that experience with a distinction in my mind between avoidable, unnecessary suffering in medicine, particularly at the end of life, and then the necessary, unavoidable suffering that is the price we pay for being human beings.

And I think all we can do is try not to flinch from that, try to embrace it, try to understand it, try to talk to other people about it. It is a human form of suffering that is bittersweet. It's hard, but it's borne out of love, how much we love people.

Martin

So, there are a lot of complex philosophical issues tied up in all of that. But where do doctors gain these insights as they go through life? I'm going to ask a question which I'm a little bit hesitant to ask because I sit on the Medical Schools Council, and my colleagues there are always being told that they should add more and more to an already crowded medical curriculum. But I'm interested to hear from you, what skills you think as a palliative care doctor should be taught in medical school but aren't.

Rachel

I think the bulk of medical school, still, in 2023, is structured around broken bits of people. So, things that go wrong with a heart, things that go wrong with a liver, with a brain. And you are taught that the body can break in these ways, and this is how you recognise that. And then this is how you go on to treat it and fix it as a doctor. And there's always a few days, usually, of palliative care tacked on to that.

But of course, if that's how you're teaching medicine, then patients as human beings have almost been erased from the curriculum. They've been pushed to the edges of the curriculum. And I understand why we teach medicine in that way. The human body is an extremely complicated bit of kit, it would be impossible to learn it all as one entity.

But I think there is a real need to try and integrate patients as people within the heart of a medical curriculum, not just as a sort of add-on extra – so, you know, a sort of communication skills module that's tacked on at the end of one of your years, and everybody hates because it's really embarrassing to do role plays in front of your peers. I loathe it and I teach communication skills.

And I think the best possible way we could, as teachers of medicine, bring the patient into the core of medical education is not through someone like me telling you what it's like to be a patient. It is having patients themselves describing their experiences. So, some of the most vivid and memorable moments of my five years of medical school took place when a patient came in and talked to us about their experience of their illness or caring for someone with an illness.

I will never forget somebody describing being diagnosed with HIV that he had contracted through contaminated blood, which he needed because he had haemophilia A. And he described, as a teenager, being told by a consultant – with the door open, so that everybody in the waiting room heard – he was told, 'I'm sorry to have to tell you, you have got HIV.' At a time when HIV was a death sentence, we didn't have antiretrovirals. It was a terrifying illness. And the teenager, as he then was, said, 'Right. OK, well, I'll just have to live my life as best I can.' And the doctor said in response to that, 'Well, for about two years, that's your life expectancy.' And that was how a teenage boy was told he was HIV positive.

And you know, someone could have told me that story, as I've just told you now Martin. But hearing the person themselves describe that, and the subsequent conversation that we had as students with this patient, was unforgettable. And it transformed how I wanted to practise as a doctor. So, that's what we should do. I think every organ that we learn about, you know, every module in medicine, we should be hearing from patients.

Martin

It does make you step back when you hear a story like that. And, you know, one thinks of the golden rule that you have in all the major religions and many philosophies, of doing unto others as you would have done unto yourself. And perhaps we need a little bit of philosophy there as well, or morals.

Rachel

Yes. But maybe also a little bit of practical psychology around how we look after ourselves as clinicians. Because the other thing that's conspicuous by its absence in medical school curricula is what it's actually going to feel like when you are spat out at the other end and become a brand-new doctor.

I certainly came out, in my first few weeks as a foundation doctor, assuming that all the other doctors could do this, were confident, knew what they were doing. I was unique in my terror. Definitely, nobody else felt the terror I did, because somehow the people who taught us gave the impression that for them it was effortless. Or even if they said, 'Oh yes, it was a bit stressful at the start,' you never quite believed them.

And I think there is something about that early experience of being really knocked for six. When you start practising, you're scared, you're overwhelmed. It's really difficult to meet patients who are very, very unwell – perhaps life-threateningly unwell – and know that you have responsibility for their lives, potentially. It's really tough to do all of that, but nobody proactively checks in and sort of mentors you and says, 'How are you doing?' Wouldn't it be good if that was a part of medical school and your early years as a doctor?

