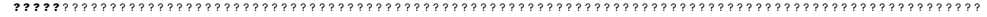




WHERE DOES IT HURT?

The New World
of the
Medical Humanities



Where does it **hurt** ?

Edited by
John Holden,
John Kieffer,
John Newbigin,
and Shelagh Wright



Acknowledgments

When we first discussed the making of this book with Ken Arnold and his team at Wellcome the four of us were intrigued and eager to learn more. When we admitted that we knew almost nothing about the ‘medical humanities’ but a lot about art, culture and creativity, Ken said “so much the better”. The people in this book who have contributed their insights, experiences and ideas have taught us a lot. Some are deeply moving, some are very witty, some are quite dark, but all are full of wisdom and illumination. These essays have been contributed under creative commons licensing so that they can be accessed and built on by anyone. We thank them all for their generosity, truthfulness and willingness to tackle a subject as wide ranging as ‘life, death and everything’.

We would also like to thank **Paul Davis** for creating another story throughout this book with his eloquent and evocative drawings and also to the designers, **Project** for their patience and creativity.

Above all we would like to give special thanks to Wellcome – Ken Arnold, Dan O’Connor, Clare Matterson, Chris Hassan, Nils Fietje (now at the World Health Organisation) and Danny Birchall – for commissioning this work and being so willing to take a few risks along the way.

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Where does it hurt?

John Holden, John Kieffer, John Newbiggin and Shelagh Wright

When someone says “I’m feeling fine” or “I’m hurting” they’re usually talking about a lot more than their medical condition, though that may be part of it. The relationship between medical science and a sense of well-being, or its opposite, is a complicated one that has evolved over time and varies from one society to another. ‘Medical humanities’ is becoming the commonly accepted term for the wider context in which that relationship can be explored and, as it gains currency, the temptation grows to file it as yet another new and discrete discipline, rather than a broad framework within which a whole web of disciplines and perspectives can be located and better understood.

Interest in the notion of medical humanities is intensified by other relatively new phenomena in most western societies, including our own: an increasing expectation that we have responsibility for ‘managing our own health care’; an exponential growth in the health-related information any of us can access online; a greater awareness, brought about by social and mass-media

as much as by scientific advances, of the intimate and complex relationship between physical, mental, emotional, and spiritual wellbeing; and, finally, the fact that the growing diversity of cultures in our national community constantly throws up new perspectives on what we mean by health and well-being.

Against this background, what common assumptions do we share? And how are those assumptions shaped and changed?

These are questions that have engaged the Wellcome Trust for many years and, more recently, have stimulated an extraordinary and, to some extent, unexpected public interest through Wellcome Collection’s exhibitions, events and other activities on London’s Euston Road. The Trust asked us to compile this collection of essays, observations and stories as a contribution to extending and deepening that public interest. Our aim has been to reach beyond a purely professional and academic audience, to introduce the curious general reader to what is meant by the term ‘medical humanities’, to encourage

debate, and to highlight the role of the Wellcome Trust in that debate.

‘We’ are a collective of four people, ‘ThreeJohnsandShelagh’, working in the creative economy and the arts as writers, policy-developers, consultants and do-ers. Synergies in our thinking and our work have led us to look for projects on which we can collaborate and where the arts and culture have a role and influence that transcends conventional expectations, much as the medical humanities transcends the boundaries of conventional medicine. We were delighted, therefore, to be invited by the Wellcome Trust to produce this book. In doing so we have extended our own understanding of the medical humanities and encountered many powerful stories. We – and the Wellcome Trust – hope that you find ‘Where Does It Hurt’ stimulating, and that it may encourage you to make your own contribution to the debate around the medical humanities

Wellcome one, Wellcome all!

Dan O'Connor
Head of Humanities and Social Science,
The Wellcome Trust

Extracted from, Oh, The Humanities! A Complete History of Non-Scientific Things (University of Batley Press, 2157), ch. 5: 'Wellcome One, Wellcome All? A Global Charitable Trust Takes on the Medical Humanities' pp.67-82. Usually attributed to the Meta-Galactic Convocation on Historical Studies.

"...guess is as good as mine. What was very clear by 2014 (some scholars would suggest an even earlier date¹) was that the Wellcome Trust had developed a clear commitment to funding the medical humanities. This is said to have resulted in generalised delight and dancing in the streets, although little of the archival record can be adduced to evidence this². More likely the announcement caused excitement at the expansion of research possibilities, but perhaps also some uncertainty as to what 'Medical Humanities' meant. As a well-known discourse on the topic notes, 'Although by no means a new term – American medical schools had been giving med students copies of Little Women in the forlorn hope of not turning them into heartless sociopaths and calling it 'medical humanities' for decades – it was clear that Wellcome intended something rather more than this.'³ But what did Wellcome intend? What did they mean by 'Medical Humanities'?

Some insight into Wellcome's thinking on

medical humanities is afforded to us by the recent (and some would say wholly unnecessary and all uninvited) publication of the collected speeches of Dan O'Connor, Wellcome's first Head of Medical Humanities. For example, in a seminar for potential applicants in or around March 2014, he is recorded as saying, *The Wellcome Trust's vision is to achieve extraordinary improvements in human and animal health. We believe this can only be achieved if advances in biomedical research are accompanied by advances in our understanding of the cultural and historical contexts of medicine, health and wellbeing. Only with an understanding of those contexts can we address the social, political and ethical challenges that are raised by the global burden of illness, disease and health disparity.*⁴

Beyond O'Connor's slavish devotion to his employer's corporate mission statement, we begin here to comprehend the work Wellcome intended medical

humanities to do. He was later (probably May of the same year) to expand upon this:

*Biomedical science does not occur in a vacuum, rather it happens in specific geographically and socially located communities whose experiences of, and beliefs about, health and disease are contingent upon their histories and cultural practices. To understand those practices, beliefs and experiences requires health-related research that can only be done with the methodologies and approaches of humanities and social science. Tackling the global challenges facing us demands an awareness of the ways in which the meanings of health and illness change over time and from place to place. This requires not just supporting medical humanities and social science research, but enabling that research to be translated into policy, practice and public engagement.*⁵

Clearly, the Wellcome Trust perceived of the medical

FINE, BUT
IT WON
THE NOBEL
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FOR
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humanities as an essential part of their health-improving mission, a way of understanding not just diseases, but the experience of them and the social and cultural challenges stemming therefrom.

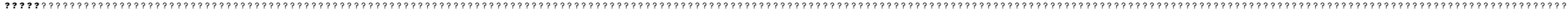
Yet we have not quite answered our question.⁶ Whilst there is no doubt that Wellcome was wholly committed to the medical humanities, there remained the outstanding issue: to what, exactly, were they committed? What were the 'medical humanities' as some literary and linguistic theorists have since pondered, require the definite article or did they stand alone?⁷ These were not questions with which Wellcome itself was unacquainted. Before O'Connor even arrived at Wellcome, they had long vexed Ken Arnold, Head of Wellcome Collection.⁸ It was Arnold who hit upon the idea of commissioning what was known then as a 'book'⁹ featuring contributions from academics, artists, medical practitioners and many

others. Contributors would be invited to dwell upon the idea of the medical humanities in personal and professional capacities and to provide short reflections upon precisely the question at hand: what is the medical humanities? With the backing of Clare Matterson (Director of Culture and Society at Wellcome and considered by some radical scholars as the driving force behind Wellcome's move to medical humanities) Arnold and O'Connor engaged the services of a maverick group of editors known as '3 Shelaghs and a John'.¹⁰ From this was to emerge an edited collection of those reflections; short, sharp thinkpieces ruminating on the myriad meanings of medical humanities.

In concert with Wellcome's open access policy the book was given away free and also made freely available online. Copies of the book were distributed amongst the contributing authors who passed along copies to friends and colleagues, all with the aim of stimulating further debates about the

meanings and uses of the medical humanities. Oral histories from the time speak of the dazzling array of themes and topics contained within the book; touching on ideas as diverse as happiness and human flourishing, curiosity and commodification, infection and imagination. At the heart of the book, so folklorists tell us, was a serious and sustained engagement with the notion that the humanities were not merely decorative add-ons to the work of medicine, but essential parts of the commitment to wellbeing. The essays in the book are said to have ranged across time and space, across eras and continents, and to have comprised not so much a linear monograph as a bricolage collection into which readers might dip at their desire. Some scholars have even speculated that the creativity of the prose was matched only by the beauty and creativity of the accompanying art and design. *Unfortunately, no copies of the book remain...*"

1 See for example the work of AJP Taylor Revnant, notably his *Of Humanities Bondage: Medicine and Morality at the End of the World* (University of New Mexico Press, Mars, 2145).
2 On the decline of the traditional archive, see: Idris P. Drechsler "Mommy, Mommy, the Archive is all in my Head, now": *The Advent of our Android Overlords* (College University College School Press, 2113).
3 Evadne Hermitage-Schloss, *Whither the Humanities?* (Overreaktion Press, Tashkent, 2097), p.34.
4 Editorbot 4.0 (ed.), O'Connor: *Speeches, Denunciations and Ravings* (OnDemand Publications, Very Occasionally), p.898632.
5 Ibid. p.898632.
6 On this as a persistent problem in academia, see Ivan P. Junxia-Smythe, "What's all this 'We' Business, White Man?" *Cooption, Appropriation and Other Strategies for Authority* (Mills & Boon, Dagenham, 2097)
7 See, in particular, Katherine RR Eddings-Jordan, "Do You Mean Like 'The' Ukraine?" A Discourse on Definite Paralysis', *Journal of Studies* (2100)1:1; pp.1-2.
8 On Arnold see Magdalena Kipyego, *And Such a Lovely Coffee Shop: A Brief History of Wellcome Collection* (Fairtrade Coffee Table Books, Vladivostok, 2123)
9 A 'book' was a sort of collection of actual physical pieces of paper that people held whilst they read it with their actual physical eyes. Contrary to what Prof. Callaterly Sisters maintains, 'books' could not be downloaded into the cerebral cortex in 2014. This, of course, only became possible when the first of the Google Glass became sentient in 2015.
10 Some sources suggest the editors were in fact '3 Johns and a Shelagh' but this seems wildly unlikely.



Being human

Victoria Bates
Lecturer in Modern History, University of Bristol

Tracing the history of the medical humanities is no simple task. The 'medical humanities' as a named field is a product of the mid-twentieth century, but the perceived links between health, wellbeing, arts and humanities have deep roots. Even in the late-twentieth century the field had not been clearly defined or coherent, although arguably therein lies its value and appeal. At first linked particularly to medical education, in recent decades the field of medical humanities has come to hold an important place in academic studies, clinical practice, art, arts therapies and arts for health movements, hospital design and much more. However,

the recent emergence and development of the medical humanities cannot be understood without looking further into the past.

The field of medical humanities was built on two interwoven assumptions: the arts and humanities 'humanise', technology and biomedicine 'dehumanises'. In the UK, these assumptions can be traced back at least to the nineteenth century. In the 1800s, Romanticism gained a cultural foothold with its emphasis on the benefits of nature for the human body and soul. This philosophy stood in contrast to the apparent dangers of modern, industrialised life for human health and morals. Concerns about

modern technologies such as the train were articulated through new disease categories such as 'railway spine'. In this context, new medical sciences and technologies were associated with the problems of modernity, while the arts and humanities maintained their association with Romanticism, nature and – by extension – humanity itself.

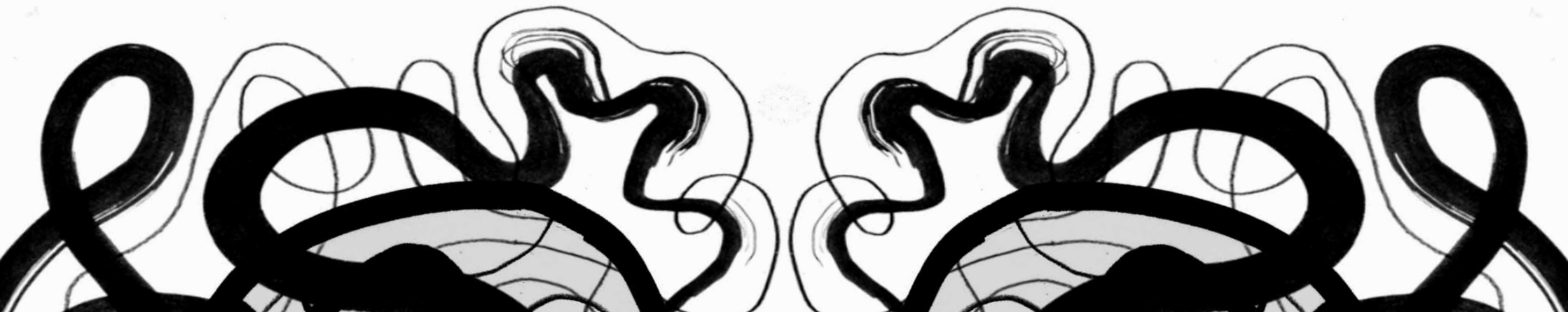
The growth of scientific knowledge in the modern period also necessitated a shift away from 'generalist' approaches to medical care. A number of important new specialisms had emerged by the end of the nineteenth century, including ophthalmology, gynaecology,

psychiatry and bacteriology, and by the mid-twentieth century there was a plethora of specialisms. The microscope in the nineteenth century and X-ray imaging in the twentieth century came to epitomise such concerns; when viewed through new technologies of this kind, the patient was understood only in terms of cells, germs and snapshots of body parts. This new type of medical knowledge apparently 'dehumanised' doctors who increasingly saw patients as 'objects' rather than 'subjects'.

This background to the field of medical humanities is crucial for understanding its emergence as a named

entity in the wake of World War Two. The scientific discoveries of the war posed further problems for 'factual overload' in the medical curriculum. The war also fuelled concerns about medical 'dehumanisation', by showing the implications of scientific knowledge without consideration of the human subject; Hiroshima and concentration camp experiments were particularly haunting examples. While apparently fuelling 'dehumanised' medicine, the war also created a backlash against it, including an emphasis on the value of educating students in the 'human' aspects of medical care and a promotion of holistic approaches.

The arts and humanities were a part of this solution because they dealt with the whole person. For this reason, early medical humanities initiatives were closely connected with medical ethics and with the integration of social and behavioural sciences in medical education. The more recent narrative medicine movement has also drawn upon literary approaches to encourage doctors to listen to patients' stories, rather than only to their list of physical symptoms. This has been deemed potentially therapeutic in itself, particularly in cases involving a psychiatric or social dimension. The 'human' in the 'humanistic'



Being human Continued

medical humanities has thus always been a holistic one, in which the patient's body, mind and soul are interconnected.

The medical humanities are therefore distinguished from biomedicine, with its apparently reductionist and corporeal conception of health. The setting up of binary positions of this kind was crucial to the success of early medical humanities initiatives. More recently, however, scholars and practitioners in the medical humanities have started to critique this opposition. One aspect of this shift has been a greater recognition of the diversity of health and illness experiences, both at cultural and individual levels. Advocates of transhumanism

challenge the notion that a 'natural' human is inherently superior and are breaking down the perceived boundaries between humanity and technology. Such work has important implications for the societal assumptions outlined in this piece.

In the long view, then, the history of the medical humanities helps us to acknowledge some of its inherent cultural assumptions. The notion of the medical humanities as a solution to 'dehumanisation' is historically and socially constituted. It has emerged from concerns about the negative impact of modernity in relation to the positive role of nature, from assumptions that modern

medicine treats the body while the arts and humanities are holistic, and that there is a fundamental difference between technology and humanity. To say that the power of the medical humanities is historically constructed in this way is not to deny the real importance of the arts and humanities. However, it does facilitate an understanding of how the concepts of health and wellbeing have been shaped by particular historical and cultural contexts. This understanding makes it possible to move on from the previous binary positions to a conception of the medical humanities that is in itself more holistic.

