The Teacher as Patient becomes Patient as Teacher

Kay Henderson, PCC member since 2003

Almost eleven years ago the School of Medicine sought to engage patients in the teaching of medical students in a rather different way than had been the practice over many generations. With more medical students to teach but fewer suitable patients in hospitals, teaching in other settings in addition to General Practices, had increasingly been undertaken since the early 1990s. The engagement of the patient as a teacher rather than as a passive 'subject' was a new initiative. In this article, former teacher, Kay Henderson, describes her journey from being "a teacher as patient' to 'a patient as teacher'.

How it all began

My first experience of the Medical School was in 2003, when I, along with other long-term patients, was invited to a meeting to talk about being a patient. Being confined to my wheelchair, the opportunity for a change of scenery and promise of lunch was very appealing! Our group consisted of patients with a variety of medical conditions and we were encouraged to talk about how our illness affected us and the effect on our lives. A lot of emotions ensued and, although our illnesses differed, we discovered that we experienced many things in common. For once I felt I was being given permission to tell the truth about how it felt to live with chronic illness. I came away feeling it had been a cathartic experience and looked forward to our next meeting. After three more meetings, we had discussed many aspects of "patienthood", including thoughts on how we were treated by members of the medical profession.

Many negative experiences were revealed which led to us considering how we would prefer to be treated. Having endured many fruitless consultations with medical people I had often thought, "Why don't they ask what I think?" and others in the group felt the same. We established that there were common themes in our thinking and looked at ways to implement them. With Jools Symons as lead - Patients as Teachers, Leeds [PATL] was born.

The Patient Journey

The word "journey" had been applied to the way our illnesses and lives had developed. What I learnt about myself in those first meetings was something of a revelation. I was used to keeping my feelings of anger, loss, sadness and frustration under wraps from day-to-day. I realised that talking about my personal "journey" enabled me to assess where I was at in respect of handling these feelings. I'd off-loaded lots of baggage, felt comfortable talking about it with others and concluded on reflection that I now accepted my illness in a more positive way. I really enjoyed the time spent with other patients and carers. I felt as if a burden had shifted, allowing me to think positively.

To be helpful to students would require us to use our experiences in a positive way. I felt I had already reached a stage of acceptance. The idea that other patients, and carers, might benefit from something similar led to the development of the Patient Learning Journey [PLJ] where, alongside experienced facilitators, those of us who were willing were encouraged to co-facilitate new groups.

This increased our confidence but was also important in making new patients and carers feel secure. I always feel privileged to be involved in these sessions as patients are revealing sensitive and intimate views about themselves and I appreciate from my own experience the value of having opportunities to disclose one's inner thoughts without any feeling of guilt. Permission to do exactly that is wonderful - so often in the past I repressed emotions for fear of upsetting family and friends.

The Importance of Good Communication

I was keen to use my experiences as a patient to help students grasp the importance of developing good communication skills. As a user of medical services for many years I had first-hand experience of both good and poor consultations. Having students visit at home enabled me to share these experiences and again allowed the chance to say what being a long-term patient is like. The response from students was positive and encouraging – they seemed genuinely pleased to meet a real patient and listen to my day-to-day experiences. Yet again I felt free to tell them things I had never discussed before. The benefits to me were enormous.

It had similar results to a counselling session I imagine, maybe greater, as answering students' questions made me focus on how exactly I do manage my life. Talking to groups at the medical school also made it obvious to me how important it is for students to hear from real patients early in their training. Students were keen to learn about life for a patient and how things I experienced could be improved upon with better communication skills. Their reaction of horror to the way I had been told of my diagnosis encouraged me to believe working with students in this way was the way forward. At first it seemed a bit daunting talking to students but now, several years on, I still enjoy the classroom visits as something new always crops up to talk about. Feedback from students confirms the interest and value they put on them too.

Training

Patients and carers, especially those new to the experience, attend a carefully structured training session, flexible enough to allow everyone full opportunity to voice opinions, make suggestions and actually plan what to include in the classroom. This acts as a safety net. I have co-facilitated such training sessions, as have other patients and carers, and feel this contributes to the authenticity of the training. Other patients and carers feel comfortable knowing they are being guided by people with similar experiences, who empathise with theirs. No two training sessions are the same so it is always valuable to attend and refresh one's ideas.

