

SUE SPENCER PODCAST

Claire Munro (00:24):

Partnerships in healthcare can be transformational. They can support healthcare professionals and bring insights and value to life science companies, and most importantly of all, they can improve outcomes and experience for patients. But it takes a lot of skill to get them right.

In this podcast, we'll hear inside stories from the experts about what it takes to make them work. And crucially, what not to do.

I'm Claire Munro, the founder and managing director of Dovetail Strategies, and this is Getting to the Heart of Health Partnerships. This week I'm delighted to be joined by Sue Spencer.

Sue's an educator and researcher who's passionate about enabling people to develop personally and professionally through creativity.

She's a former university lecturer with a wealth of experience in both nursing and the third sector, and she and I first met when she was a diabetes nurse specialist in the Northeast of England in the early 1990s.

I was really keen to invite Sue onto the podcast because she was the first person to introduce me to the then-novel idea of treating patients as partners in managing long-term conditions instead of passive recipients of care. Today, we're going to be talking about how that idea has developed over the years, how her own experience has shaped her thinking, and whether or not we are any closer to treating patients as partners in 2022.

Claire Munro (02:06):

Sue, welcome!

Sue Spencer (02:08):

Thank you, Claire. I'm very excited about being able to talk out loud about this.

Claire Munro (02:13):

I'm thrilled to have you, and I cannot believe...I didn't believe you when you said it was 1992 when we first met. It feels like yesterday.

Sue Spencer (02:23):

Palmer Hospital, Jarrow.

Claire Munro (02:27):

What an auspicious meeting that was!

Sue Spencer (02:29):

Indeed. Indeed!

Claire Munro (02:32):

So let's start then by thinking about what first got you interested in this idea of patients as partners and health partnerships in general.

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Sue Spencer (02:44):

I guess when I thought about that, it actually goes back to when I was activated, when I was at North London Poly during my district nursing course.

The lecturers at North London Polytechnic were not backwards in coming forward in terms of their political leanings, and as district nursing students, we were taught alongside social workers, probation officers, and social scientists.

The questions they kept asking us were about what kinds of circumstances our patients were finding themselves in and asking awkward questions, and I liked that.

So that was probably where the seeds were really sown, in terms of a different perspective in terms of how we approach what we are doing as a profession.

But it was really once I became a diabetes specialist nurse that you couldn't get away from patients as part of the equation in terms of actually what you were trying to do.

What I was very quickly made aware of was that the job wouldn't be there if it weren't for the people with diabetes. In South Tyneside, there was a very active British Diabetic Association as it was called then, now Diabetes UK.

A very active group of patients working with their local GP. And they just were a force to be reckoned with. So that was probably where it all started.

Claire Munro (04:20):

But that's really interesting because I'm guessing at that time, most diabetes services were not being run in that way.

Sue Spencer (04:31):

Absolutely. So, there weren't that many of us about, and certainly I realised once I got to know more diabetes specialist nurses that South Tyneside and Gateshead particularly were well known in the local area for having very active patient voices.

Certainly, it was much more that our services were having to accommodate some of those things, rather than it being about how the service grows clinically. It was about how we meet the needs of what the patients are saying we need to be doing and trying to accommodate that as well as doing what was actually possible.

Claire Munro (05:25):

So it was instigated or largely driven by vocal patients.

Sue Spencer (05:32):

Absolutely. It was very hard not to take notice of them, and I think what I quickly noticed was how difficult that was for a lot of other healthcare professionals to even consider as something that had to be accommodated.

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A simple example is that when I first went to outpatients as a diabetes nurse specialist, they were weighing people in the waiting room. So I moved the scales into a side room, and it was just a simple thing like that, you know.

It was kind of like ... let's publicly shame people, and they hadn't even thought about it.

Claire Munro (06:30):

Looking back, what was the most challenging aspect of having this very clear idea that your role was to meet patients' needs in a system that wasn't really geared up to do that?

Sue Spencer (06:48):

That it was the system, and it was particularly the attitude towards the fact that the system was sacred and that you shouldn't do anything about rocking that.

You know, this is the way we run the clinic. I didn't make many friends, but actually, looking back, it didn't matter because the consultant had my back. And that was why he appointed me. He said ... we knew that you would be the one that would really develop the service.

Claire Munro (07:23):

It's a great example of another type of really effective partnership and a very smart piece of recruiting, because I remember that the consultant was certainly not one to want to ruffle feathers, but he obviously realised that you and he had very complementary skills and that working together, you could achieve the changes that you wanted to.

Sue Spencer (07:48):

Yeah, absolutely. And also, I was much more able to communicate well with the patient group. And we take for granted some of the skill sets that we have at, you know, at that time. And looking back on that particular time in my career, I worked with two other fantastic people in our team, the dietician and the podiatrist.

We all got on really well, and we worked really well together, and we were complementary.

I was definitely the agitator and the activist, probably to my cost to some extent, but at the same time, it was part of my development. And, you know, I really enjoyed working in that team.