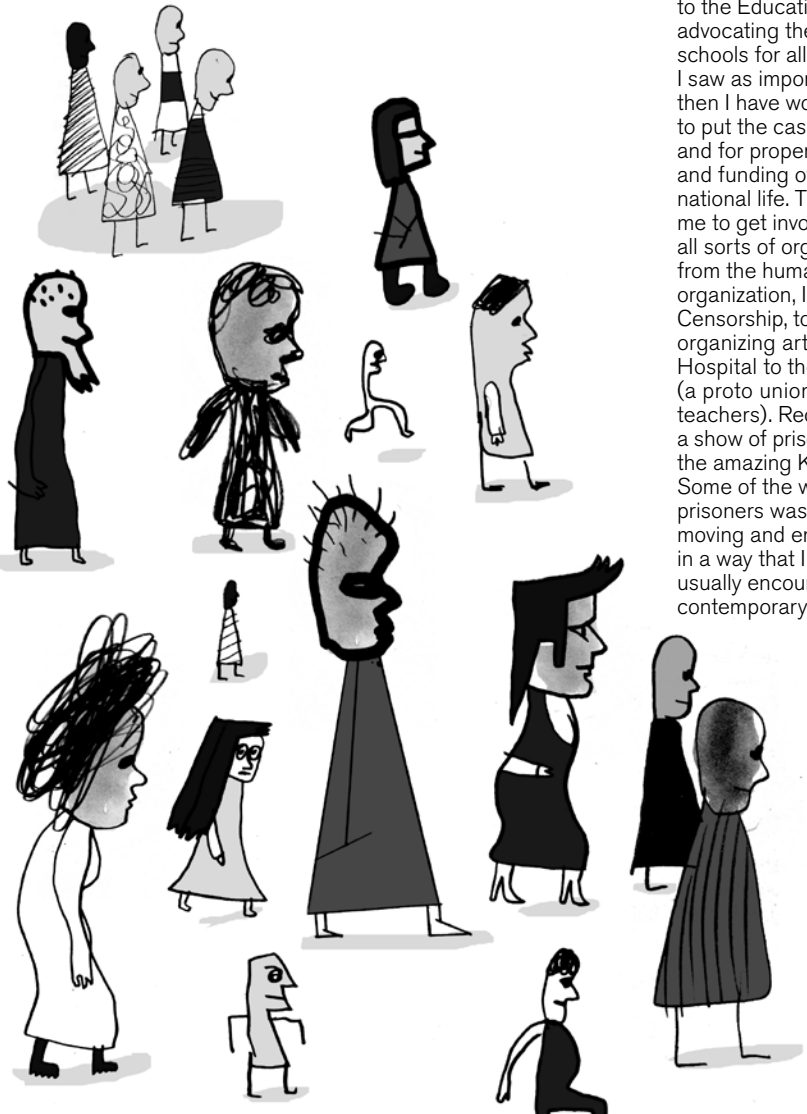
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We need to re-assert the 'human being' in everything we do

Bob and Roberta Smith
Artist

In 2011 I wrote a letter to the Education Secretary advocating the arts within schools for all the reasons I saw as important. Since then I have worked to try to put the case for the arts and for proper consideration and funding of the arts in national life. This has led me to get involved with all sorts of organizations from the human rights organization, Index on Censorship, to Vital Arts, organizing art at Bart's Hospital to the NSEAD (a proto union of Art teachers). Recently I curated a show of prisoners' art from the amazing Koestler Trust. Some of the work by the prisoners was deeply moving and emotional in a way that I don't usually encounter in contemporary art.



Every one has a subtly different reason for thinking the arts are important. People in the creative industries think that drawing is important because without it there would be no design. Lots of people within contemporary art think the language of art is important in itself and have an approach, which is characterized as 'art for arts sake'. My experience leads me to think these approaches are not mutually exclusive and in fact all have great merit.

I have discovered five broad arguments which I will briefly go through and then suggest a sixth overarching idea that seems to resonate for our times.

- 01**
Art gives a voice to the voiceless and provides a ladder to the disadvantaged.
This idea suggests art is a kind of limitless introduction to life. By introducing art to people's lives early on humanity challenges children and says 'be all you can be'.
- 02**
The Creative Industries argument.
We are very poor at telling our children all the jobs that exist for creative people, from graphic design through to digital modeling, social media and beyond. Ideas have to be made physical in order that the economy thrives.
- 03**
Think yourself brighter. (Cognitive learning).
Not until undergraduate philosophy do we encounter the idea that there are multiple answers to the questions humanity faces. Give people in an art class a task and you will get as many answers as there are people in that class. What's more, because the individuals in that class have invented – created – their own answers, they believe in those answers. This helps with their idea of selfhood and is confidence boosting.
- 04**
Good society argument.
Society needs confident people who can design their own futures, come up with answers and ask questions in a changing world.
- 05**
The Arts are about freedom of expression.
Today, when so much of the data about our lives is owned by others, awareness about how we 'construct our identity' and a real sense of

the need to have individual control over who we are and celebrate ourselves is paramount if humanity is to thrive. We used to construct our identity through clothes and hair cuts but now the task of individual identity needs skills involving data protection and the savvy of a major branding company.

Now I come to a sixth idea that resonates with me and in some ways is a thread through the previous five thoughts. We need to reassert the 'human being' in everything we do. Making human beings powerful and caring for them, respecting their needs, is in danger of being forgotten. We have to remember the purpose of our institutions, not just keep them financially sustainable.

06
We have to encourage future generations to be mindful of each other.
Underlying this is the idea of a healthy society, healthy democratically and expressively. A society that is celebratory of difference, not just tolerant, means a medically healthier society both mentally and physically. To be well we must not be pushed around by the world, we have to interpret the world and also feel confident to contribute to it.

The centrality of the arts in all of this is undeniable.

On boils, pestilence and a sow's purse

Christina Patterson
Writer, broadcaster and columnist

For quite a lot of my life, my body has been my enemy. As a teenager, for example, I thought I was too fat. I didn't like the little red lumps that started appearing on my chin, and cheeks. I wanted to look like the girls on the cover of Jackie. They had glossy hair, and perfect teeth and skin like a peach.

When I hit 23, I found out what it was like to have a body that seemed to have started a full-blown war. First, there were the spots. These weren't just teenage spots. These were deep red lumps which had doctors calling medical students in to stare. These, in fact, were the kind of spots that had you thinking of pestilence, and Job.

The spots were blasted off with ultra-violet light, in a cubicle that felt a bit like a coffin. After the light, there were drugs. For many, many years, there were drugs. There were antibiotics, and contraceptive pills, and anti-androgens and a drug they give to lepers, all prescribed by dermatologists who were getting almost as fed up with my skin as me.

After the spots, there was pain. It started in my wrist, and ankle. I wasn't sure how I *could* have sprained both a wrist and an ankle. My

doctor thought it was tendonitis, and that, with rest, it would go. Unfortunately, it didn't. Soon the pain had spread to my knees. For the next four years, I couldn't walk much more than 100 yards.

The hospital lost the blood tests. Hospitals, in my experience, are quite good at losing blood tests. When they were found, a year after they were taken, I was told I had an autoimmune disease called lupus. Lupus, they said, was incurable. It was quite likely to attack my kidneys, and my lungs. At 26, you don't want to think too much about your kidneys, or your lungs.

I tried steroids, which didn't work, and painkillers, which didn't work, and anti-malarial tablets, which didn't work, and steroid injections, which didn't work, and homeopathy, which didn't work, and Chinese herbs, which didn't work, and acupuncture, which didn't work, and special diets, which didn't work, and being wired up to some kind of energy machine, which didn't work and cost a bomb. I also had psychotherapy, which, in the end, did.

It took a few years for the pain to go, and a few years for it to come back. It has come back four or five times

since. I usually think I've sprained an ankle. Sometimes, I limp to A & E. It takes time for me to realise that this is what I've always had, which sometimes shows up in blood tests and sometimes doesn't. I always think the pain will never go, but in the end it always does. Last time I had it was nine years go. It started the day after the 7/7 bombs. That, by the way, was after I had breast cancer the first time, but before the cancer came back.

In spite of all of this, I don't think my body's my enemy now. I don't think it helps to see your body as an enemy. I think it's much, much better to see it as a friend. I wish, when I was younger, I'd known some of the things I know now. I wish, for example, that I'd known that when doctors talk about bodies and minds being linked, that isn't something that should make you feel ashamed. It also doesn't mean that you've made your symptoms up. What it means is that your body can sometimes say the things you can't, and when it does, you should probably listen.

I'm all for medicine, of course. I'm all for blasting tumours with X-rays or *very* nasty drugs. I'm all for hacking out the bits that are

trying to kill you, and trying to make a sow's purse of what's left. I've had six operations in the past 10 years, and, if it will keep me going, I'll queue up for six more. There comes a point when only drugs and surgery will do.

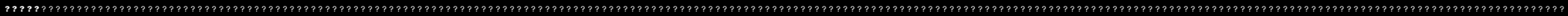
But what applies to cancer doesn't apply to everything else. The answer to disease isn't always drugs. People get ill because they're sad, or angry, or stressed. They get ill because they eat rubbish, drink too much and hardly ever move. They get ill, in fact, because they don't treat their body as a friend. If you treated a friend in the way many of us treat our bodies, that friend would probably hate you, too.

Our National Health Service promises to look after us when things go wrong, but it doesn't do all that much to help us make sure they don't. It's far too keen on hospitals. People still seem to think that the answer to sickness is hospitals. I think we should get rid of lots of hospitals, and have health workers working in the places where people live. Those health workers should show us how to eat well, and how to exercise, and how to relax when we're stressed. (They should also look as if they do these things themselves. Far, far too many people working in the NHS don't.) And when we're sad, they should point us to a listening ear. A short burst of CBT costs a lot less than drugs for the rest of your life.

We need to get a grip. If we don't want to bankrupt our NHS, we all need to get a grip. We need to get a grip on the kind of health system that will work better for most people, and we need to make more of an effort to stay well.

I have learnt, the hard way, that the best way to keep healthy is to be happy, and active, and curious, and to be grateful for the loan of this incredible machine we all live in, on the face of this incredible earth.





Medical / Humanities

Felicity Callard, Senior Lecturer in Social Science for Medical Humanities, Durham University
Des Fitzgerald, Department of Social Sciences, Health and Medicine, Kings College London

THE MEDICAL HUMANITIES

What exactly is held together by the term 'medical humanities'? More specifically: how, in 2014, might we understand the spatial and intellectual relations produced by tying the adjective 'medical' to that over-wrought abstraction, 'the humanities'? Ten years ago, Martyn Evans and Jane Macnaughton described a cohort of medical humanists 'attempting to integrate the viewpoints of whichever disciplines seem most relevant to the question they are asking'. And yet we cannot regard this telos of 'integration' as the best descriptor of our own contemporary experience in this space; we do not think that the concerns, objects, and methods of the 'medical humanities' are neatly dissociable from those of the medical and life sciences; and we are unconvinced that the density, complexity and capacity of traffic across 'the medical humanities' has yet been well-enough described, witnessed, or understood. The question

is: if the core objects of the medical humanities are, in fact, irretrievably entangled in the vital and corporeal commitments of biomedical research, then, beyond well-rehearsed encomia for 'interdisciplinarity,' how might we re-imagine the intellectual space of the medical humanities in this century?

Our pursuit of this question comes from a related preoccupation, which has engaged us for some years, and this is the relationship between the humanities (and social sciences) and the neurosciences. As scholars 'of' the neurosciences, we are increasingly gripped by the realisation that we live in an age when webs of human 'experience,' 'culture,' 'society,' 'meaning,' and 'narrative,' are being produced, reproduced, and reconfigured, within neuroscientific experiments. But in staying with this realisation, we want to shift away from an intellectual politics of advance and

retreat, and towards a methodological attention to the – hitherto ungrasped – possibilities that might be unleashed through experiments that make this realisation unmistakable. We focus on 'experiment' especially (and we do not limit this observation to our interest in neuroscience), because this term conjures epistemologies, apparatuses, and an ethos: it invites us into the epistemological space of the laboratory, but it also points to ethical and aesthetic territories of novelty, invention, and play.

How can this space be opened up? We turn to an analysis of 'entanglement,' drawing on feminist theorist Karen Barad's insight that concrete knowledge is a product of – and not a precursor to – 'interdisciplinary' mixtures of material and practice. Rather than seeing the space of the 'medical humanities' as a meeting-point for demarcated territories, we insist on the priority of mixed

knowledges, materials and practices, whose ongoing embroilment is entirely indifferent to covetous claims re disciplinary contribution. As ethnographers, geographers, experimenters and collaborators ourselves, 'entanglement' helps us to re-think the territory of the medical humanities – to focus less on who does what, what her expertise is, and where she comes from; and more on the occasional, weird, unstable and lively spaces of experimental encounter in which we tend – somehow, temporarily, unavoidably – to find ourselves. Attending to such topologies helps us to think something exterior both to the 'disciplinary' orthodoxies of experimental and conceptual practice, and the dynamics of power that underwrite much of their relationship. This stance is critical to the medical humanities: to the extent that it addresses the lives of human subjects in sickness and health, such scholarship is especially inflected by an historical moment in which

it is hard to talk about human cultural lives and experiences without an attention to the biological possibilities that texture them. The image of 'entanglement,' transposed to the strange site of the medical humanities, becomes only more potent and richly capacious.

But we also want to displace the idea that, in interactions between the humanities (or social sciences) and the life sciences, the former have a nebulous expertise in culture and society, and the latter a hard-nosed dominion over the biological body. Given what we now know about the interactions of bodies, experiences, cultures, and environments, such a view is no longer sustainable. Critically, this displacement allows us to focus on the traffic between the humanist inheritance invoked by a term like 'the medical humanities,' and contemporary figurations of the human in biomedical experiments. It allows us to ask how a more risky and

experimental medical humanities might navigate the entanglements of subjectivity, experience and pathology that cut across dominant ways in which both the 'human' and her medicine are understood today.

Our stance eschews the frequently defensive apparatus of the medical humanities. It claims privileged access neither to 'narratives' of illness, 'reflections' on doctoring, insights on 'care,' nor social and 'ethical' analysis. It also rejects any claim from the biosciences to have exclusive access to bodily ailments – or to be the only interpreter and preserver of vital capacities. Setting aside such allegiances and identifications, we want to think more experimentally about the constitution and dynamics of the medical-humanistic domain. Tracking the flight of entanglement is, we suggest, a vital first step.

Between me and we

Errol Donald
Creative facilitator and founder of Mindspray



In 1983, the film 'Wildstyle' premiered at London's ICA. The largely young cast featured pioneers of the then burgeoning culture of Hip Hop. The film's lead protagonist (graffiti artist 'Zoro') was played by a young Lee Quinones, now a celebrated figure in the contemporary art world and considered the single most influential artist to emerge from the New York City subway art movement.

As it spread across the UK, graffiti art became the start of a brand new conversation amongst young people. Good times. Our new state of mind.

The pull towards graffiti seemed driven as much by a sense of inner belief as anything else real or imagined. I couldn't explain the attraction, nor did I want to. For the first time I didn't have to justify my actions

us

– creative, or otherwise. Drawing inspiration from the trailblazers of New York City, I quickly connected with like-minded creative partners nearer to home, via London Underground's arterial tube system.

In 1841, the invention of paint in a tube revolutionised Impressionist painting. Suddenly the likes of Cezanne, Monet and Pissarro were able to free themselves from the confines of the studio and be at one with their surrounding environment. In the 1970's the likes of Stay High 149, Tracy 168, Superkool 223, Barbara 62, Eva 62, Phase II and countless others from the New York School, sparked an equally important creative revolution. Using aerosol, they amplified the collective voice of youth

culture that can still be heard to this day the world over.

In itself, aerosol provides a convenient metaphor for compressed potential. Demanding control it speaks to the urge to explore new and uncharted spaces. Its limited availability at the time added to the value and meaning of my early attempts to create something beautiful without the need for easels, canvases, studio space, or supporting statements.

Life before graffiti lacked the kind of cultural discourse that properly acknowledged young voices, especially those stirring in the Caribbean community that I grew up in. Hip Hop,

Between me and we Continued

and graffiti culture in particular opened up an incredible space for play, experimentation and learning. Suddenly, we were heard and seen via the larger than life-sized painted word. The noticeable shift in power brought the previously unattainable within reach. Individually, and as a community, we claimed the right to name our beauty, literally in our own words. Previously withheld thoughts and feelings found life through the skilled application of spray-paint on walls.

I was extremely protective of graffiti culture, its history and the contributions of the many great artists that had conquered before me. Perhaps I guarded it too closely at first, choosing to share only with my crew privately, and with the general public via the pseudonym 'Pride'. I shielded my vulnerability as I tried to separate, and eventually accept feelings of anxiety and fear. There were no examples for me to model at the time, and certainly none that acknowledged

my unique skillset and cultural background.

The inherent risks of graffiti culture were for me further removed from the ritual illegality that folklore would like you to believe. As an 'early adopter', doubt and uncertainty spoke directly to my experiences as a young, black teenager growing up in West London's Caribbean community. By then, the narrative of the outsider was an already very familiar and deeply embedded part of my experience. Hard times.

Today graffiti art is more accessible than at any other time in its short history. Hard to imagine that familiarity has made it less contemptible. In addition to sharing the public space, artists and spectators now find themselves equally invested in the creative process. Not that the public gaze is something that all writers are comfortable with. Many are still adjusting to the exposure and newfound visibility and maintain a safe distance, wary of the

caricature and criticism that comes with the territory. Others flirt with the risks and take their chances.

It can be argued that economic, social and class divisions have created a far more noxious and corrosive impact on society than graffiti art, which prides itself on free expression, collaboration, and individuality. However, despite its popularity, opportunities for meaningful discourse are still rare and limited to select audiences.

Codified and ornately camouflaged, graffiti's contribution to creative culture is undeniable. Moreover, its influence continues to extend further and further across generations and territories, evading formal classification only to reappear in new languages, and identities.

My journey through the arts, education, and corporate sectors has now led me to

the therapeutic space and engagement with young people. It's a space where the challenge and self-determination of graffiti culture inform my ability to provide a safe container for feelings of anxiety, frustration, anger and isolation. It feels both natural, and inevitable given my past that I would one day find myself on the outside looking in, this time accepting the challenge to simply remain a blank canvas.