Martin

And we're often not very good at looking after ourselves. How do you look after your mental health and deal with the emotional impact of working in palliative care?

Rachel

It is sometimes really tough. And I think my experience of the COVID-19 pandemic in particular was very gruelling for many reasons. And one of the things that's tricky is at work feeling that you can't talk to people because everyone's in the same boat, and at home being unable to talk to people because the last thing you can do is tell your husband quite the nature of the traumatic deaths you've seen that day at work. You know, he doesn't want or need, or would be able to cope with hearing that. So, who do you confide in?

And in palliative medicine, we're very lucky because we have a straightforward culture in which talking to your colleagues, crying in front of them, getting a bit of support and camaraderie from them is absolutely normalised. Not only is it something not to be ashamed of, but if one of us has been involved in a really tricky situation, such as sitting down with young children and explaining to them that their parent is dying, which is something I will sometimes do, the rest of the team will occasionally almost bully you into talking about it, even if they're really just checking in to make sure that you're OK not talking about it.

And that's wonderful. There's no stigma or shame about getting upset at work. And so, I find if I have encountered a really upsetting case, which I sometimes will, I'll just talk to a member of my team, and that's the best possible thing. And I think it's a little bit as I imagine being in the military might be, you know, if you're in a conflict, it's incredibly difficult to convey what that's like to someone who's never experienced that. But to guys and women in your small unit just around you, you talk to them, don't you?

And the black humour is another way I get through it. I mean, honestly, some of the palliative care chat, nobody could ever hear it outside of the team. And it's just necessary to be able to laugh with bleak black humour at things, it gets you through.

Martin

Although that's sometimes been criticised by others. And I think there's often a reluctance to talk about that. It is a very important means of getting mutual support, but often it's looked on a bit askance by some people from outside.

Rachel

Yes, and I just don't agree with that. I think actually patients often have magnificently black humour. You know, sometimes patients who know that they're in their last days of life will just come out with jokes that stop me in my tracks and are both exceptionally funny and exceptionally inappropriate. And why not rip up taboos at the end of life? Isn't there no better time to do it?

Martin

Indeed. Now, as well as being a doctor writer, you could also be described as a doctor activist. You've said that you were 'acutely politicised overnight' in 2015 by the then-health secretary

Jeremy Hunt's proposed new contract for junior doctors, and this would extend their normal working week to provide a seven-day service without investing in new staff.

And then you became a prominent campaigner in the 2016 junior doctors' strikes. You've been described as a 'regular hellraiser on Twitter, frequently lambasting politicians for the crisis conditions in the NHS and for the chronic underfunding by successive Conservative and coalition governments'. Do you have any advice for other doctors who would like to become more politically engaged?

Rachel

Yes, I think you have to think about it very carefully for a number of reasons. The medical profession is typically both hierarchical and small-c conservative. And the people above you, those in power within NHS England, your trust, your senior colleagues, there are likely to be individuals and institutions who will take a very disapproving view of you if you decide to speak out publicly about the things that you believe are important. And that could be as innocuous as simply a tweet on social media.

For example, many frontline staff tweeted at the start of the COVID-19 pandemic about the fact that they didn't have proper PPE, and some trusts got in touch with some of those individuals and essentially threatened them and made them feel very stressed and uncomfortable indeed, about the fact that they were, believe it or not, enacting acting their NHS duty of candour by speaking out about the truth around them.

You have to be prepared for pushback if you decide to speak out. And you also have to be prepared for being accused of being an activist as a sort of term of abuse. So sometimes people will say of me, 'Well, she's political.' To which I always think, well, I'm not in the sense that I'm party political. I couldn't care less which party is in government. What I care about is vulnerable people in society and in particular, patients. I want to speak out on behalf of patients. But I'm definitely political in a big sense.

If you believe that there are socioeconomic gradients in health, which you Martin know better than anyone, there are. And if you believe that you can improve the health of the nation by addressing inequality, by working on public health measures such as clean air, regulations around the food industry. If you care about all of those things, then surely being political in a big sense is just an extension of being a doctor.

