

# Digital Storytelling in practice

PIP HARDY AND TONY SUMNER

## Digital Storytelling in health and social care

Touching hearts and bridging the emotional, physical and digital divide

*'What is language if not a vehicle for story? And what is story if not a vehicle for our values and our passions?'* (Hardy, 2007)

What is a scar?

Is it the straight, harsh, jagged, painful, searing divide that keeps us apart, marks us forever? Or is it a sign of bad things past, of new flesh growing, of life and reunion – of healing, hope and future?

What is a scar?

'Write a short story about a scar.' This was the prompt offered to participants in a Digital Storytelling masterclass we were co-facilitating.

Patient Voices storytellers often have a long-term condition or a disability, perhaps aphasia following a stroke, rheumatoid

arthritis, MS or diabetes; they may use wheelchairs, mental health services or interpreting services, they may be dying or caring for someone who is dying, or they may have experienced untimely bereavement, premature childbirth or childhood abuse.

One of our goals as Digital Storytelling facilitators is to explain, establish and maintain the conditions and principles that support us in providing a secure, confidential, co-operative and supportive environment in which storytellers can tell, hear and refine their stories.

Story prompts help to initiate productive story circles and establish trust within the group; the prompt may be a word, a picture, an object or even a piece of music. In this case the prompt worked well. The group (we generally work in small groups of six



● Pip Hardy and Tony Sumner are Directors of Pilgrim Projects Limited and Founders of the Patient Voices Programme. They founded Patient Voices in 2003 with the original intention of developing a resource that would carry the experiences of patients and carers into e-learning materials about clinical governance. The Patient Voices Programme has won two international awards and Pip and Tony have both been recently elected as Fellows of the Royal Society of Arts.

to eight storytellers, with two facilitators to support the process) had created and shared, commented and reflected upon their own and each other's stories.

Two stories were of skinned knees from childhood – linking two colleagues and friends who had not known of each other's tumbles and falls. One was a story of a shiny-smooth scar on a wrist, so quietly innocuous. Several were stories of mental and emotional trauma; there was even a story of damage to a landscape. The facilitators shared stories in the circle as well.

And then there was a story about the scar left by a mastectomy, told by a storyteller who is also a long-time friend and who, for the first time, honoured us with an open telling of what had long been a tacit understanding.

The security and safety we seek to create – a still, attentive space (or *temenos*\*) where

\**Temenos* is a Greek word meaning sacred space. It connotes a sheltered space, a place where one can search, journey, examine and re-examine while protected from the habitual routines of the everyday world.

As each story makes its way into the circle, new and different stories take shape in the minds and hearts of other storytellers

▷ stories can be heard and creative energies can be gently nurtured – had worked.

The role of a Digital Storytelling facilitator is often physically, intellectually, technically and emotionally demanding. It is always rewarding, inspiring, humbling, a privilege and a joy. We regularly refresh our technical skills and expertise, read widely about stories and storytelling and keep up to date with the complex world of healthcare. Supervision (based on the model used in counselling and psychotherapy) maintains the emotional welfare of our facilitators and ensures their continued effectiveness in workshops while protecting the safety of storytellers.

While Marshall McLuhan's (1964) enduring prophesy was that 'the medium is the message', our Digital Storytelling workshops focus on the analogue storytelling process. We see the digital elements of Digital Storytelling as a powerful set of forces that can be harnessed to allow storytellers to tell and share their stories more powerfully and effectively – but our primary concern is always with storytellers and their stories.

Hence the first day and a half of a three-day workshop is spent considering the elements of good stories, sharing stories in a story circle, peer review, editing and distillation, in preparation for recording a voiceover. We encourage storytellers to work towards a story of 250 to 300 words which, in our experience, will result in a digital story of the most effective length – somewhere between two and three minutes.

Telling and sharing stories can be a magical experience. Every story we send out into the world changes shape and transforms into as many different stories as there are listeners.

'Each affects the other and the other affects the next, and the world is full of stories, but the

stories are all one.' (Albom, 2004)

As each story makes its way into the circle, new and different stories take shape in the minds and hearts of other storytellers; connections are made, values shared, passions discovered, stories merge and emerge.

And so I awoke at 5am on the second day of the masterclass to the dappled light of a spring morning, with a pressing need in my head for paper and pen with which to catch a story before it dissipated like the mist from the morning fields outside.