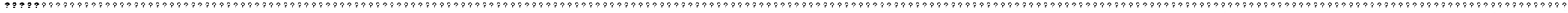
Creating and placing my work in the environment and in real time brought a true sense of awareness.

It was challenging at various times for many different and personal reasons but for that moment, the context was mine. Graffiti invited me to explore and create new relational spaces, up to and beyond the intense moment of contact between paint and surface.

Between inner and outer worlds.

Between me, and we.





Heritage and wellbeing

Gareth Maeer
Head of Research, Heritage Lottery Fund



That heritage contributes to many people's quality of life is not in any serious doubt. Surveys have easily established that people report a link between improvements to the condition of heritage assets where they live – buildings, museums, townscapes, historic parks – and their self-reported quality of life. At a deeper level of engagement, Heritage Lottery Fund research into the benefits individuals gain from volunteering on heritage projects has recorded positive responses to questions linked to both the hedonic and eudaimonic concepts of well-being.

But these results are not limited to heritage. If we want to get closer to identifying a unique contribution that heritage has for well-being, we can look more closely at the detailed qualitative descriptions that people use when explaining the importance of heritage to them. These tend to be a combination of expressions of 'identity', along with a deep-rooted interest and curiosity in the past and how it helps to explain and understand the present. This is a value of heritage that Patrick Wright was discovering in the Britain of the early 1980s, and which has influenced the more inclusive concept that the word has today.

This helps, but still doesn't get us that close to an understanding of the question that is driving the policy interest in well-being. Which is – do we have 'enough' (take your pick) open spaces, healthcare, income, social capital, cultural participation, equality? Or is the insufficiency of these things a reason for an – alleged – deficit of well-being amongst the general population? In the end these are value judgements about what contributes to well-being, whose well-being, and who gets to decide. But it is easy to see how measuring well-being and relating it to those things we believe we 'need more of' is attractive to campaign groups and policy advisers.

This has led to attempts to establish a statistical relationship between well-being and cultural engagement. With some success. But without coming close to answering the question of causation rather than correlation. And somehow, in all the regression analyses, it feels a bigger picture is being missed. Advocating the value of heritage cannot mean avoiding the self-evident truth that, on occasion, the 'new' makes lives better, and that some loss of heritage will sometimes be to the greater good.

In which case, isn't this the question we should be asking: are there structural forces that mean that the balance between the new and the old is out of kilter, to the detriment of our well-being?

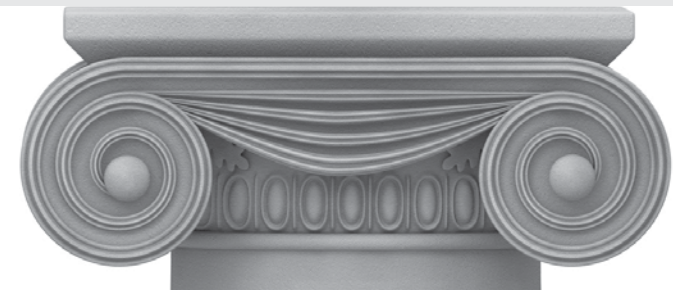
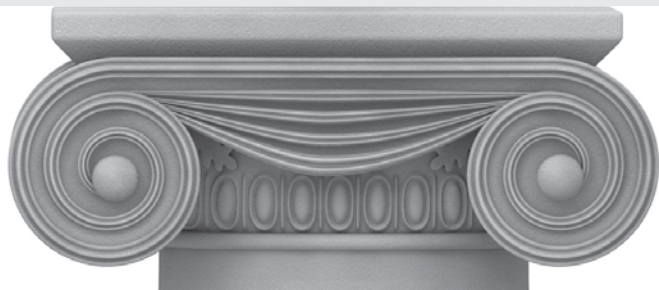
In one case – our natural heritage – this seems in little doubt, given the voracious loss of habitats and species on a worldwide and national scale. And as Nick Groom has suggested, this loss may well be bound up with the cultural loss of our connection with 'the seasons', to the passing of the rural calendar and its local customs.

A more developed case for a systemic imbalance between old and new is Tim Jackson's work on growth economics and environmental limits. In this, Jackson developed his theory of the consumer economy driven by 'novelty', arguing that the primacy of growth in public policy is explained by the necessity of maintaining overall levels of employment. And this growth is dependent on new demand being continuously created, by tapping consumers' craving for 'novelty', in the form of new and ever more exciting products.

This idea of 'novelty' as the source of economic growth is not new, and was built into Schumpeter's theory of 'creative destruction'. But Jackson adds to the idea by combining it with the 'universal values' model of psychologist Shalom Schwartz. This model – which Shwartz has tested through empirical research in over 40 countries – contains a tension between two distinct but opposing value sets in our psychological make-up; on the one hand, 'openness to change' (which Jackson re-terms as novelty) and, on the other, 'conservation'. Both are important, but a relative degree of balance – at the societal level if not within each individual – is best.

But the economic need for growth has necessitated an undue emphasis on novelty, and if growth is dependent on skewing this balance heavily towards novelty, what does that mean for conservation of heritage?

This final point, I should say, is not in Jackson – but seems a logical extension of his argument. It's also true that Schwartz doesn't refer to 'heritage' in the universal values he links to conservation. His values are 'tradition' and 'conformity'. Yet isn't the heritage case, at heart, based on the argument for conforming to existing and past customs, conforming to live and work in buildings and city districts that are already built, conforming to co-exist with the wildlife that surrounds us? These are all constraints we can choose to impose upon ourselves, and it is this notion of constraint that characterises Schwartz's conservation value set.



Medicine is bailing out the bath while the taps are running

Hugh Montgomery
Professor of Intensive Care Medicine, Director, University College London Institute for Human Health and Performance, and Consultant Intensivist, Whittington Hospital

Disease must be present if medicine, 'the art of healing' (Latin *'ars medicina'*), is to be practiced. National medical services apply increasingly technologically sophisticated means to this endeavor of diagnosis and cure. But is our focus on such a 'disease treatment' the best means by which to deliver health, to alleviate a population burden of suffering, and to promote happiness? Some 33 years since I started at medical school, I have recently considered such matters with increasing urgency.

My disquiet is driven by many factors. Now in my 50's, I am accumulating my own burden of disease. Whilst not life-threatening, back pain and a frozen shoulder do limit enjoyment and function, and are not readily amenable to absolute cure. Many of my patients are further down this path, their accumulation of ailments leading to an incurable state of frailty. Many of these contribute to the growing population of hospital-dependent patients- those whose state of wellbeing is sufficiently poor that they cannot survive outside a medical environment, in which their lives stutter to a close. One in five Americans is admitted to an intensive care unit (ICU) around the

time of their deaths, or actually die there. Meanwhile, additional technical intervention often yields only marginal gain, and many of these come with a cost: an ICU stay can lead to sustained functional debility lasting many years. This model of disease-treatment is expensive: the USA and European countries spend anywhere between 6 and 16% of GDP on healthcare, US hospital costs alone approaching \$400bn in 2011. A UK intensive care bed can cost £3000 a day. And all the while, the clamor that 'life must be preserved at any cost' grows ever louder.

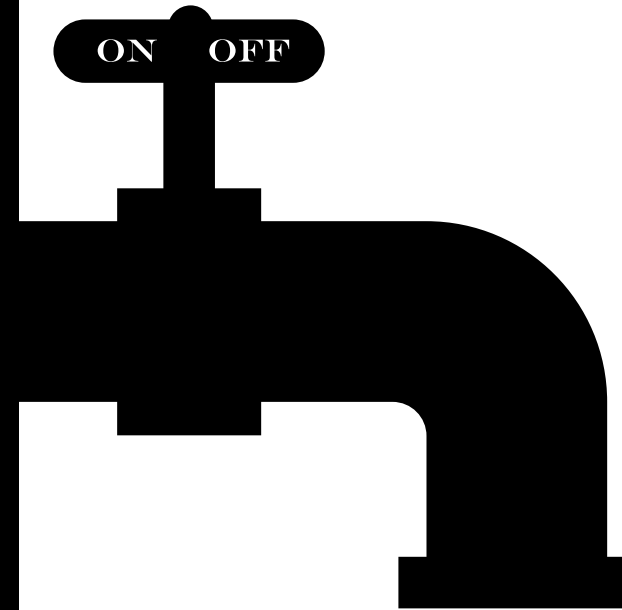
But we are bailing the bath with the taps still on. Remove smoking, alcohol, recreational drug use, poor diet and inactivity as causes of ill-health, and there would be precious few ICU patients. Deal, in addition, with diets high in sugar and saturated fat, and poor air quality, and tumbleweed will blow through many hospital wards. Resources can be diverted to supporting suffering of other sorts, or in preventing disease.

Such changes can be good for society in many other ways. Lifestyle changes (for instance in diet and active transport) not only prevent disease (from

cancer to coronary disease, from mild-moderate depression to diabetes), but helps prevent climate change (cows belching methane, and cars carbon and nitrogen oxides) and energy poverty, whilst offering national food and energy security.

These solutions are, of course, not 'medical' in process or outcome. They do not drive diagnosis and treatment. They rely on a change in policy affecting agriculture, transport, energy and food policy. They require us to alleviate inequity. They need us to envision a new economy- one which values ecosystems; one which does not allow industry to invent and market dangerous products under the license of 'freedom and rights'; one in which all value is fiscal, and one founded upon the concept of perpetual growth being both possible and beneficial.

Such societal transformation, whilst starting with policy and politics, requires holistic engagement. Underpinning this, city planners and architects can create green spaces, good for mental and physical health. Permitting pedestrianisation and pedaling reduces noise stress, and dams the rivers



of fast-moving metal which divide communities.

But can we go yet further? Should we not consider the degree to which preservation of ecosystems, and increased access to (and engagement in) theatre, sport and music can enhance happiness and wellbeing? Seek ways in which to strengthen the creation of community?

Wellbeing is thus about far more than treating disease. This is not to say that 'conventional medicine' has no place. I'd hope that my own life might be saved, or that of my wife or children, should they fall ill whilst in otherwise good health, and where our prospect of recovery to enjoyable life is good. But I'd rather dwell in a society which was healthier and happier, and avoid such illness in the first place.



Keep taking the chicken soup

Ivor Dembina
Stand up comic



YOU COULDA
BEEN A LAWYER

Here's a good Jewish joke:
A Jewish man is elected to the position of United States president and, at his inauguration ceremony, his mother sits in the front row among the assembled dignitaries. She looks fairly unimpressed but, as her son steps up to take the presidential oath she proudly turns to the person next to her and whispers, "You know something? His brother is a doctor".

If laughter is the best medicine, in Jewish humour the doctor is never far away. Medical references are everywhere: Mr Cohen gets knocked over by a car. An ambulance arrives and the paramedic asks, "Mr Cohen, are you comfortable?"

To which Cohen shrugs, "I make a living".

Throughout my lifetime ill-health, real or imagined, has always been in the foreground of Jewish life. 'Jewish penicillin' was the affectionate name given to chicken soup with good health portrayed as inextricably tied to familial nourishment – exemplified by its obsession with food, prepared and served by the omnipotent Jewish mother. Old fashioned? Yes, and unquestionably sexist but, invariably, very funny.

But it's not just physical well-being that the Jewish comedian jokes about; it's in the field of mental health and personal anxiety that Jewish humour comes into its own: "I had a dream last night," a Jewish man tells his psychiatrist. "I dreamed my mother had your face. I woke up and couldn't get back to sleep and lay awake all night until morning. Then I got up, had a cup of tea, and came straight here." The psychiatrist pauses and says, "A cup of tea? That you call a breakfast?"

Woody Allen famously created a whole genre of comedy out of his psychoanalysis and Freud pontificated at length about the significance of jokes in human psychology.

In Freud's view, jokes happened when the conscious mind allows the expression of thoughts that society usually suppresses or forbids. This theory might be true, although, as any professional comedian would point out, Freud never played the late show at the Comedy Store.

To the Jewish mother, psychiatry can have its upside too: Three of them discuss their sons. The first boasts that her son has become the head of a huge corporation. The second says her boy is now the dean of an Oxford college. But the third claims her son is doing best: "He's in analysis with a psychiatrist – sees him five times a week. And what does he talk about? Me."

All these jokes are of course incredibly old. But for Jews, old age brings no shame, just a different set of medical problems: At the Jewish care home three elderly male residents wait for a check-up. The first is having trouble with his waterworks: "Every ten minutes", he says, "I have to run to the loo and then, just a dribble." The second fellow says his problems are at the rear. "I sit there for hours at a time and then, nothing." The third fellow says he empties his bladder every

morning at seven and then fifteen minutes later, does his other business too. "So," asks his friends, "Why do you need a check-up?" The man says, "the problem is, I don't wake up until nine."

Why do Jewish people seem to obsess about their health? Well the answer is of course, they don't, well not more than anybody else, it's just I think they do so more readily. For example, I believe Jewish people are more prone to headaches than non-Jews because headaches, at least in the metaphorical sense, are things to be enjoyed. The default view is that if you have nothing wrong with you, who is going to bother to listen? And someone has to listen. Which brings us back, to Mother.

Take a deep breath....

Jane Macnaughton
Centre for Medical Humanities, Durham University

"Take a deep breath....and out again". How many of us have heard these words uttered in a rising and falling tone when visiting our GP with a cough or breathing problem while being examined with a freezing cold stethoscope? We are also familiar with them in a different context, as in girding up our loins before doing something difficult: "take a deep breath then... just do it!" But have you ever thought about what kind of a thing breath is? In the first of these two examples, breath is a packet of air that enters and exits the lungs from the outside through the voluntary exercise of the diaphragm and intercostal muscles. In the second, it is a metaphor for centering yourself, focusing on a challenge and going for it.

These examples illustrate our human capacity to understand important

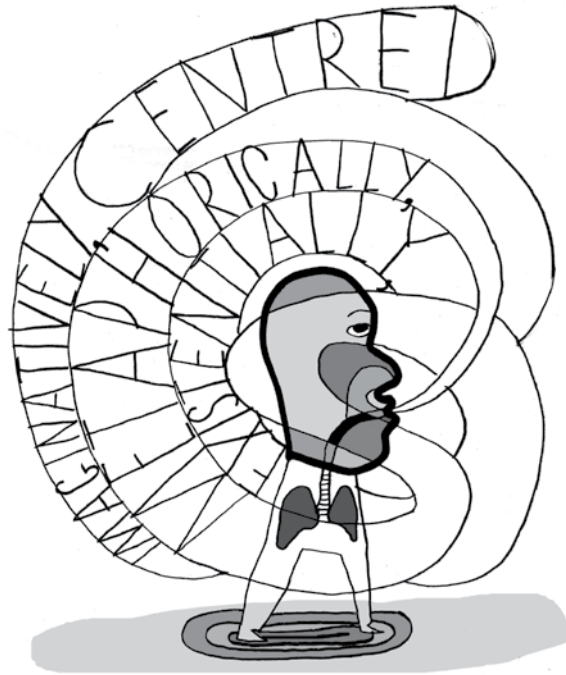
concepts in many different ways. In a clinical context, breath and breathing are thought of physiologically. There are specific sensations of breathlessness that may be associated with different conditions, such as 'tightness' being associated with asthma, or 'air hunger' related to conditions in which the blood cannot carry enough oxygen, such as heart failure. Breathing can be evaluated by listening to the chest, quantified by spirometry; or its effectiveness assessed by measuring oxygen saturation in the blood. However, most of us do not spend much of our lives in a clinical context, and when we think about breath and breathing, our ideas are influenced by our cultural and religious context, family environment, life experience, expectations and habits, gender, and – in our modern world – the

media. It is deeply embedded in western culture that breath is thought of as the infusion of life. The Biblical notion that God breathed life into man became translated in medieval times into the notion of breath as the 'vital spirit', an idea that can be traced back to Aristotle, who associates breath or pneuma with 'soul' or 'spirit'. Aristotle's treatise *On Breath* writes of the spirit or soul being taken into the body by breath, and being lost again in the last breath. This idea still has deep currency in modern life. Harry Potter book and film fans will remember the terrifying notion of the 'dementor's kiss' sucking the soul from the body of its victim through the breath.

More seriously, those of us who have sat at the deathbed of a loved one



Take a deep breath.... Continued



have experienced their last breath as the moment when their body becomes visibly inanimate and solid, as if all the vitality of the flesh has vanished.

All this points to a crucial gap in thinking that medical humanities has the potential to fill. It is a central tenet of medical humanities that biomedicine does not hold all the keys to understanding illness as it is comprehended or experienced by the patient, or how responses to treatment are mediated and outcomes and prognosis revealed over time. In as much as it has focused on clinical medicine, so far medical humanities has tended to concentrate on the manner by which symptoms are presented and discussed between clinician and patient, how potential diagnoses are handled and how prognoses might be delivered and received. This might be thought of as 'educational' medical humanities, a field that remains rooted within the culture of medicine without challenging its essentially biomedical ways of thinking. However, some of us now engaged in research in this field are interested in a new way of doing medical humanities that we call 'critically engaged'. We want to

extend the gaze of medical humanities from just focusing on the clinical interaction to critically examining the evidence base that lies at the heart of that interaction. We think medical humanities can influence not only how things are done in medicine but what is done in terms of treatment and management. This change can come about by engaging in discussion with clinical scientists using the kinds of understanding that are not usually admitted to the clinic: understanding that underpins individual experience – the metaphorical, imaginative, existential – and understanding that allows objective critique from the standpoints of different intellectual traditions, those of the humanities and social sciences.

