






## Passing past dragons: exploring the challenge of ageing through digital storytelling

Dr Pip Hardy, Grete Jamissen and Tony Sumner  
Pilgrim Projects/Patient Voices  
Narrative Practices Lab, Discovery Research Platform, Institute for Medical Humanities


Ageing as Adventure conference, Emmanuel College, Cambridge  
19<sup>th</sup> March 2024

1


## Who are we and why are we here?



Pip Hardy



Grete Jamissen




Tony Sumner

2

## Passages past dragons

*'No matter what form the dragon may take, it is of this mysterious passage past him, or into his jaws, that stories of any depth will always be concerned to tell....'*




Flannery O'Connor, 1969

3

## Why stories?

*'It's like everyone tells a story about themselves inside their own head. Always. All the time. That story makes you what you are. We build ourselves out of that story.'*

Patrick Rothfuss



*'We know what we are, but not what we may be.'*


William Shakespeare

*'Our bodies are made of stardust; our souls are made of stories.'*

Rev. Thomas Rhodes

4

## Remembering



*'Remembering is not the negative of forgetting. Remembering is a form of forgetting.'*

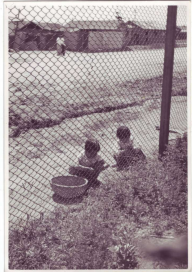
Kundera, 1995

5

## The pasts we tell ourselves

*'An important challenge to humanity is to recognise that lives are the pasts we tell ourselves.'*

Ochs and Capps, 1996



6



## EAR: a model for reflection

Effective

*What did you think?*

Affective

*What did you feel?*

Reflective

*What will you do?*

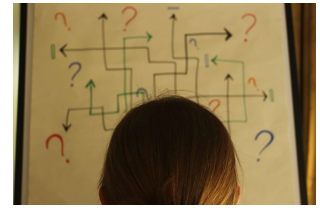


13

## What are digital stories?

Digital stories are short videos consisting of still images, a voiceover, music (usually) and video (sometimes), created by ordinary people about things that matter to them.

Digital stories are a *distillation* – they move us from the narrative to the *essential* story.



14

## What is digital storytelling?

Digital storytelling involves...

- Deep reflection
- Creative writing/scripting
- Photography, painting, drawing
- Image and video editing
- Groupwork
- Peer support & review
- Voicework & performance
- Music
- Meaning-making
- Community-building



15

## A bit of background: Patient Voices

- Established in 2003
- The first – and only – digital storytelling project focused solely on healthcare
- ~ 1500 stories facilitated/recorded
- ~ 1000 stories released
- ~ 200 workshops, plus some home visits!
- ~ 5 million hits on the website annually (> 1 TB of data)
- 15 papers and 13 book chapters published
- 3 books edited, 1 PhD and 1 MSc completed
- 3 international and 2 national awards won



16

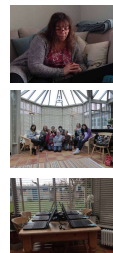
## Where we've worked, who we've met and what we've learned along the way



17

## Our philosophical approach

- 'Emotion recollected in tranquillity' (Wordsworth)
- 'Only connect' (Forster)
- Passages past dragons (O'Connor)
- Safe space (*Temenos*)
- Hospitality (*Xenia*)
- The shapes of stories (Vonnegut)
- What is your story *really, really* about?



18

### Our practical approach

- Small groups
- Careful facilitation
- Reflection
- Mindfulness and attention
- Story circle
- De-mystifying technology




19

### Walking in someone else's shoes

*'These stories allow us to walk in someone else's shoes for a few minutes.'*

Medical Officer  
National Institute of  
Medical Research  
Dar es Salaam, Tanzania