So, Rudolf Virchow, who most people know as the chap behind the eponymous Virchow's triad around the flow of blood in a vessel, is less well known as an early medical activist. So, in the 18th century, he spoke out about the need for doctors to be their patients' advocates, to advocate on behalf of the poor and the vulnerable.

And I just think he's absolutely right. I think telling the truth about conditions in the NHS, currently the lives that are being lost, avoidably, because services are overwhelmed, that's an important thing to do. It's not for everybody, but for me, it just feels like an extension of being a doctor. And I will always try to tell the truth because it matters.

There are too many people in society in positions of power, whether that's political or very senior in the NHS hierarchy, who don't tell the truth, they are not honest with the public. And I think that's completely wrong in healthcare. I want to be as honest on a public platform with the public as I am on a private, professional platform, when I'm sitting across from a patient and we're talking one-to-one.

I think the same standards of transparency and candour and honesty should apply across the board. And I think deep down most people in the NHS think that too. It's that maybe sometimes one or two of them are a bit compromised by other things that are important to them, too.

Martin

Well, Rudolf Virchow is a great hero of mine as well. And every time I'm in Berlin, I give him a nod as I pass his statue, which stands outside the Charité hospital. And of course, he famously investigated the outbreak of typhus in Silesia, and he drew attention to the cause being the power of the aristocracy, propped up by the church.

Rachel

Yes.

Martin

But of course, it's an interesting point about what is defined as political, because the NHS is political. We have a situation where any health service that is collectively organised is redistributing resources, it's redistributing resources from rich to poor and from healthy to sick and from working age to the extremes of life. And redistribution is one of the biggest issues in politics.

So, by signing up to that, as opposed to a laissez-faire, let everybody look after themselves, you are being political. It's just the way in which the accusation of being political is used as a means of shutting off any discussion.

Rachel

Precisely. And if you take a step back and say, what is politics? Well, politics is the distribution of power across society from one group to another. Who has the power and what do they try to do to maintain it? That's what politics is. It's not the Labour Party and the Conservative Party. It's much more fundamental than that.

And so of course, if you care about vulnerable people in society, which I think most doctors do, we went into medicine because we wanted to help people – of course, we care about vulnerable people. Then surely, of course, we're political by definition. And I think those sort of lazy slurs of political and activist as though they're somehow terms of abuse, you're bang on. It's absolutely an attempt to discredit you, to silence you. And sadly, these days, we're witnessing a whole repertoire of tactics to try and shut doctors up.

There's a reason why doctors' voices are particularly threatening, and it boils down to the Ipsos Mori opinion poll. So, every year the polling company, Ipsos Mori, asks a sample of the public whether or not they would trust a member of this profession to tell them the truth. And

you always have the usual suspects at the bottom. You have journalists, estate agents, and right at the bottom – I think it's 11% of the public trust them to tell the truth – you've got politicians. And of course, right at the top, you've got doctors and nurses.

So, we have the thing that politicians crave more than anything, which is the trusting ear of the public, and that makes doctors very threatening indeed.

Martin

And trust is really high on the policy agenda now. We will be having a ministerial conference with the WHO in Estonia later this year, which I very much hope you'll be speaking at, and trust and transformation will be the key themes there.

But let's stick with politics just for a minute. We will have a new government. We have an election coming up in a bit over a year or so. And so what would be your key asks? What would you be looking for, for the NHS in general and for palliative care in particular?

Rachel

So obviously the NHS needs more money. If you look at comparative European countries, our spending overall is significantly lower than France, Germany, for instance.

Martin

I'm going to come in there just because there will be the pedants who are listening to this, who are saying, well, at the minute actually it's OK. But of course, the reality of it is that we have had sustained underinvestment, so maybe we're doing temporarily better. So, before people write in, let's just clarify that point. The long-term trajectory is that we've been way below other countries.