The exploration of breathlessness provides a rich context which such critical engagement might effectively serve. As I suggested at the start of this essay, different ideas and explanations can remain in play at one and the same time in the minds of people who experience breathlessness. On the one hand, patients may comprehend the physiological processes leading to their problem,

but feel in their hearts that something else is going on. The character Baras in Michael Symmons Roberts novel *Breath*, knows that it was a gas attack that destroyed his lungs 'but it still feels like a problem with the air, not with his own body'; as if 'the air is working him like an old pair of bellows'. Clinicians are puzzled by the observation that even healthy people subjected to an artificial breathlessness stimulus in controlled laboratory conditions have reported a feeling of impending death. Similarly perplexing is that there is often a mismatch between how severe patients feel their breathlessness is to how it is measured objectively by a spirometer. From a medical humanities perspective, these things are also puzzling, but we have a way forward in treating them as challenging questions for humanities scholars and biomedical scientists to solve together.

We think this work is exciting and fascinating, but even more than this, it is crucial to ensure we can better help people who suffer the very distressing experience of breathlessness every day of their lives.

This helps people look after themselves – and each other

Jonnie Turpie and Dan Jones
Directors of Maverick TV

▶▶ JT

Our starting point was very simple – people are embarrassed to talk about their own health, but why? Why should there be any shame about it? And, in fact, if you give them a chance to talk about it, they do! Then connect them to a doctor and they can actually do something about it. So we made two 6-part documentaries for Channel 4 and some programmes for schools about children's conditions, such as stammering.

▶▶ DJ

So then we started making 'features' programmes, aimed at peak-time 8 and 9pm slots in the schedule, about health and body image issues, like 'Ten Years Younger' and 'How to Look Good Naked', which led to 'Embarrassing Illnesses' being given this less documentary, more

whenever Embarrassing Illnesses is on air, traffic peaks on 'NHS Choices' service because so many people want to ask questions. We've had stories of people feeling a lump while they're watching a programme, going to the doctor the next day, and having a potentially serious illness averted.

▶▶ DJ

If you like, we're putting a tabloid front page on broadcast content – exactly what public service broadcasting should be doing. For example, there's been lots of public information about breast cancer but when we showed women how to check their vulvas for cancer the response we got from lots of women was "I had no idea how to do that until I saw your show". Pretty crazy that that's coming

▶▶ JT

We encouraged the NHS out-of-hours service to use Skype. But we couldn't make it happen. They said the information governance restrictions made it impossible. So we thought, let's do it on TV, and now 'Live from the Clinic' lets patients have a live consultation on Skype and on-air, and get a diagnosis. Now we're starting to see the adoption of Skype services within the NHS. That's clear evidence of the power of what we're doing, if we can help people self-manage and not have to go to the doctor, then we're doing something of benefit for an NHS that's under pressure. This service helps people look after themselves – and each other.

▶▶ DJ

We're now doing stuff on mental health and that's really difficult to do on TV. What do you show? So, rather than doing a documentary about autism, for example, we've flipped it round so we ask people "where do you think you sit on the autism scale?" That engages people with the programme in an entirely different way. We devised an autism test with the Cambridge Autism Research Centre, a world-leading institute and, with 1.6m viewers for these programmes, we had 700,000 people taking the test online. Simon Baron-Cohen at the Institute was thrilled. 700,000 was a pretty big research sample – the biggest he'd ever had! When you start by suggesting to someone it's not that you're autistic and I'm not, it's more that we may be at different points on the spectrum, then you

lifestyle treatment in 2006. And since then the readiness to talk about illness has changed radically. Things that were absolutely taboo ten years ago – erectile dysfunction, cancer of the vulva – now you can put them on at 8pm and no-one raises an eyebrow – and, more importantly, people are more willing to discuss the issues with health professionals. That change is enormous.

▶▶ JT

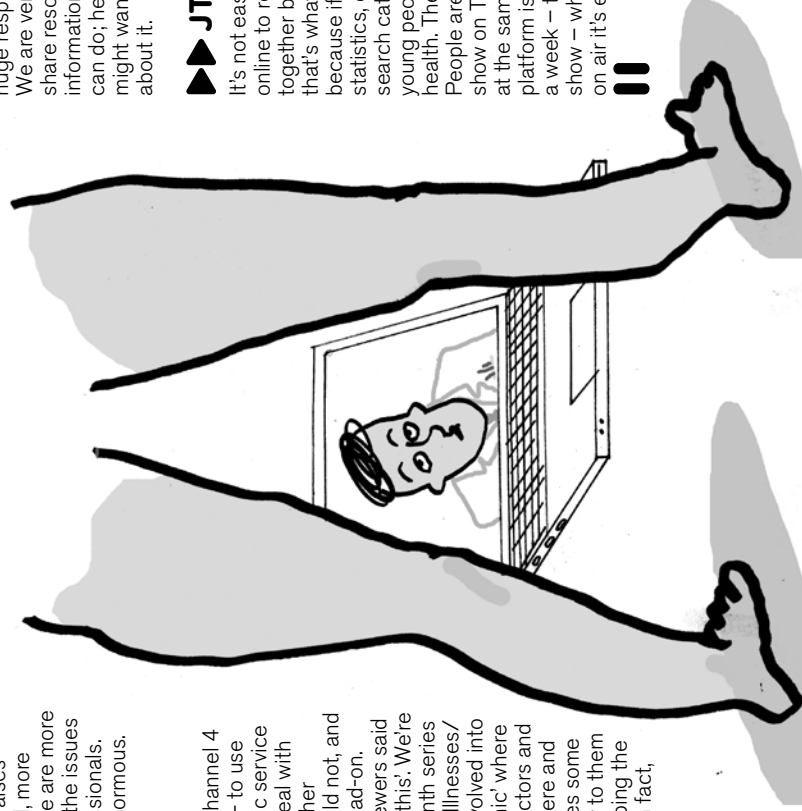
And that's what Channel 4 was set up to do – to use the power of public service broadcasting to deal with issues in a way other broadcasters would not, and deal with them head-on. Right away the viewers said 'we want more of this'. We're now into our seventh series of 'Embarrassing Illnesses/Bodies' and it's evolved into 'Live from the Clinic', where patients skype doctors and get a diagnosis there and then. Yes, it worries some medics but I'd say to them we're actually helping the NHS do it's job. In fact,

from Channel 4 and not the NHS. We now have 350,000 people sharing information and views on Facebook because they're no longer embarrassed to talk about and share information about these things that affect them.

immediately de-stigmatise the conversation. And it was the younger age groups in that sample who were the ones most at risk of serious autism – and they're the very people who want to watch the show. We recognise that we have a huge responsibility with this. We are very careful. We share resources and information; here's what you can do; here's someone you might want to speak to about it.

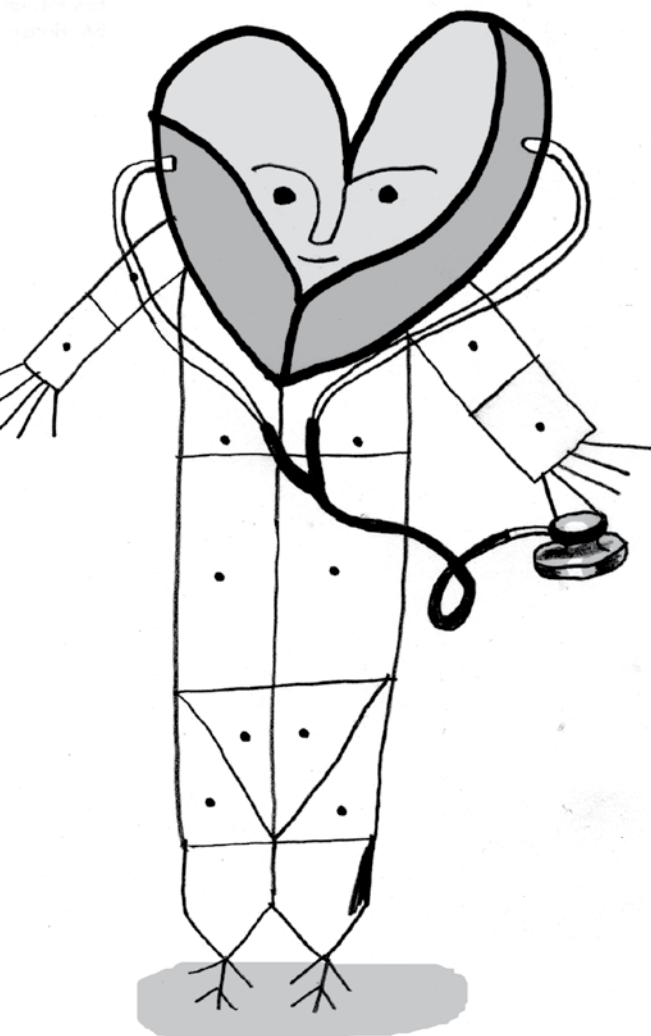
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It's not easy to get TV and online to really work well together but we recognised that's what we had to do because if you look at the statistics, one of the highest search categories online for young people is about health. They want to know. People are watching the show on TV and are online at the same time. Our online platform is getting 2m hits a week – that's without the show – when the show's on air it's even higher.



Vodou: the welfare state of the invisibles

Leah Gordon
Artist and curator, co-director of the Ghetto Biennale in Port-au-Prince, Haiti



The Republic of Vodou mirrors and predates the Welfare State and plays a key role in the protection and promotion of the economic and social well being of its citizens. It is based on the principles of spiritual and communal responsibility for those unable to avail themselves of the minimal provisions for a good life, which reflects, based on estimates by the World Bank, the situation of 78% of the population of Haiti.

The Welfare State of the Invisibles has a bureau of solicitors, each based in their own hollowed out tomb in the municipal cemetery of Port-au-Prince, armed with fifty year old Remingtons and Olivettis with which to type out the appeals and requests of the claimants to be presented to spirit judges. The Welfare State of the Invisibles has teams of counsellors giving advice on the past and its relationship to the future through Vodou lessons sharply exacted using triple decks of warped and filthy playing cards in sweltering badjis.

The Welfare State of the Invisibles also has a dose of doctors who dispense medical assistance, the nature of which mostly depends on whether the condition is supernaturally

or naturally caused. There are also other factors in the nature of your treatment, which are affected by your trade, socio-geographic location, sexuality and personality...the usual pointers to you mét-tét. A Voudouissan from the rural, agricultural mountains would more often cite the spirit, Gran Bwa, the spirit of the forests and leaves, as his healer whilst an urban member of the popular classes cites Gede, the vagabond spirit of death and lewd sex, as his obvious physician and mentor.

Many Houngan and Mambo, Vodou priests and priestesses, have intimate knowledge of folk medicine as well as the rituals of supernatural healing. The first task is to assess whether the root of the malady is physical or metaphysical. Then they will apply either their knowledge as 'dokto fey' which could, for example, use basil leaves in Florida Water to cool fevers, spider's web to stem bleeding or wood ash and orange peel to clean a wound. If the root of the illness is deemed to be supernatural then the Houngan must assess whether this might be a petulant ancestral spirit who feels neglected and demands mystical work or an expedition sent upon

the patient by a vindictive third party.

Deuli Laurent is a Vodou priest and celebrated carnival character, Bounda pa Bounda, who lives in a mountain village above the Southern town of Jacmel. He says as a priest his first objective is to assess whether this is a 'maladi fey' so he would call upon the spirit Gran Bwa or if it due to the transmission of negative spirits so Deuli would call upon 'Kafou' or 'Ezili Danto' who can dislodge negative energies from the conscious mind. When Deuli takes to the streets every carnival as Bounda pa Bounda he dances with a large basket on his head containing leaves and flowers he has brought down from the mountains. "Yes, because all leaves, are leaves. As long as nature created them they could be used for curing people. Sicknesses like upset stomach or gas, headaches or fevers can be treated with these leaves. You would take the leaves break them apart and boil them to drink. For treating fever we have 'Raymond', there's a leaf called 'Lela', 'Dedo', there is 'Asosi', 'Le Marin', 'Coral', there's many other kind of leaves." Deuli describes the process with which he works with Gran Bwa. "The way I call the spirit is with first drinking

a little moonshine sometimes through my ear, shaking the Asson and smoking tobacco. When he arrives, he comes with all of his personal things, like his machete but also leaves and sticks. He's a loving spirit, and he likes everyone. He arrives smoking cigarettes two at a time, hopping from place to place, dancing. The only thing you have to worry about is not to get too close, because he likes waving his machete around." For Deuli the environment he inhabits has a great influence on the decisions his community makes to heal themselves. "Each year we gather around the big 'Mapou' tree where we throw a big celebration for Gran Bwa, we buy two gallons of cane spirit, many packs of cigarettes, then during the ceremony a goat is sacrificed that day, cooked and eaten for the celebration. This happens every year and bestows a collective healing onto the community.

The certainty of uncertainty

Louisa Bolch
Broadcaster, producer and
Clare Leadership Wellcome Fellow (2007)

Svengali – a distinctly 19th century creation who leapt out of the pages of George du Maurier's novel *Trilby* and into the cultural lexicon (along with a dashing hat) – isn't just an iconic portrayal of manipulation, evil intent and control: he, or at least the idea of him, may well come with us if we visit a hypnotherapist. Bridey Murphy may well come along too – she was the real life 50s housewife whose amateur hypnotist friend believed he'd taken her back past birth, to a former life as an Irish peasant living in the early 1800s, and published a book which sparked an international obsession with past life regression.

Anxieties of being unwillingly controlled by a – 'now I have you in my power' figure – or abruptly finding oneself aged 9 running through a field in a crinoline, might not bear much relation to reality but they are nonetheless expectations or fears that may come into the therapist's consulting room along with the patient, and have to be managed accordingly. It so happens that hypnosis makes the relationships between mind and body, and culture, expectation and medicine particularly transparent,

partly because the role of suggestibility in how the hypnotic experience occurs makes it particularly susceptible to cultural beliefs. But those relationships are always present and usually complex. Trace the historic trajectories of practices around childbirth, mental health, or care of the dying and this soon becomes apparent.

I have to admit that I don't really like the phrase 'medical humanities'. On first encounter, one could be forgiven for thinking – What is it? – What could it possibly mean? But despite its flat and rather stolid label, for me, it is an irresistible invitation to poke and provoke the historic and cultural matrices in which medicine operates. Certainly, as a fringe benefit it can also provide a wonderful window into history as it relates to those most intimate and relatable of things – the human mind and body. Past lives can be an erudite, and hugely enjoyable form of voyeurism and gossip and there are rollicking good stories to be found in the history of medicine. Often, what they also show is that certainty is a common desire and aim; but when viewed historically,



orthodoxy is something which starts to crumble.

Art, artefacts and ideas that enable us to see, and then chisel away to reveal the gaps between belief and practice, help keep medicine honest, because they force an acknowledgement that you can't take the humanity – messy, various, imperfect, extraordinary – out of medicine.

Across many aspects of human endeavour, the impact of our expectations can be almost inversely proportional to our awareness of their importance – whether it's the possibility of a 4 minute mile, or ideas about how members of demographic, gender or ethnic groups will behave (or not), achieve (or not). It's easy in a secular society to think that belief is no longer relevant, when our beliefs are as pervasive and influential as ever. We can't eradicate the feelings, beliefs, narratives and prejudices that influence clinicians, patients or policy. But we can seek to make them visible, question them; use our curiosity and understanding about experiences of the past or of other cultures to inform, influence, and change them.

Abundant life

Daniel Chua
Professor of Music and Head of the School
of Humanities, Hong Kong University

健康*



* WELLBEING

If, as TS Eliot states, culture is 'simply that which makes life worth living' then culture is the medicine of meaning without which medicine itself is meaningless. The eradication of pain and the prolongation of life are abstract values that might guide modern medical practice, but they hardly define what it means to be a human being let alone what makes life worth living. In fact, it reduces human wellbeing to a minimum of what humanity can be. It takes away the 'everything' that makes life worth living

and replaces it with the bare bones of existence. Medical humanities, in contrast, is about the *full*-being of a society; it is wellbeing at its most abundant.

What is this fullness of meaning? As with Chinese medicine, cultural wellbeing is preventive, providing a moral resilience that outlasts whatever ills might befall us. Like Western medicine, it is diagnostic; it performs a critical and analytical dissection of our present condition in search of a cure. But it is not simply

about resilience and critique. Cultural wellbeing is an artistic stance; it is always creative and so never gives up hope: it imagines possibilities for beauty even in the darkest moment.

It is not that we want artistic doctors or more cultured ones, but doctors who make life worth living. The humanities in medicine reminds us that medicine is a ministry of care – health-care. Medicine is not simply a profession but the very heartbeat of being human.

