

Can I be honest?

Improving communication skills to build and maintain trust between medical professionals and patients is both commendable and desirable, when it comes to shared decision making

says **Cardiomyopathy UK Trustee**

Stephen Kirkham

Considerable emphasis is being given to shared decision making within the NHS and building and maintaining trust between medical professionals and patients by improving communication skills feature highly.

This is both commendable and desirable. However, effective communication is a two-way process for both medical staff and patients, requiring everyone to be effective in “transmitting” as well as “receiving”.

So if medical professionals are to be better at listening and discerning what is really going on, how can they learn to “receive” more effectively?

Communication experts say effective verbal communication is made up of the following components:

- 58% body language
- 35% voice (tone, volume, and pitch)
- 7% words used

Developing better skills in reading “body language”, listening effectively and actually interpreting the words in light of the other evidence, are all necessary and should be in play during any doctor’s contact-time with patients.

But equally, patients have to communicate effectively, which assumes the patient has the capacity, ability, or even the desire to be able to provide a rounded and complete description of their situation and symptoms, their hopes and fears.

From my own experience, various factors are likely to affect the way a patient will approach their illness and I would suggest that age, character, experience, personality type and learned behaviours will all play a part.

In the years between 2005 and 2015, I felt badly let down by NHS England and to a lesser extent, NHS Scotland. My care - from my diagnosis of cardiomyopathy and severe heart failure, right up to the moment I entered the Golden Jubilee National Hospital in Clydebank in April 2015 - was substandard at best, and downright awful at other times.

However, with the value of hindsight and I hope now armed with a vision for realistic medicine at its best, I can see how I must carry at least some responsibility for that poor care. I was complicit in it to a degree and believe there are lessons to be learnt from this – lessons for both the multi-disciplinary medical community and equally important, for my fellow patients.

The fact is, I know I will always attempt to put a positive spin to any situation. And it is part of my character, a consequence of my childhood, to want to seek approval.

Having spent 26 years as an infantry officer, this is hardly surprising. The Army's "can do" culture means the "Don't tell me what you can't do, tell me what you can do" approach to doing business comes as second nature to me.

I now see that whenever I talk about my life-saving heart transplant, I'll smile and include "and now I average 20,000 steps every day", which is true and which delights me. But a much more rounded statement would include the equally honest facts that my knees and back really hurt sometimes; my right foot is collapsing, such that I need an orthotic insert so I'm not walking on the right edge of my foot, and I often need to take a nap in the afternoon because I'm averaging a lot of minutes walking each day, which is knackered at nearly 67!

So how did my positivity and stoicism have a negative impact on my treatment and my care for dilated cardiomyopathy?

'There can be no doubt that I had been in a form of denial and my determination to carry on regardless meant I was putting myself at risk and hardly helping the medical team to do their job'

Let me start with my initial diagnosis. My story, which I've told a number of times at medical conferences and meetings whilst promoting organ donation, starts with me being frog-marched to the surgery on the orders of our GP because my wife was concerned about me, seeing things in me I couldn't see..... thence to hospital, tests, diagnosis and the news I had severe heart failure and dilated cardiomyopathy, and to be told I had five years if I was lucky. What a shock I say, and that's truly how I remember it.

Researching for this article however, I came across an old notebook, in which my wife had kept notes from that time. It says:

Tuesday – *Stephen breathless taking drum kit upstairs.*

Wednesday - *Phoned surgery but couldn't see our GP for 3 weeks; could see lady doctor.*

Friday - *Saw doctor who spent 40 minutes on Stephen; ECG trace discussed with colleague who covers in cardiac clinic at John Radcliffe. Stephen told to slow down and given GSN spray and diuretics. BP was very high.*

Early Sat morning - *Stephen woke very breathless; that evening chest pains.*

Sunday - *Stephen took morning church service. Breathless in night.*

Monday - *morning more chest pains.*

Tuesday - *Stephen looked awful colour. He walked dog, but had more chest pains. Phoned and spoke to doctor; Stephen protesting that he had a funeral to take at 2pm. GP said, "put him on" and spoke to Stephen and ordered him to surgery there and then.....*

There can be no doubt that I had been in a form of denial and my determination to carry on regardless, meant I was putting myself at risk and hardly helping the medical team to do their job.

