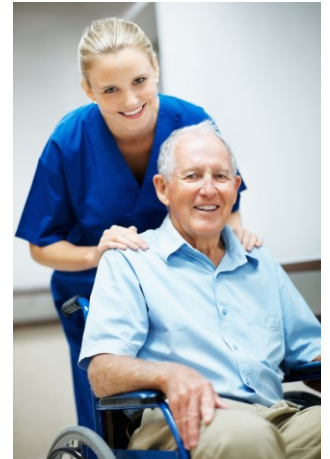




Wherever you see this symbol  you can click on it to watch a video if you are connected to the internet

Compassion: Developing clinical leadership

Compassion, the essence of caring for others, is a fundamental and sometimes neglected interaction in healthcare. Here, patients describe what it feels like to be treated as a collection of symptoms rather than an individual, to have their need for privacy ignored or to be spoken to without respect or kindness. This section also examines the powerlessness of being a patient - and how practitioners, successful in demonstrating compassion, are able to empower and build confidence in those they care for.



Why did YOU become a health care professional? The chances are that a key motivation was compassion; that profound feeling brought about by witnessing the pain or distress of others which is the essence of caring for others.

Once absorbed in training, compassion can seem less of a priority; indeed the whole idea of showing emotion can look positively dangerous. Does a busy practitioner have time to care about each individual patient when there are so many other demands on their attention? Isn't a compassionate practitioner more vulnerable to burnout? Is it healthy to experience the vulnerability that can come with exposure to other people's distress?


In any case, the vast majority of patients seem perfectly satisfied with healthcare provision that in recent decades has prioritised professionalism over the bedside manner. Surveys show that patients are grateful for the care they receive, with NHS patient satisfaction surveys showing that upwards of 90% report their care as 'good', 'very good' or 'excellent'.

Yet there is evidence that such an approach is flawed. For a start, high rates of patient satisfaction do not necessarily mean that the experience behind the statistics is wholly positive - with up to two out of three complaints about NHS healthcare today being about lack of caring and compassion. Further, a spate of recent scandals have highlighted the cruel and uncaring behaviour that can result from a culture that does not celebrate the compassion of its workforce or insist that each and every patient is treated with respect and kindness.

Here's the former director of the Kings Fund, Niall Dickson:

"Currently there is evidence to suggest that we should be worried about this most fundamental interaction between healthcare staff and their patients - how patients are cared for, how they are looked after. Many have compared the way the health service treats patients unfavourably with the way major companies handle their customers ... often at a time of anxiety, discomfort or distress, when the patient is almost invariably more vulnerable than the average consumer."

This 48-year-old man with prostate describes the way practitioners were oblivious to his need for privacy and dignity at a time when the potential for humiliation was huge.

 *"Privacy and dignity I think remain a challenge for the National Health Service. I did encounter some truly fantastic practice from some truly admirable practitioners but I also had some exposure to the other end of the spectrum, people for whom privacy and dignity of a patient is clearly not a particularly dominant concern.*

There were occasions when whilst going through some pretty undignified procedures either with the biopsy for example or the cystogram for example, there were occasions when doors were flung open and people would just walk in and out and not introduce themselves and they clearly had nothing to do with what was going on with me. And whilst I can tolerate that up to a point in a dentist's chair if the dental nurse walks in and out it's quite different from when, put bluntly, your ass is sticking up in the air."

"I'll illustrate it with just one or two examples. At the pre-operative outpatient stage after the TRUS biopsy (the trans rectal ultrasound biopsy) whilst waiting in a crowded corridor full of other patients and their relatives a clinician whom I'd not encountered at any stage during the procedure itself and who had her coat on ready to leave stuck her head into the crowded corridor to shout in my general direction that I should expect to see blood in my semen for a period of time after this biopsy.

Now admittedly that's useful information to have, I don't deny that but the circumstances under which the information was delivered was far from ideal. It caused all heads to turn in my direction for what was for me the unique experience of being in a crowded corridor of a bunch of people who all were probably thinking about my semen [laugh] and I'd rather they weren't."

Here, two young women who sought help for their weight problems describe what it's like to be treated as 'a subject for a seminar' rather than real people seeking help.