On the right are my scribbled notes of the day before, linking them with a recent personal experience – but it was a new story, unrelated to the one I had told the day before.

I took these rough notes into the second day of the masterclass, and was rewarded by feedback and support from fellow storytellers, helping me hone the words to these:

### Knitting by Tony Sumner

*My Mum,  
Knitting.  
My Mum!*

*Sixty-two. Mammogram, shadow, biopsy, benign.*

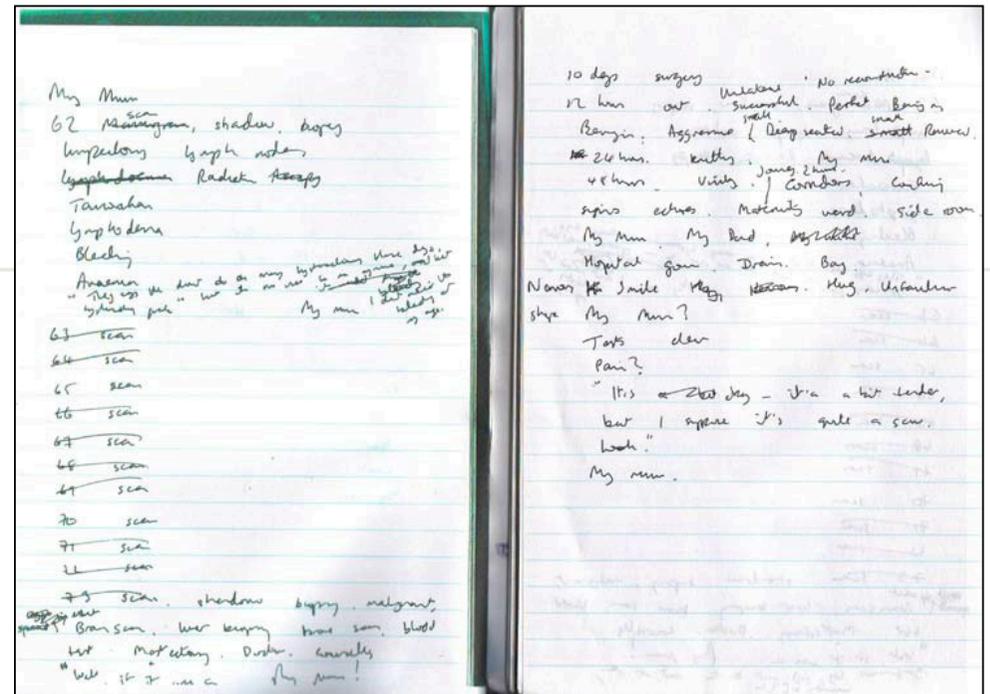
*Lumpectomy, lymph nodes.*

*Radiation therapy, Tamoxifen.*

*Lymphoedema, bleeding, anaemia.*

*'They say they don't do many hysterectomies these days, but it's no use to me any more. I don't need the bleeding at my age'*

*My Mum.*



*Sixty-five. Mammogram.*

*Seventy. Mammogram.*

*Seventy-three. Mammogram, shadow, biopsy, malignant.*

*Brainscan, liver biopsy, bone scan, blood tests.*

*Mastectomy, doctor, counselling.*

*'Well, if it was a gangrenous leg, I'd want you to take that off!'*

*My Mum.*

*'I don't want the breast, I want Mary.'*

*My Dad.*

*Ten days, surgery, queue, wait.*

*Twelve hours, out, successful, perfect.*

*Unilateral, no reconstruction.*

*Benign, benign, malignant.*

*Aggressive, small, deep-seated.*

*Twenty-four hours, knitting.*

*My Mum.*

*Two days, one hundred miles, two hours, visiting.*

*Corridors, echoes, confusing signs, maternity*

*ward (it's the same bits...) side room.*

*My Mum, my Dad.*

*Hospital gown, quiet room, sunshine.*

*Drain, bag, blood.*

*Nervous smile, careful hug.*

*Unfamiliar shape.*

*My Mum?*

*Tests, clear – maybe chemo.*

*Pain?*

*'It's okay, it's a bit tender but then, I suppose it's quite a scar – look.'*

*My Mum!*

*Knitting.*

*My Mum.*

We encourage storytellers to think carefully about the point of their stories. Here I had wanted to express how the language of medicine – guttural, Latinate, harsh, alien – contrasted, for me, with my mother's strength, openness, pragmatism and humour – her humanity.