It was a really good part of my career. It was about all four of us working well together to try and shape something that actually was responsive to the patient.

Claire Munro (08:53):

What do you think are the ingredients of that collaboration that made it so successful?

Sue Spencer (08:59):

Values. That we were all ambitious, but we weren't ambitious for ourselves, we were ambitious for the service. But also, if I look back at what we were trying to do, we were values-driven and we were explicitly

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complementary - often agreeing to disagree, but then doing something about where that disagreement might impact on patient experience.

Claire Munro (09:35):

Tell me about the impact on patient experience and outcomes that this approach had.

Sue Spencer (09:47):

That's a really good question because I think we were very clear early on that we were interested in that, but I think our hunch was that if you involve people better in both decision making but also shaping the services, the likelihood would be that they would have a better outcome with their diabetes. I can remember already noticing stuff then about how complicated it was for people to live with diabetes. I can remember pointing out to a great leading light in diabetes that we probably took for granted people's numeracy in diabetes and the fact that they will have to make complex decisions about insulin doses based on our assumption that they understood numbers. Most people I'm meeting don't have an 'O level' in maths. And if we start talking about percentages and all that sort of thing, then that we've lost them.

Claire Munro (10:58):

What did you love most about that role when you were a diabetes specialist nurse? Both in South Tyneside and then later on in Gateshead?

Sue Spencer (11:06):

It was the balance between giving status to a profession but also having a focus. But also, I really still passionately believe that we can do diabetes better. That then led me to do my master's research when I was in Gateshead. I decided to centre my research on listening to people with diabetes. And I was really interested in how we could actually listen to more voices, because I was aware that in the local diabetes groups, the active patients were a very particular type of patient. And it wasn't representative of the diversity of that population.

Claire Munro (11:59):

You've written about the role of emotional intelligence in professional practice, and this links perfectly to what you were just saying; how important is emotional intelligence, do you think, in terms of both the wellbeing of the professionals and also their ability to meet the needs of their patients?

Sue Spencer (12:27):

I don't think it can be underestimated how important it is, and I think it's the suppression of emotions that is often problematic. And also partly because emotional intelligence, to some extent, has been wrongly interpreted as being rational and being kind of, you know, well behaved. And I certainly feel that it is one of the things that doesn't get talked about. What emotions are in play, and why and how they might impact? If people are not civil, if they're disrespectful or rude or shouty or dismissive of patients and we need to ask questions about ... I said to a group of medical students earlier in the year, actually, that it's a privilege to work with patients, and therefore if we bring in stuff into that encounter, then we need to be holding our stuff in awareness. And I don't think we talk about it enough. I really don't.

Claire Munro (13:35):

But it's so fascinating because it's so rarely talked about in the context of healthcare and workforce development.

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Sue Spencer (13:45):

I guess some of that comes from conversations I had with Julia Darling 15, 16 years ago, about how poetry can actually bring to awareness some of this. And that once you start paying attention to people's experiences through different outputs, whether it's people telling their stories or writing poems, you can start noticing what matters to them, which might be the most important thing you deal with in that encounter.

So, you know, an example for me in the diabetes clinic, there was a gentleman that was always demanding when he came to outpatients, and he always came long before his appointment time. And what happened was that he was really unhappy with his work. But because he was stressed, he used to project a lot of that on outpatients.

And the first time anybody really listened to him about what was really going on for him at that particular time was that Monday afternoon when we took him to one side. And he left without having his HbA1c taken that time. But he went away and came back to see us about a week later in the diabetes centre, looking to problem solve and resolve some of the issues that were going on for him and for the rest of his life.

Claire Munro (15:20):

And that's a really essential point that can be missed. I remember from my time working in hepatitis C in particular. Healthcare professionals working in hepatitis C are trying to activate people affected by the condition to embark on a fairly grim treatment. But many of the people affected by hepatitis C have much greater priorities. They might be dealing with homelessness or still wrestling with substance use.

And if we don't understand all of the other things that are going on in patients' lives, we can't possibly understand where the potential treatment fits for them. And so then we're wrestling with these issues of adherence or compliance and blaming the person, when it's really just because they've got other stuff to deal with. Right?

Sue Spencer (16:26):

Absolutely. And I think that was what I learned when I did my master's research, which then led me to do further research. Instead of using focus groups, actually, listen to people over a period of time. And what was interesting was listening to people tell me about their encounters with the system over 18 months, which was about how little it impacted in terms of their decision making, but how emotionally it was a thing that they had to think about and would often disrupt their equilibrium. Because they'd have to worry about whether they could get parked, whether they'd find out that they had complications, whether they would be getting new tablets, whether they'd see the same doctor as last time... There were the 10 or 15 minutes when they were seen, but actually reverberating afterwards.