18 yr old: *Don't be condescending. Don't... the people you're talking to...*

17 yr old: *Professionals.*

18 year old: *... you're there to help them, not look down at them. And don't view them as through a microscope. You know, like they are your subject for some, I don't know, seminar or whatever, they're real people. Yes, they might be bigger, but they still have feelings, so you need to be respectful of that, and don't through information at them.*

17 year old: *Thank you.*

18 year old: *Do you know what I mean? The people you're talking to aren't medical professionals themselves. They are not going to understand something that has all this, you know, medical jargon in it. You need to understand that the people you are talking to, you need to be basically more on their level.*

Because sometimes I found with doctors is, sometimes they've got to the point where they're almost a little bit inhuman. Not in a bad way, but just they don't relate to the people they're talking to any more.

I don't know whether it's through years and years of being a doctor but it's sort of like they're not as personal as they were before.

So when you're talking to them, you sometimes feel that they're not really listening to what you're saying, you're just another person walking through the door with another issue and another problem, that they have to get sorted and I think that is really off putting sometimes.

This 66-year-old describes the experience of asking repeatedly for - and failing to get - an explanation for the severe symptoms that followed surgery.



"Well somebody, all I've been told now is that I've got a lymph node which I don't know what, I don't know what a lymph node is. I'm not very good medically. Some people can ask the questions and they understand the doctor's language but I don't understand the doctor's language, I don't even know what a lymph node is, even though I've had one before, I've never been explained exactly what it is.

Have you tried asking? *I have yes, yes I have asked. I've told the lung cancer nurse actually that that's one of the things we want at the meeting, our support group, and the other people have said the same we want somebody to come with a model, a diagram, or something, or and say, 'We've taken that bit of lung away and we've cut that pipe and we've,' I'm not morbid, I don't want to know, I wouldn't like to see the operation but I would like to know what they've done to cause the breathing problems, you know. You expect them to take the lung away and not cause you a breathing problem but obviously it does and nobody has really explained that to you. And the same with this cancer now, nobody has shown me a diagram and said that's where your cancer is, they've never actually said that to me.*

Right so you'd like a bit more information? *Definitely I'd like a lot more information on that side of it.*

Did you ever try asking the doctor, the consultant? *I have, yes I have asked, but whether he's told me in his language and I haven't understood because I'm a bit thick that way inclined I suppose. Perhaps he's told me in his language that I haven't understood but I haven't understood what he's told me, if he has told me I haven't understood it."*

This man in his middle 50s also describes the emotional pain of having information about his health status withheld by his clinical team.



"And the first I learned directly that I might have a mesothelioma was from the specialist cancer nurse who came into show my wife how to drain the pleural catheter which was in my right chest. And he again acting very conscientiously said to me and my wife if I wanted any information about mesothelioma he'd lots of it available.

Now I was beginning to think, I knew that mesothelioma was on the cards here it was a possibility and it's the one diagnosis you don't want. Any other cancer diagnosis you've got a fighting chance with mesothelioma you don't have a fighting chance you're going to die of this disease. So that was fantastically shocking. To hear it in that way. Because although it was becoming clear that something terrible was happening in my chest people hadn't come forward to do that. Now I think they would say that they couldn't come forward in good faith because they didn't have the histology. But I think my feeling of watching their body language was that the video was so straightforward. I had nodules in my pleura that were 1.5cm big. So you don't get that with a viral infection really. That's neoplasm before anything else.

So I left hospital the next day still without any clear understanding of what was happening to me and came home to the kitchen of my house where I opened the d.c summary because I have access to my own records obviously and the discharge summary included the phrase likely malignant mesothelioma patient aware of the diagnosis."

Equally neglected, this 63-year-old being treated for chronic pain explains what it's like to feel as though you're just a painful shoulder.

"Yes. I think it's mainly because people, professionals, you know, if they look after a certain part of your anatomy, say your shoulders or they just tend to think of that as the problem with you, they don't tend to look at you as a whole person.

And I always try to explain even earlier this week to a professional about the pain and they said that they weren't interested in that part of it.

They were only interested in the bit that they were interested in as though I was, you know, I could be chopped up as this is, you know, as though all parts of your body weren't related."

"And I think that that's where the professionals have got to look at people as people not as just a heart, or a shoulder, or a knee but as people with lots of different needs not just the one. So it just blinds them to the fact.

You know I often wonder if they just see a picture of your problem in front of them, you know not me as a whole person but say perhaps you know the shoulder person just sees a shoulder sitting in front of them or the knee person just sees a knee person sitting in front of them, you know and the same from the other side, the mental side, they tend to look on you know just the mental side and not the physical side. Which can sometimes be quite distressing because you are a whole person."

