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## **Chapter 14: Humanizing Healthcare**

### **A conversation with Pip Hardy and Tony Sumner, Pilgrim**

#### **Projects/Patient Voices**

Along our journey into Digital Storytelling, we have never been far from issues of health and well-being. From our earliest workshops stories emerged of people's confrontation with severe illness, the journey through the healthcare system, and their recovery. And of course, given the call to meaning within our work, many stories dealt with the loss of someone to illness, and including narratives about the experience within a healthcare setting.

In the late nineties, we began to see initiatives in the healthcare field, organizations interested in stories of cancer survivors, the celebration of successful healthcare practices, disability, hospice care, and public health issues. In 2006, we learned of the Patient Voices program ([www.patientvoices.org.uk](http://www.patientvoices.org.uk)) of Pilgrim Projects, a Cambridge, UK-based organization that had begun to develop extensive healthcare work in Digital Storytelling. The deeply committed work of Pip Hardy and Tony Sumner has become an inspiration to all of us in the field.

#### **JL: How did you get involved in digital storytelling?**

Pip & Tony: We have always used stories as an important element of the text-based and online education programmes and learning materials we have developed over the last 25 years. In 2003, we were trying to bring the patient's voice into e-learning materials about healthcare quality improvement and we stumbled across a community history digital story. It seemed to us that this digital technique of telling and sharing stories was the perfect way to convey the important stories of healthcare in a digital medium.

Our hope was that, by bringing the very human element of stories back into healthcare education and service improvement programs, we could contribute to the huge task of humanizing a healthcare system that was increasingly characterized by targets and checkboxes, audits and statistics. We often have said that statistics tell us the system's experience of the individual, whereas stories tell us the individual's experience of the system.

#### **JL: How did your work in Digital Storytelling evolve?**

P & T: The main emphasis of our work has always been on facilitating others telling their stories and

sharing them digitally. We began working with individual patients and care-providers in late 2003 adopting a home-grown approach, using very open questions to elicit a story about healthcare in relation to values such as equity, dignity, respect, trust, etc. At that point, it would be a further two years before we learned about CDS.

Pip first attended a CDS workshop in the spring of 2006 and we subsequently adjusted our methodology to one that was workshop-based, seeing the benefits of working in small groups.

**JL: So can you tell me something about making your own first digital stories?**

Actually, our very first story was a collaborative effort between the two of us, facilitated by our friend Brendan Routledge in late 2003. It was a little piece, created in order to investigate the technology. It was a community history piece – but the community in question was the flock of doves in our back garden. It was driven by the images, which Pip assembled into a visual story using Windows MovieMaker. When the time came for recording, Tony ad libbed the voiceover and that was ‘Dove story’.

Eventually Pip discovered the existence of CDS as part of research for a masters in Lifelong Learning, and came to California to attend an introductory workshop in March 2006.

*‘It happened to be a facilitator training workshop, although I was there as a first-timer – it was to be held in the newly-refurbished downtown art gallery but there had been delays in the work and the space was freezing cold with very few power sockets. Confusion reigned and we ended up moving the workshop out to a ranch in the country.*

*My first story was about my relationship with my father, who had died the previous year. Tony had found a picture of the house where I was born in an old Sunset magazine and that provided the prompt for the story.*

*I remember being incredibly impressed with your comments when I sat with you. You seemed to understand exactly what I was trying to say.*

*As someone with a degree in English who has earned a living by writing for many years, developing the script wasn’t too difficult for me, although the input from you, Emily and others in the story circle was invaluable. But I did need a lot of help with Premiere and Photoshop – the use of layers still eludes me today! – but was, of course, really pleased with the way the story came out. I learned a lot about my father – and myself – through making the story and the real power of the digital storytelling workshop became apparent to me.*

*When I showed my story to my half-sister, Lucia, she decided she had to make one as well. She attended a workshop in June and then we both attended the next Facilitators’ workshop. My second story turned out to be a much darker piece than I had anticipated. I remember having heart palpitations for a couple of weeks before the workshop and I could barely breathe on the story circle day but, miraculously, since completing that story, there have been no more palpitations and I feel*

*that creating that story helped me to walk past a particular dragon that had prevailed over much of my life.'*

That story, called 'Transplant', can be seen at [www.patientvoices.org.uk/pilgrim.htm](http://www.patientvoices.org.uk/pilgrim.htm) Tony's first story emerged from a masterclass held here in Cambridge with Joe and Emily in April of 2007.