20


### A chocolate watch



Eva Heymann 2009

21

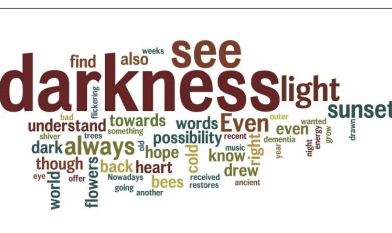
### A chocolate watch



Eva Heymann 2009

22


### The sun also rises



[www.patientvoices.org.uk/fiv/0517pv384.htm](http://www.patientvoices.org.uk/fiv/0517pv384.htm) Eva Heymann 2009

23

### The sun also rises



[www.patientvoices.org.uk/fiv/0517pv384.htm](http://www.patientvoices.org.uk/fiv/0517pv384.htm) Eva Heymann 2009

24



## Facing the dragon called 'OLD'

Thank you!

- for arranging this meeting place
- for inviting me to share and learn



31

## Ageing as adventure?

- As **'denial'**?  
"Age is just a number"  
Newspeak? "Old is young" (Orwell 1984)
- As **'coping'** or **'Coming to terms with'**  
Not to ignore or deny the sadness and pains  
– but to offer an opportunity to meet them in a different way?
- As **'something more'**  
Something exciting, or challenging or scary and rewarding –  
like passing past a dragon;-)



32

## My life with digital storytelling

- OsloMet since 2005 – "The storytelling university"
- Working with Patient Voices since 2011
- Students' placement stories and research communication
- International community
- Patient Voices workshops -
  - professionally and personally



*'What's it about?'*

*'What's it really about?'*

*'And what's it really, really about?'*

33

## What's the magic?

- Time away from daily chores and stress
- The story circle – a safe space
  - listen deeply
  - ask questions
  - suggest alternative understandings
- One-to-one guidance
- Using your creativity to complete a "film"
- Feedback after sharing your finished story



34

## 'Age is happening to ME?!'

- Patient Voices open workshop 2018
- Helped create a deeper understanding
- Tools to process emotions –  
and permission to feel melancholy
- Allowed me to linger on memories
- Contributed to see new opportunities



*Opened a new phase in my life, not only with acceptance but also curiosity*

35

## Autumn leaves

*'The real voyage of discovery consists not in seeking new landscapes, but in having new eyes.'*

Marcel Proust



36



## Autumn leaves



[www.patientvoices.org.uk/flv/1162pv384.htm](http://www.patientvoices.org.uk/flv/1162pv384.htm) Grete Jamissen 2018

37

## EAR: a model for reflection

- Effective  
*What did you think?*
- Affective  
*What did you feel?*
- Reflective  
*What will you do?*



38

## Passages past dragons

*'People reach greater maturity as they find the freedom to be themselves and to claim, accept and love their own personal story, with all its brokenness and its beauty.'*

Jean Vanier



39

## Products of reflection

*'Stories are products of reflection, but we do not usually hold onto them long enough to make them objects of reflection in their own right....'*

*'When we get into the habit of recording our stories, we can look at them again, attending to the meanings we have built into them and attending, as well, to our strategies of narrative description.'*

Schön, 1988



40

## 'Stories are always true...'



*'While telling surely assists the construction of a tale, the tale necessarily lies beyond the telling.'*  
Young 1987, cited in Ochs and Capp, 1996

*'[Stories are] a creative treatment of actuality.'*

John Grierson

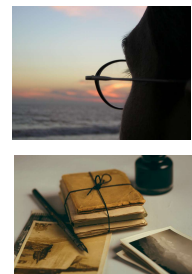
*'Stories are always true; it's the facts that mislead.'*

Jeanette Winterson

41

## Prompt: Who are you?

*'Under my bed was a dress box  
spilling old pictures,  
a sift of lost faces  
to drift beneath my dreams.  
I am from those moments --  
snapped before I budded --  
leaf-fall from the family tree.'*  
*Where I'm from* by George Ella Lyon



42

## The two-minute story

- Arrange yourselves in pairs.
- Decide who will be the storyteller and who will be the listener.
- Take a few moments to think of a story. Make a few notes if you wish.
- Now tell your story to your partner in two minutes.
- Stop! Listeners, what did you notice?
- Have a conversation and plan the story, thinking of images that might tell part of the story.
- Tell your story again.
- What were the differences between the two stories?