This 75-year-old with chronic lymphocytic leukaemia explaining what it feels like when doctors make no secret of the fact that to them your disease is frankly boring.

"Then I went back to this strange other consultant who wasn't quite so clever and I went a fortnight ago and I had a ten past two appointment and I was seen at half past three. He had two people in front of me and he just does not bother. He takes people in and you hear them laughing in the consulting room and they come out with bits of paper and then fifteen minutes later you're, or another patient is asked to go in. And I had another appointment and I knew I wouldn't be very long with this particular man because he doesn't seem to know what he was talking about. And he regarded me as completely insignificant. And I was in and out in one minute and a half. That's it.

So how did you feel all that time that you weren't having any treatment? *Invisible.*


How did you feel about it? *Completely invisible.*

Can you expand on that? *Well, nobody seemed to take any notice of me. The consultants weren't interested. I asked them the symptoms and they didn't give me any answers. I said, 'I'm so so tired. This depressive tiredness is overwhelming feeling.' They just still didn't say that it was connected. I don't know if it is or it isn't.*


Okay. So but how often did you go and see somebody in that period? *Every three months.*

And what were they doing at those check-ups? *Nothing. They just ask, they just, previous to the consultant's visit I have a blood test the week before. They just look at my blood test, tell me the white blood count and make an appointment for the next three months."*

This woman who spent several days in intensive care describes the feeling of 'being in a torture situation' while attached to equipment that kept her 'riveted' to the bed.

 *"I was spread-eagled on that bed. I didn't have a covering apart from a sheet, a terrible blue and white thing in a J-cloth kind of fabric, which was attached on either bits of the bed. And they would lift up bits of it, and you were naked underneath that with tubes coming out of you. The indignity of that, the indignity of it. The material itself, you know, you couldn't even be covered with something, a sheet stretched out. It was this J-cloth, throwaway material. That's how little worth you were. That you'd wash that up and you'd throw it in your bin in the kitchen. That was keeping my dignity so-called. That was, it was a disrespect. So I'd lost control out of my bodily functions. I couldn't speak, I couldn't communicate, I couldn't write. I was alone. Only what was in here [inside the mind]."*

The situation itself was bad enough but it was the attitude of her carers that left her feeling isolated.

 *"But sometimes they would be busy, sometimes it's because they were short-staffed I'm sure, and sometimes it was because somebody else that needed far more help they'd gone to. And you were kind of aware of that but couldn't see it. So you were, you were isolated. They would come round and fiddle with things behind you, but you couldn't see what was there and you weren't actually told what was there. And for a long time of course with the tubes in my mouth I couldn't ask.*


So things, you know, if they had actually explained what's around you, what's going on and talked to you, it would be great. But there was very little conversation at all. I could, you know, out of all the nurses that were involved, which I subsequently know were involved, there was probably two of them that stand out as being vastly different from the others."

Finally this 24-year-old woman, diagnosed with myoclonic juvenile epilepsy when she was 17, says that during frequent consultations with doctors, they 'sort of forget that you're a human being'.

"But I, one thing I find really annoying when you go and see consultants is that they read you your history. And I'm like, 'Why are you reading this to me? I know. It's my life. I've lived it' you know. And they go through every like medical thing that happened in my life. And because I was a twin, and my twin died, like the fact that they'd always tell me that I found really strange, because it didn't seem relevant. They were like, 'Yes, so you were born prematurely. You were one of twins. Your twin died. Da-da-da. You had your first this here' you know. And it just, that has always bugged me about going to see the doctor, because I don't want to hear it really. Like it just seems a bit pointless. I feel like, 'Can you not read that, and then call me into your little funny room and ask me how I'm feeling?' Which I do find, like sometimes I do find what they ask you a bit like, like they say, 'How's your epilepsy?' Like I think that's a really weird question to ask. But I suppose there's no other way of putting it. Or just like, 'How are you? How have you been coping?' I suppose."

But perhaps patients who don't get the respect and attention they feel they deserve have only themselves to blame. After all, if they feel hard done by, why don't they speak up - and insist on the kind of treatment they feel they deserve?

Here's a 27-year-old woman with Hodgkins Lymphoma's shows just how easy that is.