Rachel

Absolutely. And crucially, what we need more than anything is a proper, quantified and resourced long-term NHS workforce plan. You know, that has just been recently kicked into touch again by the Government. It's not being published.

The NHS is its staff. If we don't have the staff, we can't care for people and we desperately, desperately need proper numbers of staff at every level. Palliative care should be a core part of NHS provision. It is a national scandal that the majority of palliative care is funded not by the NHS but by charitable donations. It's a disgrace and it shows the contempt, really, with which we hold patients at the end of life. They're almost literally being regarded as an irrelevance when it comes to resources.

But more than all of those, the single most important thing I fantasise about a new government doing, is actually telling the truth about the NHS. I know that might be fanciful and naïve in 2023, but I can't tell you how corrosive it is to morale among NHS staff to constantly be barraged with this absolute disingenuous spin and lies from the Government. You know, the 40 new hospitals, they'll literally say 'and we've just given money to these two hospitals to start the building' and the two hospital trusts turn around and say, 'yeah, actually we haven't received a penny of that'. They're so brazen and they're so shameless.

And it is really, really hard for staff to see patients dying on trolleys in corridors because A&E is overwhelmed yet again, while literally listening to the British prime minister on BBC News saying there's no winter crisis, not a problem at all. That's just grotesque and it has to stop.

Martin

Although the inability of either of the main English parties to tell the truth about Brexit doesn't give us much encouragement.

Rachel

Don't get me started Martin, we'll be here all night.

Martin

Rachel, you went to Ukraine in October last year with Henry Marsh, a retired neurosurgeon and also an author, to train local doctors in palliative care. Following your visit, you co-founded the Hospice Ukraine charity with Henry to support palliative care teams in Ukraine with training, equipment, medicines, and other practical support. Can you tell us about why your visit to Ukraine prompted you to set up that charity?

Rachel

Yes. So, I went at the end of last year and I started in the west of the country, far away from the front line, on the border with Poland. And some people said to me, 'When you arrive in the city of Lviv, you'll find it's like any other European capital. It's not like the country's at war at all.'

And actually, when Henry and I arrived in Lviv, I felt it couldn't be further from the truth. Although the city is over a thousand kilometres from the conflict, the war seeped into every aspect of life. There were murals on the walls of soldiers, of rallying support for the troops.

Every day, coffins were being repatriated from the front lines of young men who had left Lviv, sometimes while still teenagers, 18, 19 years old. And they had been killed and they were coming back, and they would be walked through the streets of the city, and you would see hundreds of people falling to their knees on the pavement, bowing their heads and just crying for yet another person who had been killed in this conflict.

And almost everybody I spoke to, without exception, within minutes of asking them questions about what conditions were like, they would be weeping with the trauma of what was happening. And I realised that this was a total war in a sense, it was affecting everybody.

Palliative care in particular in Ukraine was already in a pretty fragile state before the war began. And now, of course, the pressures of war have made it so difficult to provide any proper palliative care. Several million people have been displaced internally within Ukraine. Healthcare across the board has been disrupted, so people who should be getting cancer diagnosed or treated, particularly in some of the eastern cities like Kharkiv and Curzon, they just are not getting their treatment, which means there are more patients needing palliative care, not to mention all the victims of the Russian bombs.

And so, the first hospice I visited, it was just heartbreaking. The staff were doing their absolute best, working night and day, sometimes just sleeping in the hospice, sometimes working by candlelight because electricity and gas are deliberately targeted by Putin in Ukraine. And they were struggling desperately. And when I spoke to them, they described the fight for them as being almost an existential fight for their survival. The medical director of the hospice said to me, 'Putin wants all of us dead, every single one of us. He wants to destroy our history, our culture, every single one of us. He does not want Ukraine to exist.' And then she started to weep.

I came away realising that she could have been working outside Oxford, not Lviv. She could have been living in London. This was a population so broken and traumatised, and yet so defiant and determined to keep on fighting, to do everything within their power to stop Putin from occupying their country. I just realised it could be us. And I didn't understand from the newspaper headlines how the war was affecting the civilian population. When we read about Ukraine, it's very much in terms of sort of territorial gains, not about the everyday lives of the whole population.