43

## How was that for you?



44

## In case it's of interest...

Hits on story page	Storyteller	Title
4331	Eva Heymann	From darkness into light: new worlds
4173	Eva Heymann	A chocolate watch
6378	Eva Heymann	The sun also rises
117,739	Margaret Clark	My journey with David
5517	Grete Jamissen	Autumn leaves (English and Norwegian)

45

## Questions, comments and discussion



46

## Thank you!

Tony Sumner

[tony@pilgrimprojects.co.uk](mailto:tony@pilgrimprojects.co.uk)  
[antony.j.sumner@durham.ac.uk](mailto:antony.j.sumner@durham.ac.uk)

Pip Hardy

[tony@pilgrimprojects.co.uk](mailto:tony@pilgrimprojects.co.uk)  
[v.hardy@durham.ac.uk](mailto:v.hardy@durham.ac.uk)

Grete Jamissen

[jamissen@gmail.com](mailto:jamissen@gmail.com)

[www.patientvoices.org.uk](http://www.patientvoices.org.uk)



[www.patientvoices.org.uk/present.htm](http://www.patientvoices.org.uk/present.htm)

47

## Resources: If you want to know more...

- Hardy, P. and Sumner, T. (2014) "Our stories, ourselves: exploring identities, sharing experiences and building relationships through Patient Voices" IN Pleasants, H. and Salter, D. (eds) *Community-Based Multi-Literacies and Digital Media Projects: Questioning Assumptions and Exploring Realities*. Peter Lang.
- Hardy, P., & Sumner, T. (Eds.). (2018). *Cultivating compassion: How digital storytelling is transforming healthcare* (pp. 1-384). Palgrave Macmillan.
- Jamissen, G., & Skou, G. (2010). Poetic reflection through digital storytelling—a methodology to foster professional health worker identity in students.
- Jamissen, G., Hardy, P., Nordvælle, Y., & Pleasants, H. (2017). *Digital storytelling in higher education: international perspectives*. Springer.
- Jenkins, T., & Hardy, P. (2020). "13. Silver hair, silver tongues, silver screen: recollection, reflection and representation through digital storytelling with older people". In *Communities, Archives and New Collaborative Practices*. Policy Press.
- Steinhilber, R., Tait, J., Hardy, P. and Sumner, T. (2013) "Dangling conversations: reflections on the process of creating digital stories during a workshop with people with early stage dementia". *Journal of Psychiatric and Mental Health Nursing* 20(2): 134-141.
- Sumner, T. (2024). *Including the Marginalised: Engaging People with Dementia and the Elderly in Technology-Based Participatory Citizen Storytelling*. In: Dobson, S., Soons, R., Agrawal, G., Hardy, P. (eds) *Learning Inclusion in a Digital Age: Belonging and Finding a Voice with the Disadvantaged*. Springer.
- Compassion in end of life care: <https://www.patientvoices.org.uk/painneek.htm>
- Dementia insights: <https://www.patientvoices.org.uk/di.htm>
- Living with dementia: <https://www.patientvoices.org.uk/lwd.htm>
- Power of story: <https://www.patientvoices.org.uk/pow.htm>
- Easy breathing: <https://www.patientvoices.org.uk/easybreathing.htm>
- Dangling conversations: <https://www.patientvoices.org.uk/dc.htm>
- NHS Lethian telehealth stories: <https://www.patientvoices.org.uk/nhs.htm>
- Telehealth stories: <https://www.patientvoices.org.uk/telehealth.htm>
- End of life care: <https://www.patientvoices.org.uk/aeoel.htm>
- Stories from the Isle of Wight stroke club: <https://www.patientvoices.org.uk/iowsc.htm>
- Society of the Holy Child Jesus: <https://www.patientvoices.org.uk/shcj.htm>
- Stories of life after stroke: <https://www.patientvoices.org.uk/naooson.htm>

48