 *"Initially it wasn't, I didn't have a very good relationship with my consultant. He had the view of, 'You will do what I say and not dare to question me'. But once we'd had a little discussion or two and we'd kind of evened out the doctor- patient relationship slightly. I didn't like being treated as a shell, as a disease. I was a person. I wanted to be treated with a little bit more respect and humanity. And perhaps I shouldn't have done but I told my consultant that, and from then on we've got on famously and we get on really, really well.*


I wonder if your age had anything to do with his attitude towards you? *Possibly. He was very much old school medicine. And I don't think many people would have said what I said to him because he was quite; he had a bit of a reputation for being a sort of old school scary doctor. And I think a couple of the nurses were a little bit, wouldn't have dared question him as well, but I was the patient, I had nothing to lose by doing so. And I think that really helped. Yeah I get on really well with him now and have total respect for him."*

Yet for most people it may not be that simple. At a fundamental level, says Jocelyn Cornwell, author of the King's Fund's report: *Seeing the person in the patient, "being a patient equates with feeling powerless. Even highly educated knowledgeable, articulate people can feel powerless. And the impact of well-meaning but unconsidered behaviour can be devastating. Cumulatively, subtly, the unexamined routines and ordinary behaviours inflict grievous emotional harm. Casually but firmly the patient learns that he is completely alone."*

In 'Seeing the Person in the Patient', a member of a support staff team makes this telling observation: Yes, once that person steps over the threshold, they're a different person – it's about understanding that they're scared.


Here, two patients describe the feeling of finding themselves unable to assert themselves in a hospital environment in a way that is quite unlike their normal selves.

This 68-year-old admits to being uncharacteristically tongue-tied in his interaction with doctors.

 *"And you don't get that much information out of doctors and hospitals. I don't think they can be bothered because they think maybe they underestimate us, you know, maybe they think we're a bit too, not literal enough you know maybe they classify us as underlings you know. I feel that sometimes, I do, I do. You know they don't classify you as a human being and they don't think you've got thoughts and they don't think that you're intelligent. That's nothing against them but they're in a special club and one feels that you're intruding if you ask them too many questions 'Why, what do you want to become a doctor? You know that's our game, you're the patient, you know stay where you are and we'll do the talking and we'll do the thinking for you.*


If you need an operation we'll do it, if you don't we won't,' you know (laughs) that's the kind of attitude it is. I think if they sat down like you do with me and just a one to one kind of conversation, down to earth conversation, whereas when you're talking to them you kind of forget that they are doctors, surgeons, misters, whatever they are, titled people with names behind them when they become a human being I think life would be a lot better and you could communicate better. Because you become tongue-tied with them, I don't know what it is, I've never been tongue tied in my life but there's so many questions you want to ask a doctor and when he's with you, you become like a kind of an idiot you know there's nothing you can say."

This middle-aged man describes feeling humiliated by an off the cuff attempt at humour by a member of staff.

 *"I think health care workers inadvertently heap small humiliations upon patients and they do this inadvertently. I stress this inadvertently. An example that got me early on in my days of having CAT scans was that I was told to undress. Instructed to undress. The phrase that was used was we need to get you to get your clothes off, down to your pants. And you're wearing pants and socks and shoes. That's a cool sartorial combination that I have to say I don't indulge in very frequently myself. Except when I'm having CAT scans. So you're with pants and socks and shoes. And this gown that you hope is fastening at the back and not exposing your bum to the radiology world.*


But I was sitting there with a green plastic bag holding my clothes hoping that the back of my gown was closed when a senior radiographer walked briskly into the patient's areas and said Kieran Sweeney follow I! And like a sheepdog I just got up and followed this guy. I don't know what's going to happen next. It just humiliated me. I felt utterly degraded. I felt seriously upset by it. That he should so trivialize what was for me a shocking passage into my healthcare problem. I'm so angry about that. And I think he was doing it inadvertently. I think he was trying to be, I don't know what he was trying to be witty or funny or something. But you just can't do that. You've got to be awfully careful about doing that really."

Yet despite his burning sense of injustice, the man goes on to describe his inability to protest.