*'One of the reasons Pip and I work in concert together so well is the complementary and mutually supportive nature of our respective skills. As someone who has been involved in software industries since 1981, the technology is not, for me, a problem but instead an entertaining intellectual puzzle or challenge.*

*As a sometime-physics graduate, creative writing has never figured obviously in my career path, although I have spent many years developing learning materials with Pip. So, for me the challenge and the benefit lies in the creation and perfection of the story script. Despite that, several of my stories have come, like the first one did, as one of those Eureka moments at 4 in the morning.*

*Having worked on a story during the first day to the 'scar' prompt, I found that the space in which to reflect on scars and healing, and what they meant in my recent experience, together with the catalytic and sharing input of other storytellers, some of whom were friends and colleagues, seeded and brought to life within me a story about how I had felt about my mother's very recent treatment for breast cancer.*

*I woke up early on the second morning scrabbling for a pencil and paper, wanting to write a story in which the language mirrored my experience of the inhuman, unfamiliar specialized Latinate argot – mastectomy, unilateral, biopsy, etc. – that characterized for me the way that the medical establishment had used language to protect and distance itself whilst interacting with my mother.*

*I deliberately wrote the story using as few words as possible, to be delivered in a staccato and mechanical fashion because that was how I felt my mother's care had been, despite being clinically effective and, indeed, successful.*

*Although the story was still very present in my mind when I read it in the story circle on that second day, it was still a deeply reflective and affecting experience and the story, 'Knitting', can be seen at [www.patientvoices.org.uk/pilgrim.htm](http://www.patientvoices.org.uk/pilgrim.htm).*

*I've written several other stories since, but for me, the most enjoyable part of digital storytelling is actually in facilitating others in coming to terms (as I did) with their own experiences and emotions."*

**JL: In your own experience, why do you think digital storytelling is useful as a reflective practice?**

For us there are three sides to the reflective prism of digital storytelling.

1 There is the opportunity afforded to the viewer of a digital story to reflect on his or her own practice (and the practice of others). Sometimes seeing someone else's story, about how they made a decision they might now regret, can open the viewer's eyes to assess their own practice. This can be especially

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helpful for nurses, doctors and other people involved in healthcare.

2 There is the opportunity for storytellers to reflect on life experiences and consider the most effective and affective way of conveying their stories. Storytellers tell us that the process changes them – one initially quiet, even reticent, storyteller says ‘I feel as though I could talk to anyone now.’ And we now have people coming back to make stories that are reflections of the impact that going through the digital storytelling process has had on their lives.

3 Then there is the opportunity for us as digital storytelling facilitators to reflect on our practice of DS facilitation and our own life experiences.

Our own reflective process has two main strands:

- 1) Our post-workshop wash-up meetings always reveal some small way in which we can better meet the needs of storytellers, whether through some smoothing of the technological first steps that they face, or through some refinements of the range of interpersonal skills and approaches that we use to engage storytellers and help them find the heart of their stories.
- 2) Our program of six-weekly supervision meetings with an experienced counseling supervisor. It is in these reflective meetings that we are often able to identify actual or potential issues of transference and recognise where our own issues and experiences may be affecting our ability to be clear and available for storytellers. We feel these meetings are essential in maintaining our own psychological and emotional well-being and the safety of the storytellers with whom we work.

As to why DS is so useful, we think it’s a combination of things. Firstly, it’s a bit like having three days – or 24 hours - of individual and group therapy! If we do our job right, people have the experience of being listened to and having their stories heard, often for the first time.

Digital storytelling and, in particular, the rigorous process of script revision, offers a wonderful opportunity to reflect on our experiences – and those of others. Delving deeply into the meaning of a story, refining it and distilling it to reveal its essence can help us to see it differently. Thich Nhat Hanh (2006) expresses it nicely: *‘According to the law of reflection, the perceiver and the perceived have a very close link. When the angle of incidence changes, the angle of reflection will change immediately.’*

This process of distillation is a gradual process, with the story getting a bit stronger and then a bit stronger again until there is what one of our colleagues describes as a story characterized by ‘purity, clarity and potency’ – the characteristics of any good distillation! There is something about getting rid of much of the substance in order to get to the essence and people can then see the experiences of their lives with a new clarity.