In search of a soul

Mark Jackson, Professor of the History of Medicine and Research Theme Leader for Medical Humanities, University of Exeter

At the age of twenty-six, several years earlier than expected, I experienced a midlife crisis. I had entered medicine at a turbulent time for the British profession. The National Health Service had recently been substantially re-organised, London medical schools were undergoing a controversial process of amalgamation and closure following the Flowers Report, and post-war confidence in the powers of modern Western medicine was being gradually eroded by concerns about the limits of medical intervention, the emergence and resurgence of fatal infectious diseases, the rising burden of mental illness, and the capacity for doctors on occasion to cause, as well as relieve, disease and suffering.

It would be a mistake to regard these professional and political circumstances as proximate causes of my own crisis. This can be traced more immediately to a constellation of personal dilemmas (that need not concern us) and a sense of intellectual and emotional frustration. Medical education had equipped me well for the challenge of addressing many of the biomechanical problems associated with conditions such as heart disease, cancer and arthritis. Conversely, my training had left me largely unable to alleviate pain and anxiety, to ease the trauma of death

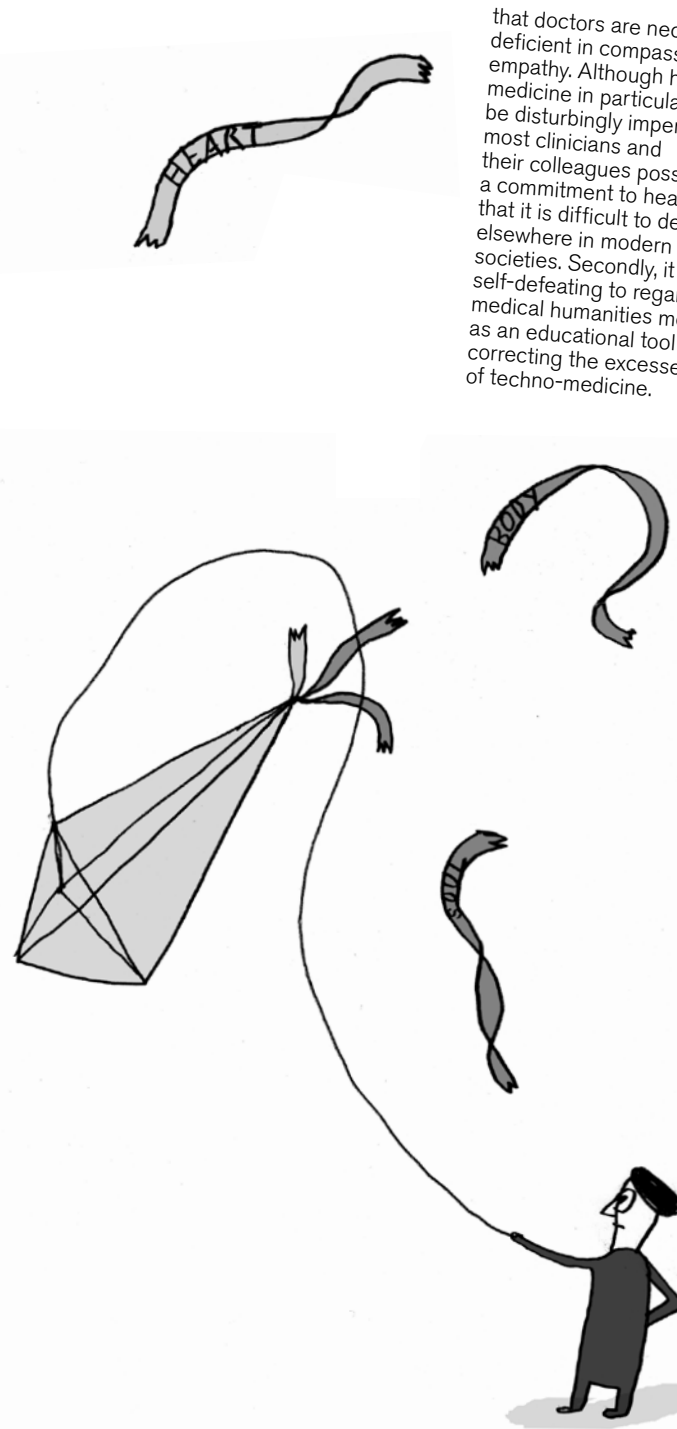
and bereavement, or to resolve the intractable social, political and economic problems that seemed often to determine individual and community patterns of illness and to shape welfare services. Believing that the socio-cultural dimensions of health and health-care deserved greater scholarly attention, and aided by research grants from the Wellcome Trust, I defected from medicine to the humanities.

Of course, my belief that medicine can and should do more than restore bodies and minds to mechanical stability or biochemical equilibrium was not new. Throughout the twentieth century, physicians (and indeed medical historians such as George Rosen) had been advocating more holistic and politically engaged approaches to health care. The biographical, psychosomatic and bio-psychosocial perspectives developed by Adolf Meyer, Helen Flanders Dunbar, Franz Alexander, John Ryle, James Halliday and George Engel were all based on a conviction that illness resulted from complex interactions between biological characteristics, psychological processes and social circumstances.

Although these approaches were often popular, at least for short periods of time and amongst particular political

and professional groups, their therapeutic potential has frequently been challenged by narrow definitions of scientific proof, marginalised by the dominance of techno-scientific models of disease, and diminished by a lack of resources. Yet, there is evidence that integrating the psychosocial and cultural insights provided by scholars in the humanities and social sciences with clinical practice can impact positively on health: psychological strategies for reducing anxiety before surgery can improve post-operative recovery; outdoor exercise in the 'blue' and 'green' gyms of the coast and countryside carries benefits for people with depression beyond those provided by indoor exercise regimes; monitoring and mitigating stressful life events can be used to predict illness onset and manage chronic disease; and knowledge of historical and cultural contingency has helped us re-evaluate practice and reshape policy.

Scholars in the medical humanities often claim that the primary purpose of their disciplines is to humanise medical students and doctors, who have supposedly been brutalised by exposure to bodies, disease and death. This argument is flawed. In the first instance, it is condescending to assume



that doctors are necessarily deficient in compassion or empathy. Although hospital medicine in particular can be disturbingly impersonal, most clinicians and their colleagues possess a commitment to healing that it is difficult to detect elsewhere in modern societies. Secondly, it is self-defeating to regard the medical humanities merely as an educational tool for correcting the excesses of techno-medicine.

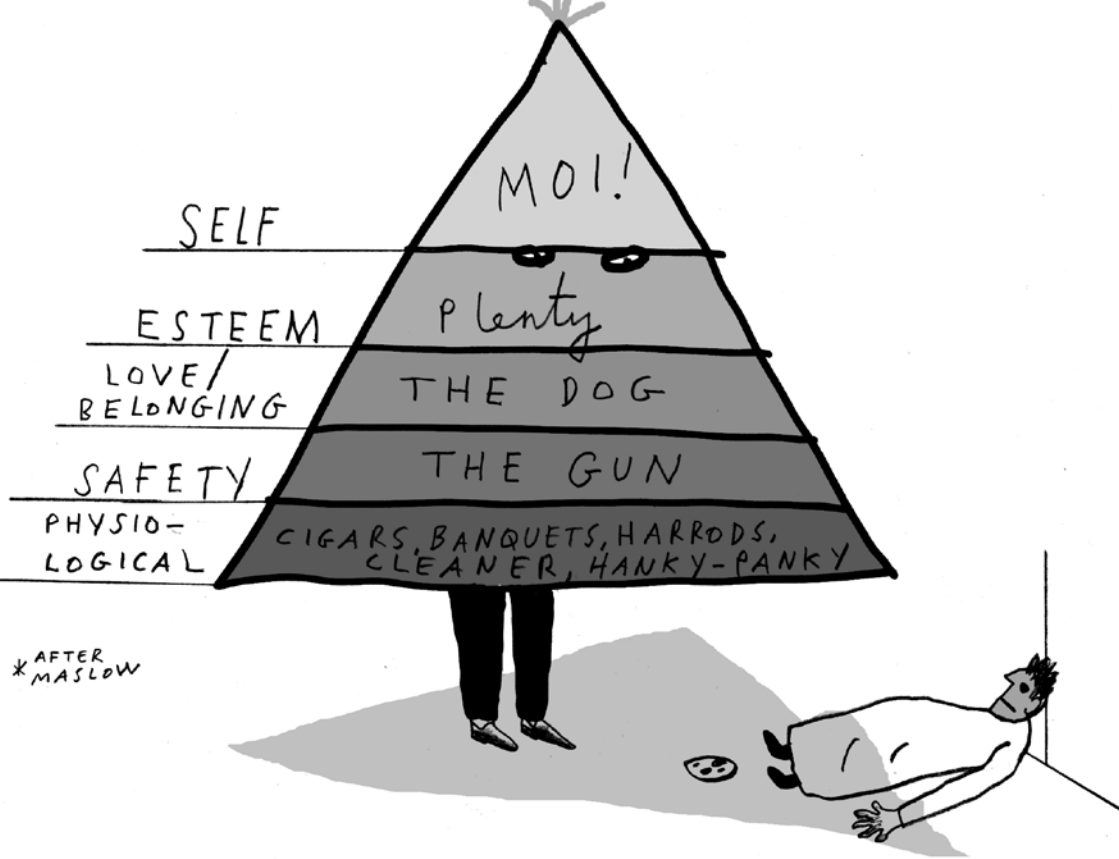
By helping us to understand, articulate and address the psychosocial determinants and experiential dimensions of disease, high-quality research in the humanities, arts and social sciences, no less than in the biosciences, should be integral to our quest for new research questions, new conceptual paradigms, and new forms of prevention and treatment.

In 1933, slightly earlier than Elliot Jacques' formal articulation of the concept of a midlife crisis, Carl Jung suggested that we should be more aware of the impact of life changes on physical and psychic health and of the value of embracing alternative pathways to fulfillment. In *Modern Man in Search of a Soul*, Jung argued that science offered only limited solutions to the physical demands, varying occupational and domestic tensions, shifting social expectations and deepening spiritual anxieties that can make us ill in middle age. Jung's insistence that we conceive and realise ourselves in psychological, social and cultural, rather than merely biological, terms reminds us of the importance of both constitution and context and of the need to mobilise all knowledge at our disposal to improve our lives. The significance of the medical humanities is this: that they furnish us with the personal, professional and political tools to reveal and resolve the multiple crises that can afflict us at any age.

We all crave a purpose

Matt Peacock
CEO Streetwise Opera

OPERA SNOB
Behavioral Pyramed*



For the last 20 years I have worked with people who have experienced homelessness, first as a volunteer in a nightshelter in London, then as a part-time support worker and now as the founder and director of Streetwise Opera. The charity runs music programmes and stages operas with members of society who have experienced homelessness.

Streetwise was born following a comment from a politician who said that, "The homeless are the people you step over when you come out of the Opera House". The people I work with want to change perceptions and show the public what they can achieve – if they are in an opera, they feel that it shows the public a different side of homeless people. As one of our performers once said to

me: "I feel I have a purpose, that I'm worth something".

Many people ask why we use the arts to help this group of people when what they need is food and shelter. In my experience, people need a lot more than that to survive. As our performer so eloquently put it, we all crave a purpose and to feel good about ourselves. Art does this – it rapidly shows people that they have a creative side; that they are considerably more than the sum of their problems. This grows self-esteem which often leads to people stepping over the barriers that have grown around them instead of being stepped over.

When I first saw Maslow's pyramid of the hierarchy of needs with physiological needs 'rated' as more

important than self-esteem and culture, I felt it didn't tell the whole story. It's easy to assume that those living in abject poverty are concerned much less with factors higher up the pyramid but I would challenge this. I recently worked in Brazil, scoping a possible future arts project. In São Paulo the situation on the streets is desperate, so it was with trepidation that I asked a group of men from a prominent homeless movement whether they thought the arts had a role in a place with much more fundamental needs. The leader of the movement looked me in the eye and said, "The arts are important because they give people dignity".

One could argue that since modern society needs to worry less about food, premature death and war,

We all crave a purpose Continued

we then worry about the next thing 'up the list' – personal aspirations, a need to fit in to society and to find a purpose. I have met so many people with close to nothing but they still have other concerns: we are all emotional beings.

I am not an academic – I am an activist and a passionate advocate for the ability of the arts to change how people feel about themselves and to alter the course of their lives. The danger is that Maslow implies that culture and the arts are luxuries we should only access when everything else is in place. This not only devalues the arts but suggests that feelings, needs and dreams are just that little bit less important than anything else.

I once heard a story of a desert that had a rain shower for the first time

in years. Plants in their thousands sprang to life having lain dormant under the sand. In 20 years working with homeless people, I come back to this analogy time and again as I see people come alive with a sprinkling of encouragement – someone believing that they have talents that are lying dormant. Yes their situation is desperate but often it is the arts and culture that is the catalyst that helps them make changes in their lives.

I often think of one of our performers who sat day after day in a homeless centre. The centre staff said that he wouldn't be interested in taking part in an arts project but he'd be no trouble. After a few months of visiting the centre and running singing workshops, he slowly showed signs of wanting

to take part – although he had just started singing, he was fragile due to many years of alcohol abuse. As we prepared for a big production, he didn't feel strong enough to perform on stage so he helped backstage. In the weeks leading up to the show, we let everyone know we had free tickets in case they had any friends or family who wanted to come. He took a few tickets but didn't look hopeful. We later found out that his two daughters came – he hadn't seen them in over 10 years and one of them brought her daughter, his granddaughter. That little girl met her grandfather for the first time at a moment he was doing something of which he was proud and was giving him purpose.

PHYSIO-LOGICAL
SAFETY
LOVE / BELONGING
ESTEEM
SELF

Sonnet 118

William Shakespeare
Playwright



From green gyms to green libraries: medical humanities and cultural environmentalism

Nick Groom
Professor of English Literature, University of Exeter

Just over a decade ago the Forestry Commission published a report on how woodlands can improve personal health and wellbeing. Recent medical research also suggests that there are real and sustainable benefits for mental as well as physical health in moving to or living in green spaces. The environment is, in other words, far more than a mesh of ecosystems and its significance and value goes far beyond what is material and quantifiable.

But even if we are at last beginning to include intangible value in our understanding of green issues, we still need to go further. Welcome as they are, what these reassessments of the countryside forget is that the environment is also – and, for many, predominantly – a cultural space. It is defined as much by literature, history, heritage, and folklore, often at a very local and distinctive level, as it is by ecology, environmental and biological science, and meteorology. The greening of medical research, while a salutary reminder that nature is good for us, therefore needs a strong cultural context because this is how people perceive and make sense of the green spaces they find so cheering.

Culture has its place in museums and the media, galleries and theatres, libraries and the classroom, but it also needs to rediscover its place working and living in the fields and woods and rivers that sustain us. If we can accomplish this, literature, art, and music; history, folklore, and tradition can become ways of ensuring a fuller and, crucially, an active engagement with the world, rather than a means of escaping from it. What we need to develop is a 'cultural environmentalism' to go hand-in-hand with the medical humanities.