This contrast expressed itself as single, ▷

# Most storytellers who participate in our Digital Storytelling workshops have a life experience they wish to share

▷ technical words of the diagnosis and treatment process set against the sentences of my mother and father.

Storytellers write in many styles, often very beautifully, and we always strive to make a place where storytellers' unique voices can be heard, speaking about their experiences in their own way. Most storytellers who participate in our Digital Storytelling workshops do so because they have a life experience, whether of care or caring, treating or treatment, patients or patience, that they wish to share, and a voice that they wish to be heard. Storytellers who wish to do so can contribute their stories to the Patient Voices Programme, which is attempting to encourage the humanisation of health and social care through sharing the stories of all the silent stakeholders in the caring processes.

## THE PATIENT VOICES PROGRAMME

The Patient Voices Programme began in an attempt to provide a powerful resource for healthcare education and quality improvement programmes. We wanted to find a way to balance the prevailing culture of evidence-based medicine based only on the evidence of randomised control trials, statistics, audits, targets and tick boxes; we wanted to restore some humanity to health and social care services that seemed to us to be increasingly driven by the financial and bureaucratic decisions.

Our original aims, as set out in the *Patient Voices Rationale* (Hardy, 2004) were to:

- Highlight gaps in the system
- Reveal near-misses and form 'free' learning opportunities
- Promote healing and reconciliation
- Allow patients', carers' and professionals' voices to be heard

- Carry forward stories that might otherwise be lost
- Promote a spirit of collaboration and partnership
- Touch hearts, thereby reinforcing the notion of patients at the heart of care.

The stories were intended to promote reflection on practice, whether that practice is clinical or educational, among students of medicine, health and social care as well as existing practitioners.

Our colleague, Professor Paul Stanton, refers to the Patient Voices stories as 'narrative art in verse; Digital Stories are a new medium through which narrative art can be explored and made accessible so that "ordinary" people can articulate their extra-ordinary understandings'. (Pilgrim Projects, 2007)

Digital Storytelling draws together elements of creative writing, the family photo album, music and digital technology through a carefully facilitated group process. It is this

particular alchemy, resulting in a sharply focused and distilled two- to three-minute story told from the heart, which provides exactly the right way to touch the hearts of providers of health and social care and those who make decisions about its delivery.

'Digital Storytelling empowers patients, carers and clinicians to convey their felt experiences of healthcare via technology so that their voices can be heard in any lecture theatre, boardroom or conference venue anywhere in the world.' (Hardy, 2007)

The Patient Voices Programme now provides one of the largest resources of freely available patient/service user, carer and clinician/practitioner stories in the world, and the website ([www.patientvoices.org.uk](http://www.patientvoices.org.uk)) receives around 2,000 hits per day from across the world.

## ETHICAL CONSIDERATIONS

To protect storytellers and their stories, we

wrap the safe and supportive workshop process in a two-stage process of informed consent that ensures that control of the story edit and release remains with the storyteller. We strive to work according to the Four Ethical Principles established by Beauchamp and Childress (2001):

### 1 Respect for autonomy

We are aware of every individual's unique gifts and abilities and their right to dignified and humane care. We respect each storyteller's ability to make informed decisions. Our consent 'protocol' is deliberately written in an accessible way; we carefully explain the intentions of the Patient Voices programme, and what will happen at every stage of the process. Editorial control rests with storytellers and no story is ever released without a signed release approval form.

### 2 Beneficence

We are aware of the risks of encouraging people to tell personal stories but we see these outweighed, time and time again, by the therapeutic benefits of telling and sharing stories. We encourage storytellers to attend workshops only after they have had a period of time to reflect on their experiences, mindful of Wordsworth's notion of 'emotion recollected in tranquillity' and recognising that telling a story in the middle of a crisis may be just too painful. Ongoing support is always available and we hear from many storytellers just how beneficial the process has been for them, in their lives and in their work.

