

Angela Camber: developing models of integrated care for chronic conditions – a patient's perspective

Talking about ageing populations, I have to tell you I am one of them, as I'm sure you can see, but it is making me feel particularly old because integrated care, be it medical, social, joined-up, whatever, has been around for a long time. Many, many years ago I did my first degree in Social Studies and I was one of the very first Seebohm – there was a report made by Seebohm on Social Care – which was piloted by various local authorities and that was how Social Service Departments were set up. So in my very first social work job I was a Child Care Officer; I had mental health cases; I had cases dealing with elderly problems, etc. So this is not entirely new. I've also dealt with integrated care issues in terms of criminal justice, adoption – all the things that I have done throughout my professional career.

But, to me, the very, very centre of all of this is people: people, people, people. It is how we react, how we are, how we are able to take in information, how we find the courage to go to the doctor to be told difficult things. So if we can just – I know we are not supposed to be talking about silo-ism, but if we can put systems aside, just for one second - this is about the patient experience. I am one of the very lucky ones, I have to say. I have had quite a horrific medical history which I am not going to bore you with, as you will all fall asleep anyway, but here I am. I'm alive. I do have heart failure. I have had a lot of open heart surgery and endocarditis and aneurisms and goodness knows what, but apart from being incredibly lucky to be alive, I am also lucky because I guess I can say I am relatively articulate; I am able to ask questions and I am able to 'chip in', if you like, in terms of my care. That is utterly crucial and the flip side is equally crucial, because there are patients who don't want to know. There are patients who are so terrified and actually don't want to be brought round to this crucial ethos of feeling empowered and frankly part of a team.

I mean, just to give you one example: I was stuck for two months in hospital with endocarditis and I had a stroke and goodness knows what happened, and when I began to re-join this planet, the doctor who was in charge of my care came to see me and said, "I want to tell you something." I thought, "Oh God! Not another problem. I can't cope with this," because I was just beginning to get better. He said to me, "I just want to tell you that the team who have been trying so hard to get you better are very impressed with you because you, you know, have come round and whatever." I immediately said, "Actually, I don't believe that's the case. I think we have done this together." That to me is the most important part of all of this. The whole joined-up and getting away from silo-ism has to be done. It has to happen.

We can see that in various parts of the country it is happening, but you can't always rely on, you know, the patient to say, "This is what I want." People have to be proactive; discussions have to take place; people need to be approachable and I cannot actually really – apart from one experience I had – I can't stand here and tell you well it's all been doom and gloom, because it hasn't. But it's partly because I was able to advocate for myself. The doom and gloom bit was one of my many admissions before they finally discovered that I did have endocarditis. They tried to keep me in hospital and I was really, really scared. I was absolutely terrified. Nobody came and explained to me why they felt it would be a good idea. All I got was, "Well we are going to have to make a note of this and be it on your head if anything happens. It's entirely your responsibility. You are not our responsibility any more. You are discharged," and I did actually have to come back the following day, but that was the one issue that I have that was really incredibly difficult to deal with, because I was very scared. I wasn't well, so I wasn't really able to say, "But can you explain it?"

So my plea is that the patient remains right there in the middle. It is about where the patient is placed and the sooner there is a national and indeed international understanding of what this means – it's not a difficult idea. It's not a tough ethos to be a part of, in my humble opinion. I mean I have worked in kind of joined-up areas for many, many years, but if the patient can begin to feel empowered and helped along, and if somebody doesn't understand something, why can't they ask a question? At the moment it's the luck of the draw. You may get a doctor who is an absolutely brilliant communicator; who is kind; who is empathetic; who is helpful, and you may get the reverse because they simply don't have the time.

So to me it really to me is about empowering; people making themselves approachable. A lot of it is about training, because people are going to have to learn that they are going to have to work with these dreaded social workers who moan and groan the whole time. They are going to have to work – whether through education, housing, whichever – everybody has their own culture. I mean, I chaired the amalgamation of a very, very large probation service. It was five autonomous services into one London service and if I tell you, it was a nightmare. The incoming, the new Chief Executive of this monolith service in London actually said to me, "You are forbidden, Angela, to allow any member of staff to go back to where it was. You are not allowed to do that." I just shrugged and said, "Look, I'm older than you. I can do what I want. You are not going to tell me what to do."

To me that is so important because as integrated care moves on, for many practitioners, be they social workers, teachers, mental health workers, it is going to be hard because they are going to want to hang on

to what they had. Change is tough for many people and people do need to be able to go through, whether it's that mourning or grieving, in order to actually move on. So that is my plea and I do agree with whoever it was who said, "No decisions without me," because the patient is right at the centre. I also agree with this end to silo-ism and really, let's just think about the person right in the centre.

Thank you.