Or put another way, stories spring from and are linked to people’s past and current life experiences. Inevitably then, within the process of reflecting upon and distilling their digital story, storytellers are given the opportunity, space and tools with and within which to reflect upon their own life stories. If

they get to the essence of their story they usually have a better grasp of the essence of the experience.

There is also something about seeing the final story on the big screen at the end of the workshop – things hitherto buried are now out in the open and outside of the storyteller, creating a new kind of freedom. As one storyteller has said, *‘When you’ve made your digital story, you don’t have to hold it in your head any more, you can put it behind you and it doesn’t take up any more space, so you can move on. You’ve named the beast.’*

### **JL: What do you see is unique to your approach to digital storytelling?**

We have tried to take our original open and facilitative approach to education and blend it with the very best elements of CDS’ approach and with our particular mix of personal and professional skills and life experiences from counseling and groupwork, teaching, writing and editing, software development, educational materials design and project management to develop our own subtle variant of the process. We feel this is well suited to the vulnerable people with whom we work in health and social care – patients, service users, care-providers (and even clinicians and educators!).

As our original intention was always to create an educational resource, we have come at DS slightly differently, but because we also know that healing and learning are closely connected, we are able to combine the various elements that will, hopefully, contribute to both.

People have described our approach as caring, nourishing and mindful and we try very hard to ensure that those qualities are always present in every encounter.

### **JL: Pip can you tell us more about your background and how it has shaped your work?**

Well, my background has been more in education than in therapy although, as I said earlier, I think the two are closely linked. I’ve always been interested in non-traditional forms of education, those approaches that really help people to learn, rather than just pouring in information. So I trained as Montessori teacher and eventually ended up in adult education, working firstly with unemployed and homeless people and then moving on to teach communication and what was once known in the UK as ‘liberal studies’ – an opportunity for people training to be hairdressers and bricklayers and carpenters to engage with movies and books and discussions about what makes us human. Gradually I moved into writing and editing open learning materials with a real focus always on the learner and trying to find ways of translating the qualities of a good teacher – someone who motivates and stimulates and informs and encourages and guides and inspires and so on – into written words that would offer people who had missed out on education an opportunity to follow some of their dreams. Of course I read Carl Rogers and, being a child of the sixties, I was pretty interested in self-development and becoming more aware. I became interested in Buddhism in the late seventies and that has really underpinned my life and work in different ways.

After working for quite a few years in education, I trained as a psychodynamic counselor and did some

group work. I started training as a homeopath but practicalities meant that I had to return to the world of educational development. But the common themes running through all this have always been around looking at people as a whole – whether you are offering education or healing.

In fact, the dissertation I wrote for the counseling course was an exploration of different ways of viewing and understanding the self – from a Buddhist perspective and a psychodynamic perspective – and an attempt to see whether the two could work in harmony to promote healing. That was some time ago now, and Buddhist approaches are now commonly adopted in the talking therapies – but it wasn't so common back in the dim and distant past of the last century!

Buddhist practice, with its emphasis on being in the present moment and the need to be aware of what's going on in both body and mind, provides the foundation for cultivating understanding and compassion that are all too often missing in both education and healthcare. Such an approach affords an opportunity to link past experiences with current understanding, learning and healing and is essential to the functioning of a successful story circle – the core of our practice as DS facilitators.

In all of these traditions (education, psychotherapy, homeopathy, Buddhism) stories play a huge part in leading people to new ways of understanding.

So, as our practice has developed, we have become aware from feedback and responses (and indeed, follow-up stories!), that many people experience the process in ways they describe as 'cathartic', 'therapeutic', 'retreat-like', 'transformative' and even 'spiritual'. Whether this is partly due to the aspects of counseling, groupwork and Buddhist practice that Pip brings to our work or whether it's inherent in the DS process is debatable. I think that having an awareness of what may be going on for people is an important part of the role of any DS facilitator. If nothing else, it seems to make people feel safe to know that there is this strong ethical and therapeutic underpinning to our work. And, of course, if they feel safe, they are more likely to tell truly authentic stories....