Of course, the health benefits of getting out into the fresh air, walking in woods and meadows, escaping urban sprawl, have been celebrated in western literature from the earliest times. Indeed, this is how the popular idea of the idyllic countryside emerged: the pastoral and georgic literature of classical Rome being rediscovered and revived in the Renaissance, providing a homely pastoral and picturesque alternative to the horrors of civil war in the seventeenth-century, the mass-commercialization and colonialism of the eighteenth-century, the industrialization and imperialism of the nineteenth-century, and

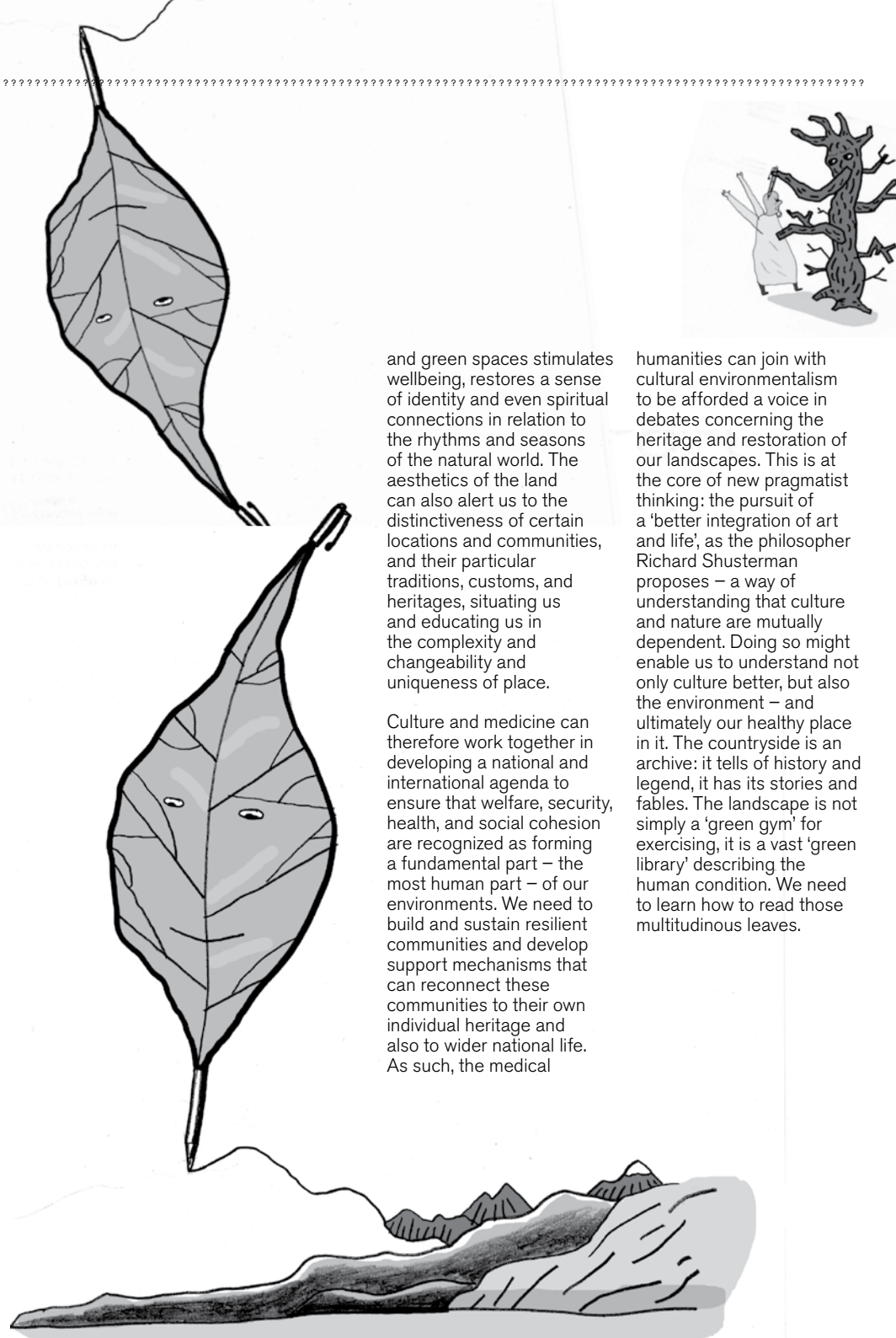
the wholesale destruction of the twentieth century. The pastoralization of the land certainly carried with it its own political and economic agenda in enclosing common land and forcing rural labourers into the growing cities, but it has nevertheless left us with a landscape of hedgerows and coppices, gardens and ponds, that seems indomitably English, whether described by Wordsworth or Housman, Orwell or Tolkien. Indeed, the passionate desire to preserve the landscapes that had inspired Wordsworth drove the whole concept of the National Parks and associated conservation legislation.

So the landscape and the values and expectations we attach to it are the result of at least five hundred years of cultural encoding – a mix of half-remembered poems and songs, birdcalls and trees, customs and proverbs, heritage and lore that creates powerful feelings of local attachment even to places we may never have visited before. Aesthetic qualities are nigh-on impossible to define, let alone quantify, but they are nevertheless deep influences on why many people visit and holiday and indeed live in the countryside: the engagement with the natural world

and green spaces stimulates wellbeing, restores a sense of identity and even spiritual connections in relation to the rhythms and seasons of the natural world. The aesthetics of the land can also alert us to the distinctiveness of certain locations and communities, and their particular traditions, customs, and heritages, situating us and educating us in the complexity and changeability and uniqueness of place.

Culture and medicine can therefore work together in developing a national and international agenda to ensure that welfare, security, health, and social cohesion are recognized as forming a fundamental part – the most human part – of our environments. We need to build and sustain resilient communities and develop support mechanisms that can reconnect these communities to their own individual heritage and also to wider national life. As such, the medical

humanities can join with cultural environmentalism to be afforded a voice in debates concerning the heritage and restoration of our landscapes. This is at the core of new pragmatist thinking: the pursuit of a 'better integration of art and life', as the philosopher Richard Shusterman proposes – a way of understanding that culture and nature are mutually dependent. Doing so might enable us to understand not only culture better, but also the environment – and ultimately our healthy place in it. The countryside is an archive: it tells of history and legend, it has its stories and fables. The landscape is not simply a 'green gym' for exercising, it is a vast 'green library' describing the human condition. We need to learn how to read those multitudinous leaves.



It really works!! For me!

Paul Boross
'The Pitch Doctor', author and business communication expert in media, music, stand-up comedy and television

The relationship between mind and body is one which philosophers and scientists have debated for millennia. Descartes famously saw us as observers of our own theatrics, some believe that there is an objective reality 'out there' that we are part of, and some believe that everything we experience is created by us. One of the competing theories of quantum physics, the von Neumann interpretation, holds that reality is created by the observer and therefore the only place where anything is 'real' is in our own consciousness.

Whether we think of the incantations of Mesmer, the power of beliefs instilled by stage hypnotists or the medical advice to take a walk in the countryside to alleviate depression, there is no doubt that the connection between mind and body goes beyond what we can comprehend, yet it has still been exploited throughout history.

I don't really understand how television broadcast works, nor the Internet, nor the internal combustion engine, even though I'm very happy to have such devices in my life and use them every day.

So, even if we don't really understand the relationship between mind and body,

should that prevent us from making use of what we can intuitively know, what we can figure out for ourselves, or even what we blindly and irrationally believe in?

If I believe that a mascot is lucky, does it help me to succeed in a business meeting because it's lucky, or because it gives me faith in myself? Does it really hold the power to alter the sequence of events, or is it like Dumbo's magic feather or Popeye's spinach? And perhaps most importantly, should I care?

Scientists often say that we should care. We shouldn't put our faith in miracle cures and the empty promises of fake gurus. We shouldn't believe in psychic mediums or fortune tellers, because they only take our money and offer false hope, or worse, fear. Yet, for many people, such gurus offer comfort.

I believe that both points of view have merit. If one person feels comforted by a Tarot reader's words, then that's good. But equally, shouldn't we make it clear that the psychic's gifts are nothing more than a parlour trick, to protect the countless people who receive no such comfort?

I AM
A QUANTUM BURGER,
THEREFORE I'M NOT
SURE WHAT I AM



And here we reach the central point that I want to make to you, dear reader.

Whether we consider the therapeutic benefits of fresh air, or the success brought by a childhood mascot, or the truths offered by a palm reader, these are all practices that work very well indeed for the person who is subject to the beliefs that make them work. To anyone else, they're ridiculous, unscientific, unproven. Con tricks peddled by charlatans.

So when you discover a new wonder-diet or find insightful truth in your daily horoscope, I want you to practice adding just two words to your claims of miraculous discoveries. "For me".

"I just tried a new diet I read about where I can eat anything I want as long as I stand on my head for half an hour a day. It really works!! For me."

"We create reality in our own minds, and so if we make it all up, why wouldn't we make good things happen? It really works! For me."

We may never understand the true nature of reality, because there is one variable which we can never exclude from our

experiments – the human observer. Scientists sometimes wonder why the universe just so happens to be perfectly balanced to support life on Earth, and other scientists answer, perhaps obviously, that if it wasn't, we wouldn't be here to ask the question.

We are inseparable – from the universe, and from each other.

Life didn't come with a user guide, so perhaps we are like video recorders trying to figure out how to program themselves, or cakes trying to figure out why cakes come in different flavours. Whether you believe in God, or some other higher power or ultimate creator, or unifying life force, perhaps we can never know all of the answers because we just can't step back far enough to see the questions.

All I know is that the mind is a powerful asset that can be mastered and exploited to have wide reaching effects and wonderful benefits both for me and for the people I live and work with. I know that exploiting just a tiny part of my mind's power, I can be more successful, and happier, and healthier. And I know all this because it is absolutely true. For me.

Different kinds of madness

Penny Woolcock
Writer, artist, film and opera director

Parents die, people we love don't love us back, we get ill, we lose our jobs, we feel lonely, miss planes, get shouted at by strangers, have problems with our children, have no children when we want them, people we trust betray us and so on and on. Good things happen too of course but that's another story.

Shit happens.

The question is whether we have the resilience to suffer these unfair inevitabilities and keep living and breathing.

I spent eight months ON THE STREETS making a film about homelessness. I met dozens of fragile people who were broken into little pieces and the slightest thing would set them careening off to self-destruction, howling uncontrollably. Everyone I spoke to had suffered hideous childhood abuse, mostly sexual or bizarrely brutal; one man who lay on the pavement with a hideously infected gangrenous foot yelling abuse at passersby had been routinely beaten and

forced to spend the night naked in a cold bath. A woman had been tied to her bed at twelve and repeatedly raped by her stepfather, his brother and their two friends. She still has their voices in her head. Cruelty and neglect had not equipped any of them for normal life. They were not able to get up every day, get dressed, go to work, be financially independent, resist addiction to drink or drugs and maintain relationships with other functional people. Most of us struggle but we bounce back. Some people can't because too many bad things happened to them when they were learning about the world, things that made no sense at the time and will never make any sense and keeping it together makes no sense either because what you have learnt is that however hard you try nothing you do makes any difference because you will get the punch anyway or be penetrated by some abusive bastard. And some people cannot unlearn that and they remain wailing forever like distraught toddlers. *Help me.*



Language matters, finding the right words for things. Calling people 'homeless' suggests that the solution is a roof over their heads. That is not their problem so that is not the solution.

I know a multiple killer. He feels no remorse. And he told me all about it and I sat there and listened because I didn't know what else to do and I have tried to understand why. This man was hideously bullied as a child for seven years. Nobody was kind to him and he confided in no one. Finally he retaliated and viciously broke a boy's arm. Now he was somebody. Those he had been afraid of were now afraid of him and he rampaged around stabbing and hurting people and that made him happy. So he carried on. And on. And on. He did not grow up with his brother or father but both of them are killers too – from the same social environment where violence is considered to be real.

I have learnt that severe abuse in childhood causes structural damage to the brain, preventing the formation of neural pathways between the

pre-frontal cortex, the thoughtful and inhibiting part of the brain and the amygdala, the primitive fight or flight 'lizard brain' that sits behind it. Nobody knows yet whether this damage can be repaired. Not everyone who is badly bullied becomes a killer, not every abused child becomes homeless – I have two friends who have survived magnificently – but in a brutal social context it is more likely.

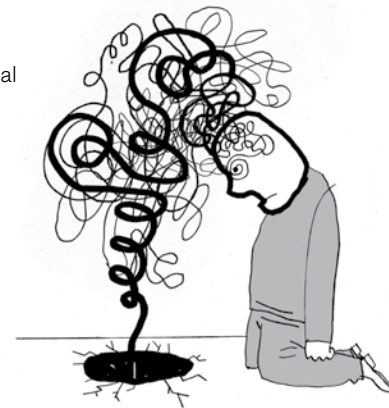
In my film journeys into inner city gangland, 1 DAY, ONE MILE AWAY and GOING TO THE DOGS, I have encountered countless young men with no self control, who stab and kill each other over imagined slights or post codes they don't own, who live criminal lives and smoke a lot of skunk, increasing their paranoia, and too many of them end up in the nuthouse too. This madness is avoidable.

Social exclusion is a political and social problem. At present our response is witless, even insane. We provide no mental health services for homeless people. We stick them in isolated bedsits without

support and are surprised when they pitch up on the streets again within months. We lock up inner city young men in vast numbers. And if a large black man is aggressive we send them to the Block with a bed nailed to the floor and administer the liquid cosh, a cocktail of psychotropic drugs that turns them into shuffling cretins.

I have a lovely friend who grew up in a loving family, has no financial problems and a long happy marriage to a husband who adores her. Shit happens to her too and sometimes when it does or even, terrifyingly, when it doesn't, she falls down the rabbit hole spiralling into crippling depressions that last for months.

Sometimes shit really does just happen.



A resource for reminiscence

Sue Howard
Director of Yorkshire Film Archive

Yorkshire Film Archive runs an ongoing programme of community events and screenings, but in recent years we've had countless enquiries, and a growing demand for content from healthcare professionals, older people's groups, networks and organisations looking for visually engaging resources to support some of the particular challenges of ageing – memory loss, poor communication, isolation, lack of sociability and sense of self identity. People were asking us for archive footage that had been curated and packaged so that it could be used as a resource for reminiscence work, and they wanted content that was meaningful, relevant, enjoyable, fun to watch – and to talk about.

With that in mind, in 2010, we began working with health care experts, carers and families to test how archive content could be packaged and presented for those purposes. That research resulted in our Memory Bank packs, containing carefully selected films based on familiar themes to promote shared memories of childhood, growing up, schooldays, holidays, loved ones and family, sense of place, home and work life.

Most of the films are non-fiction, and a large proportion of them are 'amateur' or 'home movie' collections, dating from the 1920's to the 1970's. The films show family life, local events, people, places, holidays – all familiar themes and scenes which we can recognise and identify with, and that will strike a familiar chord with anyone who has grown up in the UK during that period.

All the films have been drawn from the collections housed at the Yorkshire Film Archive, where the core of our work is about preservation of the original films, and transferring them to digital formats so that we can continue to provide access to these precious gems which hold so much rich information about life throughout the 20th century. Our whole ethos at the Archive is about opening up the collections for everyone to see, share and enjoy, and developing Memory Bank has been an important way for us to reach out to new audiences who might otherwise only have very limited opportunities to access our collections.

In addition to the films themselves, we were asked for further supporting material, and so we created

a complete resource package. Each Memory Bank pack comes with a wealth of additional material and information: a step by step User Guide about how to use it in different settings, notes to the films, suggestions for things to talk about, memory prompts, activities, songs, photographs and ideas for memory boxes. It also gives a comprehensive record of life over the decades – remember the swinging sixties, the advent of television, knitted bathing costumes, or how much we paid for a pint of milk in the 1950s?

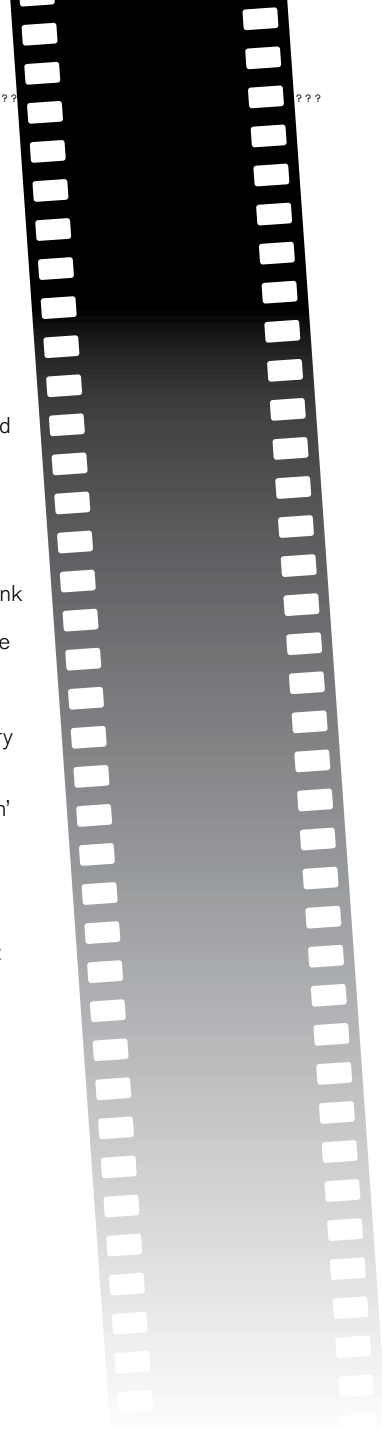
Watching Memory Bank films together, either at home, by a bedside, or in social or residential settings, is an easy, enjoyable and engaging thing to do. The films relate to people's lives, their knowledge, their memories, and so the conversations began to flow. This brings benefits for everyone – people watching the films begin to share their stories, and in turn new, sometimes surprising snippets of information about their lives are revealed to the people caring for them, helping them to see the whole person as they were, not just as they are now.

Family members, carers and activities organisers tell us that 'for people with dementia, the film footage can sometimes provide the key to unlock their world', and that Memory Bank gives them another way of getting to know people, and finding new things to talk about. Care staff tell us that one of the most important results of using Memory Bank is that it gives them the opportunity to learn more about people's lives. Talking about something like school days 'provides common ground and crosses age boundaries'. Another said that "older people have a wealth of knowledge and experience to share, and something like this helps bring it all back to life again" and that "using the packs definitely improves communication and encourages people to join in...it gets people to relate what they are seeing to their own experience, and to share those memories."

Currently we have six Memory Bank packs – Holidays, Schooldays, Working Life, Domestic Life, Sporting Fun, and Fetes, Fairs & Fireworks – and it is fantastic to see them being used so widely, in residential and day care settings, dementia cafes, hospitals and hospices, and at home.