Sue Spencer (17:35):

And so they were navigating those transitions, and dealing with the emotional labour of that. But I can remember being really struck by how much work they were doing by coming up to the clinic appointment and then how to make sense of it after. And when I then interviewed healthcare professionals to see if they actually even noticed this as a thing, the only people who talked a bit about that were the psychologists and a couple of the nurses. But the doctors didn't. They just saw it as, you know, people come to the clinic, and this is what we're doing, and this is why we're doing it. We've got all these standards to achieve in diabetes care, but

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emotional labour and all that work that people were doing in terms of thinking through the implications of that encounter wasn't something they even considered.

Claire Munro (18:34):

I was really struck when you and I were working together recently on a patient insights initiative. You said to me that people with long-term conditions work really hard not to be a bother to their healthcare professionals.

Sue Spencer (18:52):

Yeah. I cite that quite a bit recently because it made me quite cross. Because I know we've been in strict times at the moment in terms of the pandemic, but even so, I do think we are enormously privileged to have that role in somebody else's life. And I must admit that when I heard on that project about exactly how much deliberation and decision-making patients were going through with some fairly unpleasant symptoms about whether to bother their nurse, I was a little cross because it's hard enough living with an intermittently horrible disease with painful embarrassing symptoms, that's often really unpredictable as well.

Claire Munro (19:58):

Yes. And those were people with inflammatory bowel disease, which, as you say, can be unpredictable. And when you have a flare, you really need to know who to contact.

So I want to move on because our listeners will want to hear your experience and your advice. When healthcare professionals and life science companies, pharma companies, or device companies decide to embark on or improve their patient engagement, what do they get wrong?

Sue Spencer (20:30):

Ooh, what a good question. I guess the things that probably are often mistaken is making lots of assumptions about how you go about it. I think the most important thing is finding out what you want out of it. Why are you doing it? Are you prepared to have people disagree with you? And how are you going to manage very strong opinions? Because you are almost certainly going to get somebody volunteering to participate who has very clear reasons why they're there. And it is about managing that situation in terms of your experience. It's not everybody's experience. And finding the respectful way of actually recognising that that experience is valued, but it's not everybody's experience. And, I think that can often be the thing that gets done wrong. In life, the ones that speak loudest to the ones that are heard, and I would be far more concerned about the ones that aren't saying very much. And it's like, you know when I was working in diabetes, and they did a lot of research about people not attending the clinic, I was much more interested in why they even bothered coming half the time. They're really obedient. They come to the clinic, they turn up on time, and they stay, and they have to wait two hours to be seen for 20 minutes. Why are they still coming?

Claire Munro (22:17):

That's great advice! So what would you do differently now, knowing what you know? What else would you do differently if you were back in that situation?

Sue Spencer (22:30):

I think I'd be more confident about myself, that I was on the right track. If I'm honest, I can remember that I was very clear about how we ought to be involving service users, more inclusivity, and different models of care because, at one point, I commented on the fact that we could probably learn quite a bit from the palliative care

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movement in terms of how more patient centred we could be. And I was nearly thrown out of the room. People were absolutely furious with me. And then, you know, a few years ago, I read about how in chronic disease, we could be learning from palliative care and ... there we go! I wouldn't have left diabetes nursing. I would have ignored what was going on and been more forceful and rattled a few more cages. I think, you know, in terms of service users needing a voice, I worried too much about what other people thought at the time. So yeah. If I could do anything differently, it would've been to not leave that job.

Claire Munro (23:46):

I love that. I think that's great advice for all of us under most circumstances. Actually rattle more cages! What do you think is the future for patient engagement? We've seen it developing, and there's certainly much more talk about patient-centricity, and I see a genuine desire in a lot of organisations to be more patient-centric. Where do we go next?

Sue Spencer (24:16):

I think we just need to talk about it more and talk about where the resistance is. It's like with anything in, in terms of where there are defences put up or obstacles put in the way, what's that about? Because if we didn't have patients in healthcare, we wouldn't have a job, they are our purpose.

And so, therefore, if we are not listening to the people who are meant to be the beneficiaries, then what are we doing?

You know, that early influence in the eighties from academics has never left me in terms of we often need to just examine where the power and control are and why people hold onto that. And what is that about?

So I think that that's often where the challenges are. It's often about working to find out what that resistance is about.

Claire Munro (25:16):

Sue thank you so much for joining me today. It's been a brilliant conversation, and I think people will learn so much from your experience. So thank you so much for sharing.

Sue Spencer (25:27):

Oh, it's a pleasure.

Claire Munro (25:37):

Next time I'll be joined by Jeremy Thorpe, the managing director of Tillotts Pharma, UK. Jeremy committed Tillotts to be a preferred partner to the NHS through consistently delivering quality and value and supporting them to improve patient outcomes.

And as we'll hear, that approach has been extremely successful commercially. He started out ten years ago with two staff and no sales and now leads a team of 42 with sales of over £42.5m. So please send your questions for Jeremy to claire@dovetailstrategies.com or contact me via LinkedIn. Thank you for listening, and goodbye.

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