**JL: In Healthcare, there are many concerns about patient's rights, about protecting people's anonymity, and about not exploiting the suffering of others as part of the promotional efforts of healthcare agencies. How have you addressed these concerns?**

Because of the area in which we work, and the nature of our storytellers, one of our key concerns has always been to wrap an appropriate and open ethical consent and release process around the digital storytelling experience which would protect and empower the storytellers, ensuring that they are able to give fully informed consent at every stage of the process. So we have a three-stage consent and release process, which gives people plenty of time to think about whether they want to take part in a workshop, whether to release their story and whether to participate in the Patient Voices program.

In our experience, storytellers have almost always been very enthusiastic about their stories being given a wider audience. Objections to this have usually come from educational institutions and the

medical establishment who have been concerned that what we were doing was 'research' and the stories should therefore be made anonymous. But the desire to be heard is very strong and, in the end, 'our hearts rebel against the heartlessness' of the researchers and the statisticians who would anonymize the stories of those who wish to tell them and, repeatedly, people choose voice over silence, the heartfulness of a personal story over the heartlessness of a randomized control trial.

**JL: As you mentioned, our healthcare systems, while seeking to heal and support others, often leave people feeling dehumanized and disempowered. Can you expand upon the issues of how storytelling helps to humanize healthcare?**

De-humanization takes many shapes, including restriction of access to health and social care services, poor quality care, inhumane care as well as terrible violence done to the human spirit by crushing a voice that wishes to be heard. We are fond of quoting James Earl Jones who says *'One of the hardest things in life is having words in your heart that you can't utter.'*

The majority of our storytellers are patients, professionals or family carers and, as such, a great many of them have stories of experiences that have been damaging to them or their loved ones. What they all have in common is a desire that, through the telling and, more importantly the sharing and dissemination of their stories, they can make a contribution towards the cessation of those experiences, whether of sexual abuse, health inequalities, prejudice on the grounds of race, sexuality or disability or simply the ravages or the lack of crucial information that can prevent or alleviate disease.

Storytellers certainly tell us that they are happy if, by sharing their story, someone else may be spared a similar experience. In that sense, I think people do feel they are contributing to the struggle to create a more humane and compassionate society. The notion of Ubuntu sums up pretty well what we are trying to do and why we are trying to do it:

*'When I dehumanise you, I inexorably dehumanise myself. The solitary human being is a contradiction in terms and therefore you seek to work for the common good because your humanity comes into its own in belonging.'* Bishop Desmond Tutu

In our view, unless the healthcare system, or indeed any system or organisation, is prepared to learn from the felt experiences of all the people who make up that system it cannot develop other than for its own benefit because, as Tony is fond of saying:

*'Statistics tell us the system's experience of the individual, whereas stories tell us the individual's experience of the system.'*

**JL: Even in our public workshops, people are willing to take risks with emotional material, and ordinarily they are prepared for the emotional impact of this work, but sometimes they are not. How do you address people's potential for going into crisis as part of the workshop experience?**

Our primary concern is to ensure a place of safety for storytellers. We always have at least two

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facilitators, one of whom is a trained counselor (and the other makes sure the technology is always working!!). In the event of a crisis, one person can stay with the group while the other supports the person in crisis.

We try to make the whole process a caring one and, where possible, that process begins several weeks before the actual workshop, with a introductory briefing day for potential storytellers. We take this opportunity to show some stories, describe the process, explain the Patient Voices programme, and do a little bit of story work. It gives people a chance to meet us and other storytellers, to ask questions and make a well –informed decision about whether to attend the workshop. It also gives us a chance to assess things like literacy levels, technical ability, emotional and mental states. This means that people who don't feel comfortable with any aspect of the process we've outlined need go no further while we, as facilitators, can make suitable preparations to ensure that the workshop is as comfortable and safe as possible for the participants.

We prefer to keep the groups small - usually six to eight storytellers – as we think this helps to create a comfortable, safe space in which to share personal stories

We ensure that our facilitators are themselves kept emotionally and psychologically fit through having supervision as well as through their own spiritual practices, including meditation, walking, motorcycle maintenance and other Zen-like and mindfulness-based activities.

We strive, aided by our consent and release procedures, to set clear guidelines for the group, to provide a comfortable, holding and nourishing environment (physically, emotionally and spiritually), to make a safe place or *temenos* (the Greek's concept of a sacred place for telling stories) within which storytellers can explore a range of feelings.