Training to work with students as a simulated patient [SP] allowed me to further my own skills whilst helping students develop theirs. For some time actors had been role-playing pre-written scenarios to give students practice in communication skills. Having observed a couple of these I had a go myself, feeling slightly confused as to who I was really being and how to give feedback to students on their performance. The tried and tested model for giving feedback was very useful and mostly worked extremely well. However, sometimes I felt under-used, with assumptions being made and little reference to me. I couldn't always make my patient voice heard. I quickly learned that the value of these interactions for the student was in hearing my patient voice, not in the quality of the performance of the scenario. Having the personal experience of emotions which may arise during a consultation makes the interactions as real as can be and I react to students as truthfully as I would in a real situation.

Training for simulated patients has further developed so that patients are now not only encouraged but expected to be co-facilitators. This, too, gives greater prominence to the patient voice. Students take more heed of feedback from a patient, making the whole experience of such interactions more rewarding for both.

Examinations and Curriculum Development

The Patient Voice Group [PVG] developed out of all the other activities and led me into other areas of working alongside patients and carers. I have contributed my patient expertise in developing and writing new scenarios reflecting real-life experience of patients for use with students both in the classroom and in grading students' communication skills in OSCEs. As part of the PVG I took part in discussions about what needed to be included in the School of Medicine's new 2010 curriculum. The Patient Voice Group has now developed into the Patient |Carer Community. I feel proud to be a member of this team for several reasons, one of which is that we are recognised by the University as having a vital and valid place in several areas of medical education.

I have also helped to make short videos about being a patient, for use with students, worked with a wide range of clinicians on their communication skills and facilitated groups of students practising the same. As a Patient Mentor I am able to talk to students about their experiences out on placements, in relation to topics they have chosen to reflect upon. I can provide them with my perspectives as a patient to help them have an all-round view. Students are mostly very responsive and appreciative and yet again the benefits are two-way and I feel valued and respected for my life experiences. Sometimes looking at situations through a patient's eyes helps students find solutions to difficulties they've experienced.

My Personal Journey

I have gained immense personal value from being part of a team, with all the support and friendship that goes with it. We are aiming for the same goal - preparing students to be the kind of doctors we need and want and we help each other towards achieving it.

Helping deliver the new curriculum and leading workshops at conferences in Vancouver and Cambridge University, showcasing how real patients and carers work in medical education, were wonderful experiences and ones that made me reflect on how far I had come on my own personal journey. My confidence had returned and I even felt more comfortable with my appearance. Feeling disabled was no longer my primary concern. I stopped hiding my arthritic hands and stopped worrying how badly I walked. Family and friends commented how much better I seemed, both physically and mentally and I truly believe working with medical students turned my life around.

When my career as a teacher ended because of ill health I felt that I had nothing much to offer. Starting the journey I have described gave me a purpose again. I felt more positive and confident. My self-esteem increased and I had things to look forward to. I managed my illness better because I wanted to continue being a part of the whole wonderful experience of working at the medical school. I was and am still determined to do it and the pleasure and satisfaction it still gives me has made painful joints much more bearable. I actually think my health has improved because of it. It has also made a difference to family and friends who can hardly believe the change in me. Depression is a thing of the past and those around me reap the benefits of seeing me so very happy and involved. I am much less dependent as I have so many other things to focus on.

The other major impact of being involved with medical education is in me as a patient and the way I feel towards doctors. In the past I was much more passive, believing it was a doctor's job to treat me. I now realise what I need to do in order that a doctor may do his job well. Learning what is required of students and helping them achieve it has shown me the difficulties they can experience.

I feel sure I am now a much better patient when I see my own doctors and consultants. I think in terms of it being a partnership. I am confident to share my expertise with doctors, challenge their opinions if need be and be involved in any decision making. I come away from consultations feeling much more satisfied.

I hope to be involved in medical education for some time to come. Over the long summers I miss both the work and the contact with others in the team. We have become like a large family and genuinely support and care for each other. I think about my “old life” less and less. Whilst ever I am needed and can drag my bones to the Medical School, I’ll be there!!