So, I came back thinking, as I think many of us do, I want to help, I want to do something. And I wanted to tell those stories and find a way of raising money so that we could help all those patients in such desperate need of palliative care in Ukraine who just aren't getting it because of the war. And the great thing about palliative care is it's relatively cheap. We don't need much in the way of very fancy, expensive kit. You can do so much good with relatively inexpensive drugs, equipment. And so, the idea was borne out of that – a simple desire to help civilians.

Martin

So sad, isn't it? Because I can remember just about a decade ago when we used to have project meetings with my colleagues from across the former Soviet Union, from Russia, Belarus and Ukraine. And we all went to Yalta in what is now Russian-occupied Crimea, and that was actually something everybody looked forward to because many of them had gone there during the Soviet period, it was an escape from their everyday life and everybody got on so well, and then you see what happens now.

So, by the time this podcast airs, you'll actually have had your inaugural fundraiser, which will be on June the 6th, 2023. Going forward, people are listening to what you've said. How can people donate to the charity or how can they help in any other way?

Rachel

Well, the charity website is very easy to find. It's just www.hospiceukraine.com. And there's a 'donate' button there, and if anybody wants to get in touch, there is an email on that website.

If they want to volunteer in any way, we're looking once we've had our fundraiser to do a number of things. We're going to be supplying equipment and drugs to Ukraine, supporting local teams, but also we're hoping to actually run online and even potentially in-person palliative care teaching in collaboration with Ukraine and maybe arrange some exchanges so that doctors and nurses in Ukraine can come out and spend some time in a hospice or an NHS setting in the UK. So, lots of sharing of skills.

So, get in touch via the website. We'd love to hear from people.

Martin

Please do if you're listening.

Now I'm going to close with two questions that I've been asking all of my guests on these podcasts. We're talking about doctors as role models. You've already mentioned your father and you've mentioned a haematologist that you've worked with, but who are the ones who've inspired you other than those, or who are still inspiring you and why?

Rachel

So, there are two. One is the great Kathryn Mannix, a now-retired palliative care consultant, who wrote an absolutely beautiful book about palliative medicine called *With the End in Mind*. And that book was part of a mission she has embarked on to demystify death and dying, to try and encourage the general public to feel a little more confident in talking about death and mortality, and helping medics across the board feel more confident as well. She's an exceptional woman and for her, medicine is a humane enterprise. It's all about the humanity.

And I think another doctor who inspires me in so many different ways is Sir Michael Marmot, a great, great public health doctor who has done such incredible research looking at the social and economic determinants of health and also as a champion of addressing those.

So, when a public policy makes inequality worse and therefore makes people who are not wealthy more likely to get sick, more likely to die, he speaks out about it, and he speaks out with such eloquence and passion and also judiciousness that means he is heard. He is respected by everybody, Michael Marmot, I've never heard anyone say a bad word against him, because he is so obviously driven by the data and by trying to increase overall health in society. And he's a wonderful inspiration.

Martin

And my very last question, what advice would you give to someone who's just graduated in medicine and who would like to follow in your footsteps?

Rachel

Don't be put off by the people who tell you how awful medicine is these days, what a state the NHS is in, it's not like it used to be, blah blah blah. You'll always get people who say that.

Medicine is an absolute joy and a privilege despite everything. It is so astonishingly wonderful to walk into a consultation room and meet someone who may be going through the most frightening, distressing, anguish-filled day of their life and entrust their life to you as a doctor. It is an absolute privilege and an inspiration to be in that role with people.

And you can do so much good, even in an understaffed, overstretched NHS, simply by holding on to your humanity and trying to reach out – human being to human being – with that frightened individual. It is a wonderful thing to spend your life doing. It's the most interesting, inspiring, thrilling ride of your life, being a doctor. It is magnificent, so look forward to it.

Martin

Rachel Clarke, thank you very much indeed.

Rachel

Thank you, Martin.