One of the things we do customarily is to have dinner with storytellers on the night before a workshop begins. This offers an opportunity for us to break bread and drink wine (literally!), and to get to know one another. After dinner, we go through the program for the workshop and invite people to ask questions and air concerns so that they can begin the next morning with clear hearts and heads. We have observed that a well-formed group is very supportive of its members and this initial process of sharing seems to be quite important in helping the group to bond.

We may also invite people to share dinner with us on the second night if they wish to do so. . It's an opportunity to relax a bit and we often take this time to show people more cheerful stories than those they are likely to have heard and seen – stories of joy and celebration, including some that we have made ourselves – and that's a way of letting people know us a little better. They can be reassured that we have walked the same road they are now walking....

We hope that our attempts to create this environment of safety reduces the risk of people going into crisis and, if they do, we make sure that one facilitator is available solely for that person.

We also keep in touch with people after the workshop ends. We let them know that they are now a

part of the growing Patient Voices community of storytellers and that we will be contacting them. We always send out an email to everyone after a workshop and we let them know we are going to do that. Sometimes that is enough to help people to feel reassured and safe. We thank them for their time and their stories and let them know roughly when we will be doing the post-production – this also links people up with one another, which most groups want. Sometimes people reply and let us know that they have been a bit shaky or wobbly in the first days after a workshop and then we keep an extra eye on them (usually via email).

We contact them again when the tidied versions of their stories are ready for them to see and, hopefully, approve for the Patient Voices website.

If someone has told a particularly hard or painful story, we usually give them a call after a week or so to make sure they are ok. Some storytellers are keen to stay in touch and then we just fall into an email correspondence – several have joined and become enthusiastic supporters of our humanizing healthcare initiative.

If we feel that someone is particularly vulnerable, we make an extra effort to maintain reasonably regular contact. Often the people who want to keep in touch are those who have experienced a real sense of transformation. They often make good use of their stories in their own work, want to go on to make other stories, and are great at spreading the word!

**JL: Do you have an intuitive assessment of how your experience of working in these therapeutic contexts might be relevant to other areas of the health professions?**

Our work was not originally intended initially to be therapeutic, nor were we working with people for whom that was the main objective. Our intention was always to embed the stories in educational and quality improvement programs, conferences and elearning to further our aim of humanizing healthcare through highlighting the human side of experience of health, illness, healthcare and the lack of it.

However, it becomes clearer with every workshop and from every storyteller's feedback that the process *is* inherently therapeutic. We know that digital storytelling is a powerful process and that digital stories can be powerful tools for learning and change. Like all powerful tools, we believe that DS needs to be used with care and knowledge and understanding and, as you remind us, Joe, with love.

We find that people are quite creative in devising new uses for the stories.

We have also noticed the wide relevance of any one story to other areas of the health service. Jimmy's story ([www.patientvoices.org.uk/nhstay.htm](http://www.patientvoices.org.uk/nhstay.htm)), for example, is used by one lecturer we know to highlight deficiencies in record-keeping, patient safety, health inequalities, unnecessary transfers, professional behaviour and corporate liability ... she can engage students in five or six lectures through the use of that one story!

The process of creating and sharing a digital story is definitely being taken up in a number of different areas of the health professions in the UK at least. So, for example, we have had junior doctors telling stories about clinical placements as a means of reflecting on their experiences ([www.patientvoices.org.uk/lssc.htm](http://www.patientvoices.org.uk/lssc.htm)); newly qualified mental health nurses have told stories intended to be used in training their preceptors and for preparing future students for the reality of life after graduation ([www.patientvoices.org.uk/un.htm](http://www.patientvoices.org.uk/un.htm)); stories are being used to inform the design of services and devices for people with rheumatoid arthritis ([www.patientvoices.org.uk/wr.htm](http://www.patientvoices.org.uk/wr.htm)) and to share knowledge within and between organizations

I'm not sure whether that really answers your question. But our sense is that people are slowly beginning to recognize the links between learning and healing. As more and more educators and clinicians come to make their stories, understanding is growing about the importance of careful reflection on experience and of listening and attending to patients as one human being to another – and that is the really therapeutic element for any of us.