 *"But you see, the guy said to me when I was making sure my arse wasn't sticking out: 'Follow I' and I just followed him like some dumpling. I was like a lapdog. OK. I'll just follow you. I guess you don't want to complain. You don't want to compromise your care, get them on the right side of you. You feel embarrassed and you don't feel like Joe Cool, when you are living through it, it is unpleasant. It shouldn't be. But it certainly was for me."*


It's in this context - one that is perhaps insufficiently considered within the medical or even the nursing curriculum - that health professionals must judge the need for compassion, privacy and respect for patients. Generic kindness isn't enough, it seems. What a powerless, frightened person needs is for their individual situation to be recognised by a compassionate practitioner - as can be seen by the different satisfactory transactions that the following patients describe.

This 68-year-old man required surgery colorectal cancer and was delighted with his surgeon's robustly direct approach.


 *"I was in no condition to know what was happening actually but I do remember the surgeon that operated on me he was looking at the pictures up in the air like they do yeah and he came over to me and he says: 'Can I explain what happened?' It was quite funny actually because it was like a TV comedy. He came over to me with the team of guys, this surgeon, and he said to me: 'I'm afraid you know that you've got a blocked bowel and we've got to operate immediately.'*

One of the doctors next to him said: 'Don't you think he needs further examinations?' So he said: 'F%! the examinations this man has got to go straight to surgery.' [laughs] So as soon as he said that I had a lot of confidence in him. I know it sounds strange, but I did have a lot of confidence in him and I thought he was terrific. He shot from the hip and that's why when I went in for the operation I felt completely relaxed, it's amazing that. You know some surgeons are very, very aloof and very, very business-like, this guy was the direct opposite and he was terrific you know. I think out of everybody that's the type of guy that one feels you know you could put all your, well you put your life in his hands really."*


How have the staff been all the way through this, the staff at the hospital, and the chemotherapy unit? Any comment on them?

 "Chemotherapy absolutely wonderful. You know, all the nurses there were wonderful, I felt like I was going to see an old friend every time I went there. And you know, when you're at the end of the treatment and you're obviously doing well, you know, they're very, very happy for you and they're evidently so. And, you know, it is like saying goodbye to an old friend. You know, you're there for such a long time you get to know them, you know, quite well, and their characters and different personalities, and they get to know you quite well. I couldn't fault them at all, you know, they give a hundred and ten per cent, and they're brilliant, wonderful."

And this woman with cervical cancer describes a doctor with the ability to make her feel special.

 "He was always talking, telling me before what he was going to do to me and he was talking through and it was just his, for example he calls me 'pet', probably he calls every woman who visits 'pet', but he made me sort of feel a bit special to him. Which is, reasoning I know it's not but at the same time it's pleasant and then you're good, that everything is fine and don't worry. All these are sort of pleasant way of, which you know and as I say he was going to tell me before 'Now I'm doing this. Oh I know it's a bit cold, it's a bit unpleasant. Yes it's going well.' You know these sorts of reassuring little words of chit chat which it's probably part of his routine and it's extremely pleasant and comforting and reassuring."


This 49-year-old heart failure patient describes the 'fantastic' care he received when his cardiologist recognised his terror of having an angiogram.

 "The one I'm under, the specialist, is fantastic. He's that good that the wife and I always say if we won the lottery we wouldn't go abroad because I couldn't take my specialist with me! That's the way we talk, it's...when you go abroad because I wouldn't get the same treatment. He's really, he's a caring doctor as well as, you know, he'll talk to you, it's... he talks you down to earth like it's not all medical. He'll speak to me on my terms rather than speak to me and talk about cardiomyopathy and things like that, whereas he'll talk to me 'Your heart's not working well'. It's a good system.

He's a caring doctor, he's, it was him that done my angiogram and I thought, 'Oh he'll just get some young doctor to do it', and when I went in he was standing there, joking with the nurses talking about his family. And you know it helps, it reassures you that you're getting something like the angiogram, I'd never had it before, this was the first time, I was terrified, I was crying with the wife before you know, are they going to find something here that they're going to say, 'You've got 6 months to live'. Because before I got the angiogram it was a case of they thought maybe that the tubes were blocked, they thought I'd angina.

So going for the angiogram I was terrified what they were going to find, and yet the doctor reassures you, he jokes with you, laughs with you, you know, that helps you to settle down and then as soon as he's finished he explains what he found, that there wasn't any blocked tubes, I've not got angina and he explained it all. As soon as I got back to the hospital ward again he was inside in 20 minutes, he was by the side of the bed, explaining what he'd done, how he'd done it and what he found. I felt a different man after that!"