Fast-forward to August/September 2014 when we moved from Oxfordshire to Scotland. Nine years of hospital notes and printouts remained in the hospital in England; in their place I was given only a side-and-half of A4 paper, which I was to hand to my new GP.

By this time I was on maximum doses of the available medications and had been told I needed a CRT(P). It had also been a year of considerable stress with my mother's death, the problems around clearing and selling her home, and selling and moving ourselves. I was not well, I knew it and so did Heather.

We met our new GP who was a nice bloke; we chatted, and I smiled and asked when I could see my new consultant, only to be told I'd have to wait the regulation 14 weeks.

The GP's verdict was that I was just another routine heart failure case. Yet only eight months later, I would be carried into the GJNH Advanced Heart Failure Unit to be told that I didn't have very long to live and that a transplant was my only hope; indeed, less than two weeks after being listed for transplant, I had a cardiac arrest on the unit, was resuscitated and placed on the urgent transplant list.

That September, October and November, I really did have to wait the 14 weeks to meet my new Scottish consultant - a time of considerable anxiety and stress for us, which I believe contributed to my rapid decline from that point onwards.

In a recent conversation about that time with my GP, he was both frank and apologetic. He had no idea I was so ill; if he'd known he could have got me seen sooner; I hadn't looked that ill, he understood me to be saying that I was coping... After all, I'd told him how I was walking 2kms every day... I hadn't mentioned what a struggle that was; how the slope halfway there had me gasping for breath and how my gut really hurt at that point as the fluid in my abdomen pressed down as I was breathing so hard.

Heather has since told me that if he had looked towards her as I was telling him about my daily walks, he would have seen her shaking head, trying to signal that there was more to tell than I was letting on.

So what are some of the lessons here?

Firstly, for the patient to trust the professionals and for the professionals to be able to know that they are being given a complete picture and fully understand where the patient is coming from, requires discernment, openness and honesty on both sides.

'Not every patient wants to be an active participant, but we owe it to ourselves and loved ones, and to the medical team, to all be doing our best'

Secondly, I believe the patient organisations - charities like our own Cardiomyopathy UK - have a key role to play in helping us to help ourselves by entering fully into shared decision making.

Not every patient wants to be an active participant, but we do owe it to ourselves, our loved ones, and to the medical team, to all be doing our best.

- It may be that as a charity we can provide help through our Support Groups, at our Regional Open Days, and at our patient conferences. How well do we as individual patients do? Open and honest discussions addressing the fears and difficulties we encounter during consultations and meetings with doctors and other MDT professionals could be valuable.
- There's possibly a place for role play exercises where we help each other to represent ourselves better. Indeed, perhaps the time has come for joint learning, with medics and patients working together to develop the skills we each need?
- CM UK's "My Symptoms Diary" is an excellent personal resource, and members should be given every encouragement to make use of it. Equally, GPs, consultants and HF nurses should be encouraged to recommend it, and to consider building a conversation around it.

Thirdly, for all the members of the MDT:

- Listening skills, involving the ability to read body language, and to "hear" more than just the words, are vital skills that need developing and practise.
- An invitation to honesty and openness at the start of a consultation can only help.
- Certainly the input from HF nurses who see patients in their own homes where there is more chance of weighing up the whole situation is essential.
- Perhaps too some simple functional tests to go alongside the medical tests, along the lines that an Occupational Therapist might employ, will help reveal more of the truth. Something as simple as "please take off your shoes, pick them up... and now put them back on again" might prove very insightful.

Finally, I believe there is a key role for the carer, supporter, or relative to play when such a person is available, and every effort should be made to involve them. I appreciate there will need to be permissions requested and granted to involve this "significant other" in any conversation or discussion, but their input is likely to prove invaluable in establishing how things really are.