### 3 Non-maleficence

We are aware that all powerful tools have the capacity to do harm as well as good. We ▷



Telling and sharing stories can be a magical experience

**‘Through its carefully developed methodology, the programme facilitates the telling and sharing of stories of care by all stakeholders. The innovative model of free distribution of resulting stories for use in health and social care education and quality improvement ensures that those voices are heard, and that the investment of storytellers is nurtured to develop maximum social capital.’**  
*(Patient Voices Programme, 2008)*



**Storytellers are encouraged to attend workshops only after reflecting on their experiences**

▷ use the ‘tools’ of Digital Storytelling and facilitation with great care, building on firm professional foundations in education, counselling, group work and technology, underpinned by personal commitments to the principles of Buddhist practice and social justice.

Our efforts to ensure a safe and contained environment for sharing personal stories, and to teach the use of the digital tools are underpinned by our desire to empower storytellers to create their own stories in ways that often help them to resolve past issues and move on with their lives. The letters and emails we receive suggest that many storytellers experience the process as ‘life-changing’, ‘transformative’ and, at the very least, good fun, resulting in the creation of an ‘artefact’ of which they can be justifiably proud.

#### 4 Justice

Digital Storytelling is part of a worldwide movement towards social justice and personal empowerment. According to both tellers and users of stories, the potential risks of sharing personal stories are far outweighed by the myriad benefits to those who create them and those who view them. The cost is minuscule in comparison to the benefits that accrue from both the process and the products of Digital Storytelling workshops.

#### USING DIGITAL TECHNOLOGY

The digital dimension to the storytelling process is woven into the workshop as a challenging (initially), fascinating (inevitably) and empowering (eventually!) technology that storytellers can use to deepen and enrich the way their story is heard. We use, where possible, pictures and artefacts

from storytellers’ own lives and personal albums. We show storytellers how to use photo editing software to prepare their images and photographs, and video editing software to bring the ingredients of their Digital Story (images, recorded voiceover, musical accompaniment, sounds, videos clips if necessary) harmoniously together to create an effective – and, we hope, affective – Digital Story.

The stories, the way they are written and expressed through digital media and the Digital Storytelling process, are richly evocative and expressive of storytellers’ experiences, and as varied in subject and style as are storytellers themselves.

We have enjoyed the company and humanity of all the storytellers who have amazed us with their creative use of Digital Storytelling to go beyond the written word and create stories that, as Pascal said,

‘entertain and teach’ and, in our experience, also heal. Here are a few of the stories that have touched us, and many others:  
**Paul’s story:** [‘Something from nothing’](#)  
**Jools’ story:** [‘CPR’](#)  
**Rizia’s story:** [‘A brighter world waiting’](#)  
**Jean’s story:** [‘Getting to the bottom of things’](#)  
 And what became of my story? Well that story, ‘Knitting’, eventually came to fruition and can be seen [here](#).

We hope that you find these stories as thought-provoking, humbling and engaging in the viewing as we have in facilitating their creation. □

#### REFERENCES

- Albom, M, *The Five People You Meet in Heaven*, Time Warner, 2004.  
 Beauchamp, T L and Childress, J F, *Principles of Biomedical Ethics*, 5th edition, OUP, 2001.

- Center for Digital Storytelling, [www.storycenter.org](http://www.storycenter.org)  
 Hardy, P, *Patient Voices: the rationale*, Pilgrim Projects, 2004, [www.patientvoices.org.uk](http://www.patientvoices.org.uk)  
 Hardy, P, Patient Voices website, Pilgrim Projects, 2007, [www.patientvoices.org.uk](http://www.patientvoices.org.uk)  
 Hardy, P, ‘An investigation into the application of digital patient stories in healthcare education: quality of learning, policy impact and practice-based value’ (master’s dissertation, University of Ulster), 2007, [www.patientvoices.org.uk](http://www.patientvoices.org.uk)  
 McLuhan, M, *Understanding Media: The Extensions of Man*, Mentor, 1964.  
 Patient Voices Programme, [www.patientvoices.org.uk](http://www.patientvoices.org.uk)  
 Pilgrim Projects, ‘E-health Connections Nursing Workshop: Connecting to the Future,’ Connecting for Health, NHS. Pilgrim Projects, 2007.  
[E-health Connections Nursing Workshop: Connecting to the Future](#)  
 Wordsworth, W, ‘Preface to the Lyrical Ballads’ in Hutchinson, T and de Selincourt, E (eds), *Wordsworth Poetical Works*, OUP, 1978.