



Patient Voices

THE NEWSLETTER

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Transformation and change

As we approach the holiday season, and the shortest day of the year here in England, we are mindful of changes affecting the entire world and thankful that there is a new and hopeful US President who just may bring about some improvements. In the meantime, if we are ever feeling weary or disheartened, we have only to think about the young woman who said to us at the end of a workshop, 'This has been the best three days of my life. I feel like I could do anything now!' Given a chance to be heard, and the opportunity to think creatively about their lives, storytellers change and grow in subtle and important ways, discovering things about themselves and growing in compassion in the process.

Much has happened since our last, April, newsletter. On May 16, we participated, along with people in 80 other countries, in the first International Day for Sharing Life Stories. Around 20 past storytellers joined us in person, and many others sent us their miraculous and marvellous stories, which were read out in the story circle on the day. You can see a report of the day at <http://internationaldayblog.storycenter.org/?paged=2>

Here and there

Our travels have taken us from the balmy Isle of Wight to rainy Aberdeen, from the gentility of Harrogate to the diversity of Newham, from the stunning beauty of Vancouver, to leafy Nottingham, from Dublin to London—and quite a few places in between! Highlights included: speaking at the Centre for Digital Storytelling's *Healthcare Perspectives in Digital Storytelling* Retreat on Vancouver's Bowen Island; presenting a symposium at the NETNEP conference in Dublin, and another at the NET conference in Cambridge, both focusing on the potential of digital storytelling to humanise healthcare; speaking to Macmillan professionals at the Quality Improvement for Cancer Services conference in Leeds, focusing on palliative care; presenting the



communication power of digital stories at a discussion in London jointly hosted by Panos and Healthlink Worldwide; talking to a group from NIACE (National Institute of Adult and Continuing Education), about how digital storytelling might be a useful means of incorporating mental health into the post-16 curriculum.

Patient Voices workshops and stories

Arthur and Co. is the name of a project funded by the White Rose Partnership and intended to inform the design of services and assistive devices for people with Arthritis, through the stories created by people who themselves have the disease.



We travelled to Leeds and worked with five wonderful storytellers, adapting our usual process to take into account limited energy levels. The stories were launched in July and the project was one of only four (out of 40) to be showcased at the White Rose Health Innovation Partnership conference in Harrogate in October. The stories can be seen on the Patient Voices website at www.patientvoices.org.uk/wr.htm.

We worked with storytellers from Newham PCT's Communities of Health to create stories that illuminate understandings of life, death and illness, and the words we use to describe these all-too-human experiences, whatever our language or culture. See the stories at www.patientvoices.org.uk/newham.htm



The stories attracted the attention of Newham's director of public health and, as a result, a new and larger project is planned for 2009, which will see the creation of stories about HIV/AIDs, diabetes, heart disease, hypertension and breast cancer.

Six stories about in-patient experiences of people with diabetes were created during a three-day workshop in Warwick, funded by the NHS Institute of Innovation and Improvement. The food was so plentiful and delicious that our storytellers had to be especially mindful of their blood sugar levels! Their stories can be seen at

www.patientvoices.org.uk/nhsii.htm

We enjoy all the workshops we facilitate and all the storytellers we meet, but a particular highlight of the summer was working with fourth year medical students at the University of Leicester, who created digital stories as a means of reflecting on their clinical placements. The stories reveal thoughtful, compassionate young people who, despite some initial reservations, realised the power of digital storytelling as a reflective methodology and grasped it enthusiastically. Their stories can be seen at

www.patientvoices.org.uk/lssc.htm

Introduction to Digital Storytelling workshops

Our introductory weekend workshops, held every six – eight weeks, continue to be well-attended by storytellers from a range of backgrounds and interests, including some second-timers.

We have been fortunate to work with several sisters from



the Society of the Holy Child Jesus. Their stories offer a different perspective on health, healing and vocation, and can be seen at www.patientvoices.org.uk/shcj.htm - more of their stories, including ten from their most elderly sisters (ranging in age from 72-101!), are in the pipeline.

We recently enjoyed a lively three days with eight storytellers from the University of Huddersfield's School of Human and Health Sciences; they made brilliant stories and are now convinced of the potential of digital storytelling for use in education, research and reflection.

Introduction to Facilitation workshop



Our first Introduction to Facilitation workshop was held in July. After two preparatory days, we sat back while our three aspiring facilitators led four

first-time storytellers through the process of creating their

digital stories. Joe Lambert, from the Centre for Digital Storytelling, was on hand to make sure that all went well. Fiona O'Neill, from the University of Leeds, Jenny Gordon, from the Royal College of Nursing, and Julie Coleman, from Sheffield Hallam University, jumped through all the hoops we could find for them with grace and good humour. They have returned to their organisations with a deeper appreciation of the power of digital storytelling and even greater enthusiasm to co-facilitate with us on digital storytelling projects.



The website and discussion group

Since the last newsletter went out in April, 39 new stories have been released to the website, bringing the total number of stories to 172. Hit rates remain close to 2000 per day, with approximately 30-40 stories being downloaded every day. The largest single user of the stories is the UK NHS, but interest continues to grow, especially in universities, and from further afield; we are delighted to have had several enquiries from Australia.

We invite you to share your experiences with others and help to contribute to our growing community of practice by joining the discussion group.

Using and sharing the stories

We would love to hear about your experiences of using the stories. It is only by this means that we can continue to let others know about the enormous potential of the digital stories. We welcome your thoughts and ideas and, even better, short case studies to put on the website, so that others might be inspired by your experiences.

Looking ahead

We are looking forward to working with Newham Communities of Health, with stroke survivors in the Isle of Wight, with newly qualified nurses in Nottingham. Our plan to hold a retreat to celebrate five years of Patient Voices and consider how we can best harness the power of digital storytelling in the service of Humanising Healthcare will come to fruition in April; we hope to develop a strategy paper as a result of the discussions.

In the meantime, we send you all our good wishes for a peaceful and joyful holiday and, as always, our thanks to those of you who have shared your stories with us.

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