**JL: In the UK, and much of the world, “Complementary” or alternative therapies have gained greater acceptance. How would you position your work in the context of “Complementary” medical work?**

Good question. We have neither tried to position ourselves as an opposition nor as an alternative to anything, but rather have tried to help all stakeholders in health and social care heal the system from within. We want to build bridges rather than tear them down, recognizing that, as Tony has said, *'...the ability to tell, hear and share stories of experience and aspiration is a prerequisite for the development of a learning organisation of reflective individuals.'*

We want to promote thoughtful use of language and mindful sharing of experiences. We seek to help people tell their stories not in an angry or aggressive way but rather in a way that will attract and hold the attention of those who devise and deliver healthcare, without antagonizing them, while still retaining the integrity of the story and the storyteller.

Within the context of this question therefore, if DS is therapeutic, then it must be considered as a complementary therapy and a key component to the holistic approach to the patient, rather than an alternative one.

It is our strong view that facilitators need to be well-trained and experienced not just in digital storytelling, but in a range of other skills and knowledge and in life experience and self-awareness – otherwise the wonderful alchemy that is digital storytelling at its best is likely to be diminished to little more than a Powerpoint presentation – as we've seen happen – where a formulaic use of digital technology takes precedence over the 'analogue' storytelling and the distillation that results in something that is clear, pure and potent.

**JL: Are there other adaptations in your practice?**

In very many ways, our workshops are pretty much like CDS workshops – we have tried hard to maintain the spirit of CDS’ work while making a few adaptations that we feel are appropriate for the groups with whom we work. I think we’ve mentioned most of them already, but sharing a meal before the workshop begins, keeping groups small, feeding people, providing a pleasant (retreat-like) physical environment, adaptation of workshop hours to suit mental, emotional and physical capabilities, mindfulness, the use of simple software e.g. Windows Moviemaker where this may be more appropriate for people with physical disabilities; briefing/induction days to ensure fully informed consent and, most importantly, the development of social capital through the public distribution of the stories via the Patient Voices website. According to Tony, *‘the innovative model of free distribution of the stories for use in health and social care education and quality improvement work ensures that those voices are heard, and that the investment of storytellers is nurtured and invested to develop maximum social capital.’*

**JL: The issue of access to healthcare is quite different in the UK, and much of the developed world, to how it is here in the United States or in the developing world. We have attempted to link the struggle for voice of recipients of healthcare within our system, to expanded healthcare access. Do you have any thoughts about how the UK system is still challenged by issues of access, and how your work could be instrumental in bringing about change?**

Whilst there is a universal health service in the UK, free for all at the point of need, inevitably, given the social and economic variations across the country, health inequality remains an important issue. Health inequality for us encompasses not only inequality in access to or quality of healthcare services, but also inequality of voice and influence in the shaping and improvement of those services.

One of our original intentions with the Patient Voices programme, and one of the reasons for its name, was to give a voice to those people who have waited patiently to be heard: those ‘ordinary’ people who come from all walks of life. We have worked with people from across the resource spectrum as well as with those on the edges of society and in ‘hard-to-reach’ communities, including ethnic minorities, , refugees and economic migrants , people disabled as a result of stroke or other cataclysmic events, people with mental health disorders and those who have been impoverished by disease or economic deprivation as well as the family members and friends who care for them....

By offering a voice to people who are seldom heard, and by distributing their stories as widely as possible, we are able to ensure that the stories are as widely heard as possible. It’s really a kind of guerrilla advocacy, whereby the voices of ordinary people can be heard at the highest levels in the National Health Service and beyond.

From our monitoring of the website, we know that the stories are being widely used within the the NHS as well as in medical schools and schools of nursing in many UK, US, Canadian and Australian universities, which means that storytellers have a voice in, and contribute to, the education of the next generation of healthcare professionals.

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We are really pleased that some of the stories have been used, and hence given a platform, by the Chief Medical Officer and Chief Nursing Officer as well as the health minister, Lord Darzi. We have also worked on several projects with the National Audit Office, a body charged with auditing value for money in public sector spending. Their reports, and hence any accompanying Patient Voices stories, go directly to the Parliamentary Accounts Committee.

This means that the stories, and hence the storytellers, have the potential to affect healthcare policy. It may be coincidence, but we have noticed a greater emphasis on words like dignity, respect and even humanity in policy documents. Patient involvement is now a statutory duty of healthcare organizations in the UK and several recent projects have focused on the benefits of patient involvement.

From a slightly different perspective, in our workshops we try to model the kind of ethos we would like to see in the health service, ie, where everyone has an equal voice and people are treated with respect and dignity.