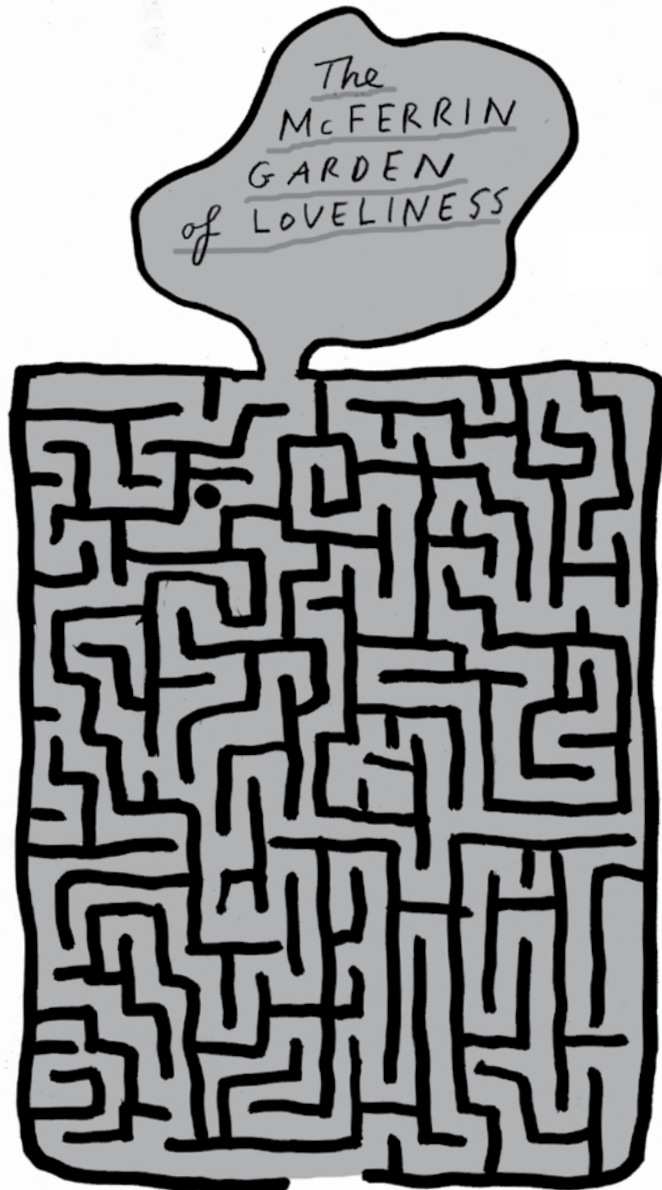
We've made the packs, and the films themselves, as versatile as possible – the DVD's can be projected onto larger screens, or simply shown on the TV, or you can download the films from our Memory Bank website to show them on laptops, tablets, and mobile devices – whatever works for you.

In November 2013 Memory Bank was awarded the 'Outstanding Dementia Care Product or Innovation' at the National Dementia Care Awards. We were delighted with the news and it has been a great incentive for everyone working on the project but the most rewarding thing is still hearing comments from people actually using Memory Bank: *"the memories are all there, you just need a trigger"*.



Don't worry, be happy (or the use of art in tricky places)

Rebecca Salter
Artist



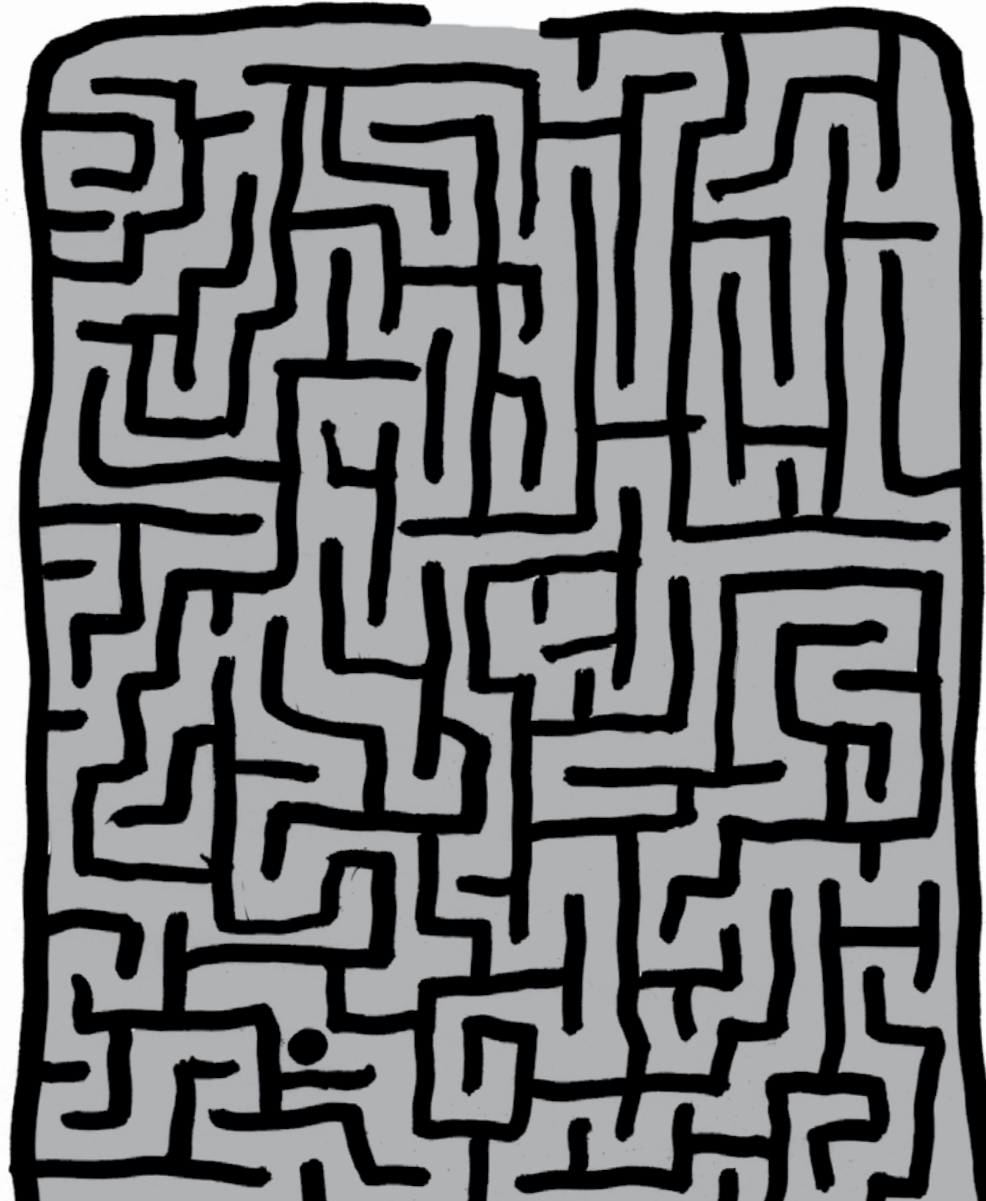
I imagine that in 2014 it would be hard to find anyone who would object strongly to the inclusion of art in the healthcare setting. The argument about improving the quality of the therapeutic environment has largely been won but I think there is still space for a more probing discussion as to the type of art used, how it is incorporated into the architecture and what it is expected to do. In inexperienced hands there is still a tendency to settle for what I call 'Don't Worry, Be Happy' hospital art. The hope seems to be that the whole complex emotional and physical business of going into hospital will be ameliorated by an encounter with a jolly piece of art, usually in bright primary colours. In some wards (children's, perhaps) this may be entirely appropriate but this process of choosing art so often fails to involve any in-depth reflection on the anxieties of visiting patients or the stresses faced by hospital staff. The hospital is the meeting place for the worlds of the well and the ill and it is that profoundly moving encounter which makes it so interesting for artists if they are given the freedom to engage properly.

In 2008 I was selected to work alongside the architects redesigning the main entrance to St George's Hospital, Tooting, a major London teaching hospital. The hospital is in fact the size of a small town (approximately 10,000 people go through the doors each day) and they wanted an entrance which better reflected the ethos of the hospital. Preliminary consultations with various interested parties revealed a real difficulty in trying to define an appropriate 'look' for a hospital entrance. The responses often hinted at a yearning for a bit of luxury (five star hotel reception, airport lounge or carpeted private hospital). This is understandable, but for many reasons (MRSA, maintenance and the attentions of the NHS mop) this was impractical and inappropriate. In the end, we decided that the standard of design, attention to detail and the qualities of the materials would subliminally communicate a message about the professionalism and competencies of the hospital that would inspire a feeling of confidence. But above all else, the entrance was designed to give the people who work there and the local community, a place of which they could feel proud.

Don't worry, be happy (or the use of art in tricky places) Continued

Vision

When an artist more used to the solitary activity of working in a studio becomes involved in a major commission, the challenge is how to communicate a personal artistic vision firstly to a design team and then to a wider public. The artist involved with any architectural project has to maintain the clarity of a singular artistic vision while taking account of problems encountered on the way. This is complicated enough in what could be termed a 'neutral' space such as an office building, but when the project is a hospital or religious building where the space is laden with meaning, then the task is even more daunting. The work of art is being asked to play a part in the process of transforming a 'space' into a 'place' which bears witness to some of life's most important and meaningful events. To imagine the St George's space, how it would be used and how it would be experienced, I made a series of brush and ink drawings with my eyes closed, the brush 'tracing' in ink the progress of a visitor through the space. The final appearance of the scheme was rooted in this simple exercise.



● = YOU ARE HERE

Wayfinding

This initial imaginative act with the brush also informed the fundamentally important role of wayfinding. As with so many hospitals which have grown in an ad hoc fashion, the approach to St George's was confusing. Wayfinding in public spaces and hospitals in particular is vital if the visit is not to spiral into confusion and irritation particularly for those arriving in a state of fear or anxiety. And good wayfinding is intuitive wayfinding. At St George's we used selected materials, colour and light to lead the visitor through a new garden, into the main entrance and along a corridor into the heart of the hospital. The inspiration came from the design concepts of Japanese gardens and architecture where subtle changes in texture or scale indicate points of departure, transition or arrival. Japanese architecture also stresses the importance of blurring the internal and external worlds, valuing the ambiguous nature of the liminal zone of the threshold. The new entrance at St George's plays host to the encounter between the worlds of the well and the ill and sets the stage for their ongoing relationship.

So, why is reading good for you?

Rick Rylance, Chief Executive, Arts and Humanities Research Council and Chair of Research Councils UK
Adam Zeman, Professor of Neurology, University of Exeter Medical School

The medical humanities come in diverse forms, as this volume illustrates. Our own interests are eclectic, from the history of the case history to explorations of the brain's mechanisms. We share an interest in the role of the imagination in how humans function and how they adapt (or mal-adapt) to their circumstances, sometimes transforming them. One of us (Rylance) is a humanist with a background in English and the history of psychology. The other (Zeman) is a clinical neurologist whose work focuses on disorders of memory and sleep. We are both committed to interdisciplinary explorations of the wonder of human cognition.

What follows describes a particular piece of research: Adam Zeman, Fraser Milton, Alicia Smith and Rick Rylance, 'By Heart: an fMRI study of brain activation by poetry and prose', *Journal of Consciousness Studies*, 20, 9-10 (2013), 132-58. We are interested in what happens in the brain when people read complex literary language. We asked volunteers with an expert background in literature (university staff or

postgraduates) to read chosen texts in an fMRI scanner. We also asked them to choose texts of their own which they found personally evocative (this was similar to experiments done by others on pieces of music).

The texts were in poetry and prose and were rated by us to be 'functional' (for example, the Highway Code), demanding at a middle level of 'literariness', and very demanding under the same criterion. The poems were all sonnets (Shakespeare or Wilfred Owen for example), and the prose passages, many from novels (Dickens, Lawrence Durrell, etc.), were cut to size. Practical considerations determined this. Readers need to keep their heads very still in an fMRI scanner, and in any case the task-specific duration of a 'clean' signal is around a minute. The brain is a busy beast, and soon multi-tracks its attention. We needed focus, and for this we needed short texts. The experiment required ethics committee approval.

The passages were read on a conventionally sized computer screen suspended above the reclining reader who wore thick ear

defenders against the pulsing noise. S/he controlled the transition from one passage to the next. The sequence of poetry and prose, and their different orders of difficulty, were randomly distributed. Afterwards, readers completed a qualitative questionnaire on their experiences including questions relating to such things as the emotional power of each passage and relative levels of literary difficulty. These were correlated with the findings from the scanner.

fMRI works by detecting small changes in oxygen levels related to changes in neuronal activation. It therefore tracks the networks of activity in the brain under stimulus from the reading. Much of the research on language and the brain has focused on small units (words or phrases) and not on larger ones. But larger units are crucial to the experience of literature, and are a reason why it carries greater emotional depth and sense of meaningfulness than more functional writing, we suppose. It is tempting to correlate this with the complex patterns of excitation observable from

the scanner. It has long been observed that language processing in the brain is a function of networked activity. But complex, literary writing evokes responses across a greater variety of those parts of the brain associated with, for example, visual as well as semantic functions, and personal memory. Its literariness may lie in its distributed variety.

Among our conclusions from this experiment are these: texts of every kind engaged the previously identified 'reading network', as we expected; more emotional passages activated a set of regions associated with the brain's response to emotionally-resonant music, reinforcing the thought that poetry's effects require the musical use of language; favourite poems, selected by our participants, strongly excited areas linked to memory, as if they were being recollected rather than read. These were our strongest findings. There were other, more tentative, but suggestive results. In particular, we were intrigued by a relationship we observed between the reading of poetry and activation of the brain's so-called 'default

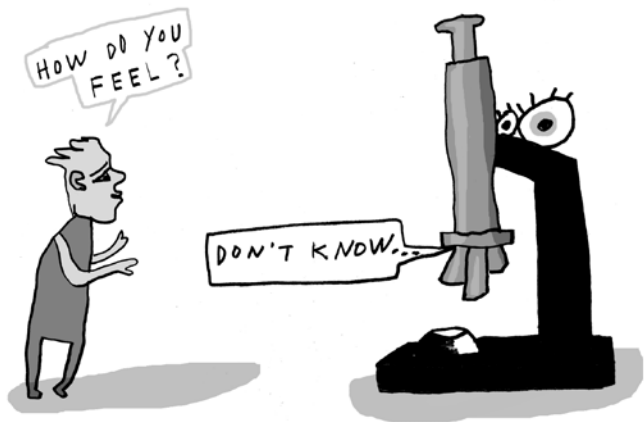
network', a set of areas that becomes especially active when external demands fall away. It is the supposed locus for autobiographical memory and daydreaming and may be one of the neural keys to our sense of personal identity.

It can be a habit of humanists to draw large inferences from slender data. We can only indicate fields of interest from this work that encourage investigation. Among them are these; in terms of clinical benefit, reading may help us recover a valuable sense of connection with our past selves when identity is threatened by, for example, trauma or dementia. For literary thinkers, there may be opportunity to develop a better sense of what establishes 'literariness', a powerful notion launched by Russian theorists a century ago and still potent. And, beyond these, there is the temptation of an old question: why is culture good for our wellbeing? Maybe it is because, through relationship with wide-ranging brain networks including the default, it substantiates our sense of self, enriches memory, and sustains our potential.



Medical what?

Roger Smith
Independent scholar, Moscow, Reader Emeritus in the History of Science, Lancaster University



As a description of a field of activity, created in the UK by the Wellcome Trust, the term 'medical humanities' describes money in search of a target. Both 'medicine' and 'the humanities' are umbrella words, descriptors of a huge range of things which share family resemblance but no more; it is, moreover, hard to say in what the resemblance consists. So also 'medical humanities'.

In previous decades, we have had medical sociology, medical history and medical ethics, each at least in part beginning in concern to furnish scientific medicine with a humanistic perspective, a perspective which will show medical knowledge and activity inter-woven with choices about ways to live – social,

historical and ethical. Each area received funds and became a specialist academic field. Now we have medical humanities, and we hear the claim that it is a response to ordinary people's interest in and knowledge of health and illness. Yet that interest and knowledge has always been there, especially in the lives of women as they have cared for others as well as themselves. Further, surely, few people, apart from a few ardent scientific materialists, have ever doubted the place in health and illness of the imagination, feelings of well-being and what people in many cultures would, unabashed, call the life of the spirit. There was and is a wealth of knowledge around the world. So why is there a new term?

Is the purpose of medical humanities to introduce a humane dimension into medical education; to serve as public relations for the vast industry of medical researchers (and administrators) and for the companies whose profits lie with commercialising what it is to be a person in material ways which can be calculated and manipulated; to redirect funds from academic specialities to 'the public'; or to serve as an administrative umbrella under which to fund

whatever local projects stimulate and suit local, particular purposes? Why is the chosen heading not, for instance, 'medical politics'? After all, for AIDS sufferers in South Africa, where a large factor is the spread of illness through the dislocation of young men from families, or for convicts in Russian prisons contracting TB, the need is not for new medical knowledge but for political solutions, changes in ways of life. (In Russia, where I live, let me add, 'medical humanities' is not a known term.)

