

effective
affective **Voices**
Patient
reflective

**'Do not go gentle into that good night':
Giving voice to patients, families and staff**

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11th March 2020 'Giving voice to suffering' Royal Society of Medicine, London UK

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'Suffering I teach...'



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Compassion

'Compassion is not a relationship between the healer and the wounded. It's a relationship between equals. Only when we know our own darkness well can we be present with the darkness of others. Compassion becomes real when we recognize our shared humanity.'



Pema Chödrön

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Finding a voice



'One of the hardest things in life is having words in your heart that you can't utter.'

James Earl Jones

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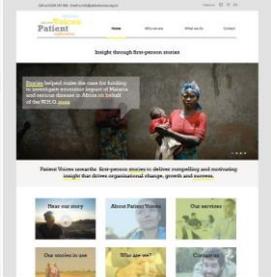
Patient Voices

patience, noun. calm endurance of pain or any provocation; perseverance

patient, adj. having or showing patience

voice, verb. give utterance to, express

Concise Oxford Dictionary, 1964



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Stories and statistics

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



Tony Sumner, 2009

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What really matters to patients? Patient Voices reflective

'To the typical physician, my illness is a routine incident in his rounds, while for me it's the crisis of my life. I would feel better if I had a doctor who at least perceived this incongruity... I just wish he would... give me his whole mind just once, be bonded with me for a brief space, survey my soul as well as my flesh, to get at my illness, for each man is ill in his own way.'



Anatole Broyard, 1992

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What really matters to patients? Patient Voices reflective

'Patients care more about being treated with dignity and respect than they do about mortality rates.'



Ben Page, 2004

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Our aspiration Patient Voices reflective

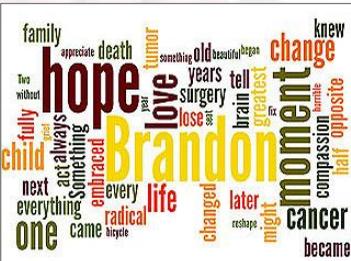
'...to capture some of the unwritten and unspoken stories of ordinary people so that those who devise and implement strategy, as well as clinicians directly involved in care, may carry out their duties in a more informed and compassionate manner.'



Hardy 2004

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The gift of hopelessness Patient Voices reflective



www.patientvoices.org.uk/flv/1180pv384.htm Rita Berglund 2018

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A moment to reflect Patient Voices reflective



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Markers and guides Patient Voices reflective



'Every light was a story and the flashes themselves were the stories going out over the waves, as markers and guides, comfort and warning.'

Jeanette Winterson, 2005

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Claudia's reflections

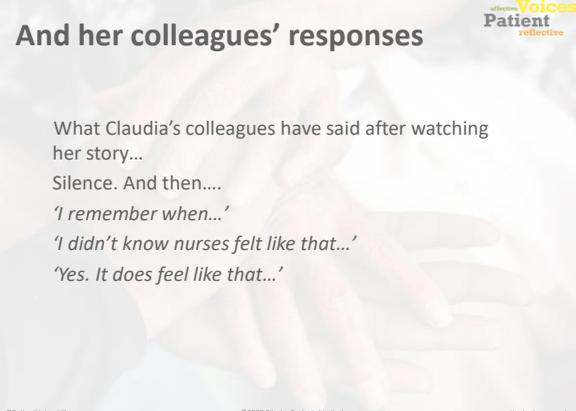
'I am so glad I made this story. I was also really, really pleased to learn that our bereavement team has started doing workshops with nurses for emotional support. Shockingly, a few said, that the finger of blame is often pointed by doctors, especially in non-paediatric specialities. This is so upsetting and so unnecessary.'



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And her colleagues' responses

What Claudia's colleagues have said after watching her story...
 Silence. And then...
'I remember when...'
'I didn't know nurses felt like that...'
'Yes. It does feel like that...'



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Sharing suffering, changing culture

'In the meantime, one story at a time, we can leave a lasting impression with those who come behind us.'
'I felt the stories were so powerful and did a much better job than any other safety lecture in telling the true story.'
'The ability to share these, and other stories like them, is critical if organisations are to learn from mistakes and develop a just culture in which every voice can be heard.'
'Stories are essential in creating a culture where safety and humanity are prized and the values of intellectual, emotional and spiritual intelligence inform 'the way we do things here.'



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The essence of medicine

- Attitude
- Behaviour
- Compassion
- Dialogue



Chochinov, H. (2007) 'Dignity and the essence of medicine: the A, B, C and D of dignity conserving care'. *BMJ*

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Can I have a hand, please?



www.patientvoices.org.uk/ftv/0262pv384.htm Weehaan Pang 2008

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EAR: a model for reflection

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



Tony Sumner, 2009

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Transforming healthcare

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How Patient Voices digital stories are being used:

- 'the evidence of experience' for NAO reports
- prompts for reflection, discussion and debate
- Board meetings > action planning
- staff induction and training
- basis for educational resources
- communicate research results
- highlight areas for improvement
- Virtual Schwartz Rounds
- inform NHSE staff development programme

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A call to action

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The stories are all one

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*'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, 2004

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www.patientvoices.org.uk/stories.htm

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