This 61-year-old describes how she had both good and bad experiences of specialist care when she was diagnosed with Non Hodgkin's lymphoma.

 *"Anyway, eventually, in the middle of August I got to see my local consultant and I went armed with a list of questions and he let me work through a certain number of questions and then he got up and opened the door and held it open and I said, 'Oh, excuse me, I haven't finished asking questions yet' and he said, 'What do you expect me to do about that? I've got a waiting room full of patients!' and I thought that was so insensitive, and he obviously had a spiel which he recited and he didn't do what we used to do in social work, which is 'start where the client is'.*

He didn't say, 'Do you know anything about lymphoma? Do you know, you know, have you read blah, blah, blah?' with a consequence that I didn't get a chance to have a proper discussion about the fact that I'd read up about all the new treatments and I knew that monoclonal antibodies, rituximab, were the treatment of choice for non-Hodgkin's lymphoma, and I'd also found out that there was a research trial going on and I wanted to be on it so I asked him about it but he said, 'Oh, no, no, that's winding down, that's finished' and I thought, 'That's odd, because why was it still on the internet, looking very much alive, if it was actually finished' so I had to wait another month till I had my next appointment with him, check my facts and go back armed with the documentation saying this trial is very much, it's still recruiting and it's only just begun to recruit in fact, you know, far from what he'd said, so he then said, 'Oh well, all right, if you want to go on that trial I will recommend you, or refer you,' or whatever the procedure was."

"As a result of the letter that my local consultant wrote I went to see the teaching hospital consultant, who was like a breath of fresh air. He was, he believed in sort of two way consultations, having a conversation with the patient, and at the end of it he said, 'Have you got any more questions?' which I thought was absolutely wonderful, and he's also got, it's making me cry to think of it now actually, because he's so lovely.

The teaching hospital consultant was everything that a consultant should be. He was, he believed in having a two way conversation with the patient, finding out what the patient wanted to know, making sure that all questions were answered and even using metaphors that would, getting to know his patient and using metaphors to describe the illness that would fit in with the patient's experience, so he apparently said to one patient, or one patient asked him, 'What will chemotherapy be like?' and that patient was a yachtsman, and he said, some, I don't know the technical terms but something like, 'Well it won't be storm force, hurricane force twelve,' whatever it is, 'but it'll be gale force nine' and there was just such a gulf between these two consultants that when I met the one in the teaching hospital I thought, I never want to see the one who'd ignored my letter and who'd refused to answer my questions and who'd actually, well, I'm reluctant to say lied to me about the trials but had misinformed me about the trials. And I didn't feel confident enough of my knowledge at the time to contradict him."

Earlier in this section, a man being treated for prostate cancer describes how a clinician he'd never seen before stuck her head into a crowded corridor where he was sitting - to inform him in a loud voice that he should expect to see blood in his semen. Here he reflects on how this interaction could have been prevented - and concludes the behaviour cannot simply be blamed on the individual practitioner.



"Now that was a highly avoidable example. It would have taken literally just seconds longer for me to be taken to a room somewhere or even just behind a curtain somewhere for this information to be imparted to me with a little greater discretion. So I firmly believe that that has nothing to do with resources. It has to do with personal choice, personal practice. It has to do with training. It has to do with culture. Perhaps it has also has to do with managerial performance management practice because these things go on because we work in a system that allows them to go on. If we stopped allowing them to go on then they wouldn't go on."

Of course individuals put their stamp on the kind of care patients receive. But as these two examples underline, health care today is about how teams work together and how systems influence individual behaviour. That's the subject under investigation of the next part of this e-article.

* The case studies are taken from www.healthtalkonline.org as well as from other sources. Healthtalkonline.org is an award winning website that allows visitors to share in over 2,000 people's experience of health and illness. It provides information about conditions, treatment choices and support by allowing visitors to watch or listen to videos of the interviews or read about people's experiences. The information on Healthtalkonline is based on qualitative research into patient experiences, led by experts at the University of Oxford.

About the author

Jane Feinmann is an award-winning medical journalist writing for the consumer and medical press. She is the author of several books as well as being a freelance producer for Radio 4. She can be contacted at jane@janefeinmann.com.

Bibliography

Seeing the person in the patient, the Point of Care review paper by Joanna Goodrich and Jocelyn Cornwell. The King's Fund, November 2008.