We really do try to do it together (to quote Michael Gerrard's story), as part of the move towards patient empowerment and our own personal commitment to facilitative and participatory learning and facilitative and participatory healthcare. Storytellers often remark on the novelty of being treated as equals, as people with something worthwhile to say, as people worthy of respect and they tell us that this experience of having their voices heard and valued gives them greater confidence and, perhaps, a new voice with which they can engage more effectively with healthcare providers and the system.

**JL: In thinking about this discussion for the book, it seemed that the lessons of this work would be relevant to discussions about doing work in the context of disability, life threatening disease, hospice care, etc. What are your thoughts on how this relates?**

Well, yes. That was the 'starting prompt' in the small story circle of our digital storytelling work. Many of our friends, family members and colleagues have had really terrible experiences of illness, disease and care. Working within the health sector and trying to ensure that patients really were at 'the heart of healthcare' as the UK Department of Health said they should be presented us with the challenge that resulted in the Patient Voices programme. We've now worked on projects covering all the areas that you mention and we share the responses of one of our client/partner/collaborators that the stories of health, life, death and disease can offer us deep insights into not only the storyteller, but into the storytellers' family and cultural traditions – if only we are prepared to listen (see Newham Communities of Health stories [www.patientvoices.org.uk/newham.htm](http://www.patientvoices.org.uk/newham.htm) and National Audit Office End of Life stories [www.patientvoices.org.uk/naeol.htm](http://www.patientvoices.org.uk/naeol.htm))

Our experience and observations are that, given the opportunity to reflect on, craft and shape their stories, storytellers feel empowered and enthusiastic about telling and sharing their stories and, when given the opportunity to see and reflect on the stories, policy makers, deliverers and providers of care

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are deeply affected by them. In addition, it is particularly important to offer medical, nursing and other healthcare students the opportunity to see and, where possible, to create, their own stories of healthcare so that they begin to develop greater empathy for one another. When a group of final year medical students made stories, they commented on the powerfully reflective nature of the process and how it enabled them to see their patients more as human beings and less as opportunities for practising new skills.

Our goal is to facilitate the telling and sharing of stories that are effective, affective and reflective (EAR) in that they are short, transmissible and distributable; compelling, honest and human; and provocative, challenging and mindful.

### **JL: Final thoughts?**

Just a few things...

It seems to us that many individuals and groups feel that they have the monopoly on suffering. People who have lost someone dear to them, people who are caring for a relative with a life threatening disease, people with psychosis, people who have been discriminated against, people who have been uprooted from their home.... they think their situation is worse than someone else's.

But when you get a group of people together to share stories, there is a realization that we all suffer – it is just a part of the human condition. It is what we do with that suffering that is the really important thing.

And people realize that they can begin to transform their suffering by sharing it – first by articulating it to themselves, then to the small group and eventually, perhaps, to the world. Then the sense of isolation and hopelessness begins to diminish and a new hope is found in the community and communion of storytellers.

The next thing is to do with different kinds of knowledge. Here in the west we specialize in knowing stuff, learning things, analyzing and criticising and acquiring more knowledge. That's the knowledge of the intellect.

Gradually we are recognizing, with the help of people like Daniel Goleman, the Dalai Lama and other Buddhist teachers, that it's important to balance intellectual knowledge with emotional knowledge. Indeed, as Ghandi said, 'the culture of the mind must be subservient to the culture of the heart'.

Going one step further, Parker Palmer, and doubtless many others, feel that there is a spiritual knowledge which informs the way we are in the world and that is also crucial to our understanding of ourselves and others.

Finally, there is what we might call physical knowledge – knowledge of our bodies and how they work (or don't work) and why. There is much to be learned from our bodies.

Together, these four kinds of knowledge represent a holistic approach to knowing and might be called

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wisdom. We feel that the Patient Voices stories offer the opportunity to learn in these four different ways and have the capacity to contribute to a wiser, deeper, more loving knowledge of humanity.

And one final thing...

One of our most common observations and greatest joys over these years has been of the universality of stories and the commonality of shared experiences across and within workshop groups. We constantly see common themes – the themes of humanity – emerging.

*'Each affects the other and the other affects the next and the world is full of stories... and the stories are all one.'* Mitch Albom (from *The Five People You Meet in Heaven*)

Thanks, Joe, for showing us the way.

Pip Hardy and Tony Sumner

9th August 2009