Different conceptions and embodiments of health and illness, of suffering and healing, imply different understandings of what it is to be a person. Medical sociology, medical history and medical anthropology are crucial sources of knowledge about the relations between ways of life and conceptions – ethical as well as factual, spiritual as well as material – of being a person, that is, a human being in general and being this type of person, belonging to this group and having this individuality, in particular. We study these things in 'disciplines' in order to be rational and critical about our knowledge and practices and to imagine,

not fantasise, about alternatives. To my mind, therefore, if there is a meaningful notion of medical humanities, that is, a meaning of the term beyond its use as an administrative label, it is to describe the use of the resources of the humanities – philosophy, history, qualitative social science, the arts and so on – to question the view of what it is to be a person which medical practices presuppose and propagate. Such a view leads to particular questions. What, for example, does representation of a person's mental world as a function of the brain mean for ways of being human? Advocates say it will enable us to cure illness, such as Alzheimer's or depression, that is, through material knowledge, to increase control over our own lives (and deaths). Critics say it empties the world of its many levels of reality, and it hands over decisions about shaping a person and a life to agencies and companies which some don't trust.

If we live in a world which is as materialist natural scientists describe it, there is stuff moving, re-distributions of energy, or whatever, that's it. But of course we don't live in such a world, and even such scientists

themselves value truth, love their partners and thrill with a sense of injustice as Othello kills his wife. Whether you argue what we thus value comes from a god (religion), from the development of civilization (history), from the intrinsic character of conscious reflection itself (phenomenology), from social structure (sociology), or, as some scientists would say, from evolution (biology), the qualitative values are there, the stuff of living. For me, then, if there is any focus to the medical humanities, it is the large question mark attached to values in a medical world where materialist knowledge carries authority.

Perhaps such a focus doesn't have to be, and couldn't be, defined. Many of the things which go on under the heading of medical humanities, the seminars or the art works, for instance, are explorations of this question in particular, and, we trust, widely accessible terms. Through practice, necessarily particular, the hope is to find ways to shape life in which the values which people have or want, find a place in medicine. There is and could be no agreement about the scope of such activity.

Medicine's humanity?

Sam Guglani
Director and Curator, Medicine Unboxed and Consultant Clinical Oncologist

First off they're not ours, the humanities, they're not medical. Not medicine's. It brings to mind that pin-striped consultant (sharply in focus, the ward behind him a wash of activity) talking authoritatively about his nurses.

Not his.

Why do we insist on these ownerships? Primary care, secondary care, nurses, doctors, all of us battling it out in claims of owning the real patient, the beds, the budget, the challenges, the answers. Even diagnoses, owning then pathologising so much of human experience, to the extent of actually renaming that man in bed four, so he's now called 'an oesophageal carcinoma'. Or words, big words, like care, compassion, empathy and leadership, claimed, sentimentalised then squashed like ticks into boxes.

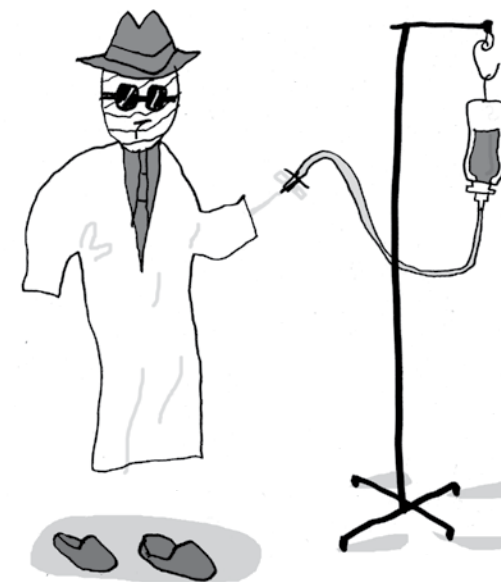
Not surprising then that the arts and the humanities become the 'medical humanities', or now the 'med hums'. Med Hums. We don't even hear it anymore, the word actually humming like blood in the heart of the concept: humanity.

Medicine's humanity – already so easily missed: human beings recoded into patients, into health professionals; the emotive, subjective and ambivalent elements of a medical encounter denied. This isn't just sentimental, look: the oesophageal carcinoma in bed four is, in fact, named Jack – he's thirty-five next week and was planning a big night out, he was held once by his mother, ran for the under-11s, doesn't like his job, wants children, is hungry, is in pain, can't swallow and now is terrified for the first time. Through medicine's filters it becomes hard to find him, and the consequences, as the newspapers tell us every morning, are profound.

Given the chance, what could we ask for the NHS? Funding, efficiencies, more staff? Or perhaps eyes and ears. Clear sight and hearing for all of us, to see and hear the person in front of us. It's what Linda Loman asks for her husband Willy, in Arthur Miller's *Death of a Salesman* – 'he's a human being, and a terrible thing is happening to him. So attention must be paid.'¹ When we do see the person in bed four, it's clear that, but for the thinnest line, we could be him. This kind of attention, as Ian McEwan

suggests, moves us to care: 'Imagining what it is like to be someone other than yourself is at the core of our humanity. It is the essence of compassion and the beginning of morality.'

Not just a hand-holding, post-Mid Staffs, newsworthy 'care', like icing attached to the real business of medicine, not that. But care that drives a health service. Care that insists we break into a sweat for our patients, that we push to navigate them through the labyrinthine and exhausting obstacle course of the NHS. Care that demands we have necessary and difficult conversations with each other and our patients. That makes it impossible for us to move with lassitude or avarice. That stops us from medicalising with blind momentum in the face of obvious human mortality. Care that moves us to push strategically and politically to develop better services and systems. That binds us to proceed ethically, justly and equitably for current and future patients. Ian McEwan's empathic 'imagination' is Arthur Miller's 'attention', propelling us utterly to see, to identify, to care and so to act.



We worry a little at the idea of empathy, hesitating at the possible hubris of claiming to know another's experience. But might empathy be a subtler thing? Might it be the stretch to hear and know versions of rage, longing, love, fear, hope and pride: notes in the voice of human experience? As nurses, physiotherapists, doctors, don't we need to hear these, as much as we hear and reiterate the clicks and tones of anatomy, pathology and pharmacology?

Where are these versions kept? – In the arts, in all of literature, in the humanities; T S Eliot said, 'we read many books because we cannot know enough people.'² The arts transcribe human experience and present the aspirations, questions and struggles of it against vast shores of

uncertainty, fear and wonder. They tell of our common and fragile humanity. They illuminate other perspectives, beyond the ones we have grown settled and accustomed to. They don't necessarily make us better people (there are enough examples of that). But then, of course, neither necessarily does science (ditto).

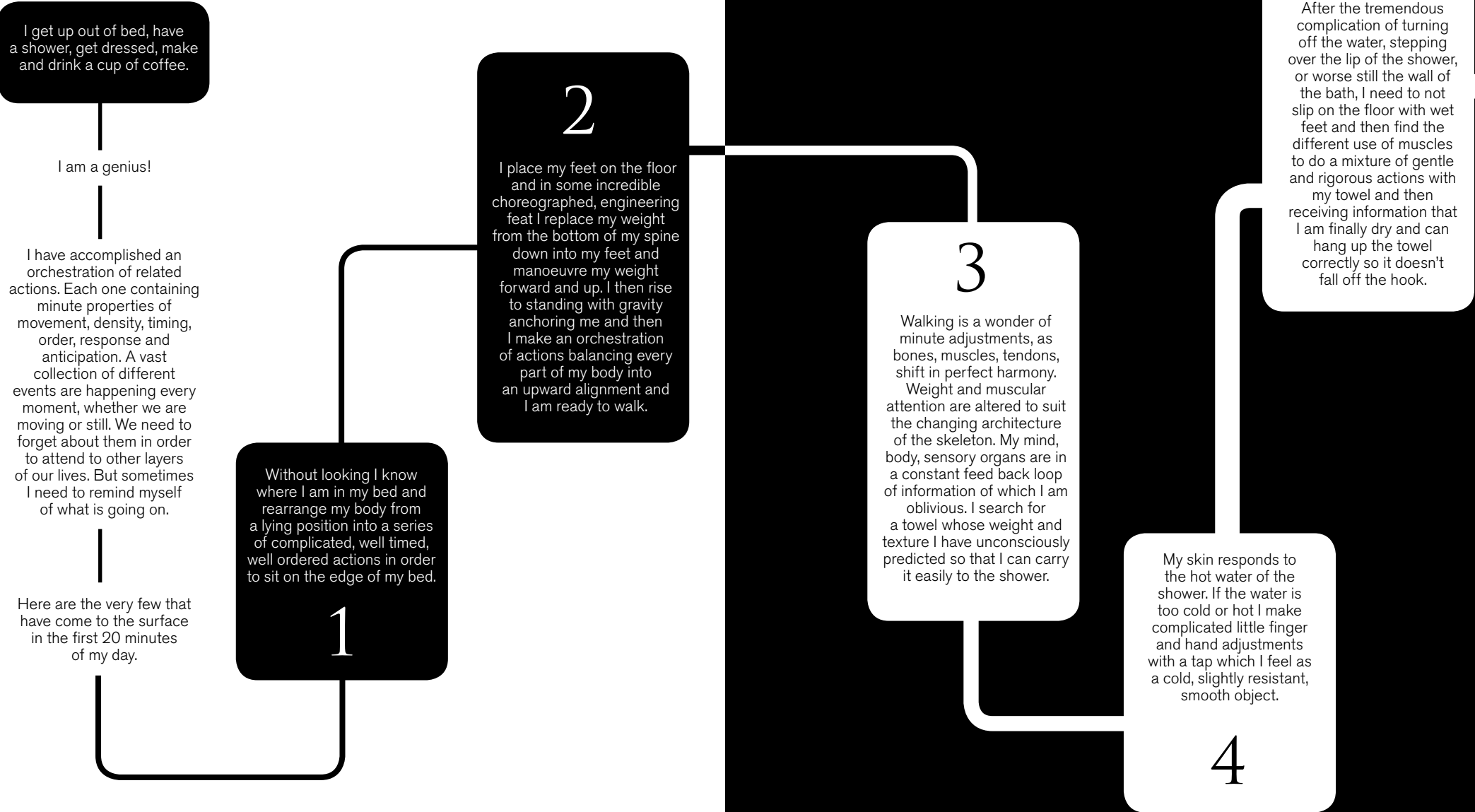
Medicine's frontier with the world, the point at which it steps from the page and the lab, is with human beings. This encounter is as much with person as it is with flesh. So, good medicine can only ever be partially realised through technical, rational or reductive paradigms. What's more, authentic encounters with our patients almost drive us to go on and practice medicine well, both technically and ethically.

In illuminating what it is to be a person, the arts contain the possibility to move us to better medicine. But they are not the medical arts, or the medical humanities. They surround and infuse medicine. They hold its experience. And they have necessary wisdom for us.

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Everyday wonders

Siobhan Davies
Artist, choreographer, Artistic Director, Siobhan Davies Dance



Everyday wonders Continued

6

I notice the texture of the cold floor changing to a warmer carpeted one and I get dressed. Having explained in a very minimal way the previous moves you can imagine my virtuosity when putting my clothes on.

7

By now I need the coffee and my pride in myself spills over as I notice that my hand reaches out the perfect distance to pick up a favourite mug. Its shape pleases me to look at and also how it feels. I sense its heft, the curve of it, its feel on my lips, I tip it just the right amount so the liquid enters my mouth. As I swallow, an extraordinary action in itself, I tip the mug more, I alter my understanding of the weight of the mug as the liquid leaves it and passes over my taste buds and pleasurablely down my throat. I can feel that I have satiated my need and place the, by now, differently weighted mug back down on the table without banging it or spilling the coffee.

I was a young woman when I heard a radio program in which different people were asked for a new Wonder of the World. A man offered the idea that the human act of standing was a Wonder. Hearing this has had an increasing impact on my life.

To begin with as a dancer and choreographer I committed myself to finding a complicated movement language, one that might deal with the virtuosity of the mind and one I could develop for use in performance. But as I have become older I work more with the image of the mind and body working on a constant feed back loop. I want to make movement that helps us to explore the relationship without one element being exaggerated to a degree which blinds our ability to see or explore the other.

I want to look at what we all know and frame that in such a way that we can be surprised.

After a recent performance of our company I overheard a member of our audience laugh delightedly as she said to her companion, "Oooh look what I am doing when I walk downstairs. Isn't it fantastic?". She quickly moved back to her pattern of unconscious movements but there was a glimmer of pride there.

She did not have to exaggerate anything. She simply recognised in herself something creative and quietly positive.



A conversation with a health economist

Tessa Peasgood
Health Economics and Decision Science, University of Sheffield

Where does it hurt?



Fred:
Do you use health or well-being to make recommendations about which health care interventions to fund?

Health Economist:
We use Health-Related Quality of Life

Fred:
Did you just make that up?

Health Economist:
Yes. It's those aspects of quality of life that are impacted upon by health and treatment – so it's physical and psychological functioning and maybe social functioning – but we can't seem to agree on that.

Fred:
You're not filling me with confidence here.

Health Economist:
Well in most cases health care interventions will be impacting upon health and we like to think that the impact on broader aspects of well-being, such as intimate relationships or spirituality, would be minimal. Also, because many more things influence well-being than health, our health care evaluations would need many more patients to be able to detect

a significant and meaningful improvement if we used well-being. So Health-Related Quality of Life is a pragmatic solution.

Fred: OK.

Health Economist:
And we collectively fund the NHS in part because we care more about inequality in health, than other inequalities. In other words, we might be happier to pay for improvements in everyone's health, than to pay for improvements in everyone's well-being.

Fred:
OK – so you sacrifice including information on some things that matter to people (well-being stuff) because it's just more practical. But won't your Health-Related Quality of Life measures capture the way health interventions impact on well-being (or Quality of Life if that's what you want to call it)?

Health Economist:
Well... they might. Our preferred measure is called the EQ-5D – it has 5 aspects of health (mobility, self-care, usual functioning, pain/discomfort and depression/anxiety), and 3 (or now 5) levels of severity

of problem. We generate a social value or tariff for each of these possible health states by asking a sample of the general public to choose between living in a particular EQ-5D health state for a certain amount of years or living a shorter time in full health. That way we have a kind of social preference for the health states, we can give a weight to changes in each of the dimensions and trade-off changes in the dimensions against years of life.

Fred:
Neat.

Health Economist:
Oh yes.

Fred:
But surely your social tariff weights would show us how these different aspects of health actually impact upon people's lives overall, not just their health?

Health Economist:
They might. The people we ask don't necessarily have any experience of these health states – it's just a preference they express. A few studies have found that when we compare these preference based tariffs to the actual impact the health states have on

people's well-being they differ. There is some indication that the physical functioning and pain states might not be as important and the mental health states might be more important than the preference based tariffs suggest. Also, when we ask people who are experiencing the health states to value that health state, we find their valuations are different to those given by the general public.

Fred:
Why?

Health Economist:
Maybe its because the public doesn't take into consideration people's ability to adapt to health states, particularly losses in physical health.

Fred:
And should they?

Health Economist:
Not if they want to value the presence of a capability (let's say being able to run) regardless of the impact it has on someone's happiness or their own view of their well-being.

Fred:
So you allow our preferences to override the impact of a health state on someone's well-being.

Health Economist:
Yes.

Fred:
Oh that's interesting. So do you have lots of evidence that shows that people know about how different aspects of health impact upon well-being but then choose to use different criteria when valuing health states?

Health Economist:
err not exactly...



Don't forget the flowers

Tom Andrews, co-Director of People United
John Ballatt, health and social care consultant

*Nay you remember our Emmie; you used to send her the flowers.
How she would smile at 'em, play with 'em, talk to 'em hours after hours!
They that can wander at will where the works of the Lord are reveal'd
Little guess what joy can be got from a cowslip out of the field;
Flowers to these 'spirits in prison' are all they can know of the spring,
They freshen and sweeten the wards like the waft of an angel's wing.*

EXCERPT FROM IN THE CHILDREN'S HOSPITAL
BY ALFRED LORD TENNYSON



A bunch of flowers in a vase. Nothing special, and, let's face it, like Tennyson's lines, easily dismissed as sentimental. But place them by the bed of someone frightened, hurting, displaced from familiar surroundings, 'not feeling themselves today'. Brought in to a hospital ward by a friend or loved one as a gift, they express, and stand for, all sorts of connections. Above all, they are a visual, sensory and living sign that the patient is a person, held in mind by another, the cherished object of tender feelings, sympathy, encouragement and concern. They express the continuity of such connection beyond visiting hours, and, above all, remind the patient that they are more than the sufferer in the bed, the object of strange and unpleasant investigations and treatments. When no one is around, they are a constant reminder that the patient is not alone. When only strangers and staff are there, they assert intimate and truly affectionate personal connectedness.

Flowers have been widely forbidden in hospitals for some time. Spurious risks of infection have been argued. In reality, working around vases, refreshing them, cleaning them, is just yet

more work for busy ward staff. The problem is that the more we can do for more and more patients thanks to the often awe-inspiring advances of medical science, the less space there is for the human. Not just for the flowers.

The problem is there for both patients and healthcare workers. Both clinical staff and the patients in the sites of frequent scandal, have been de-humanised, objectified and neglected. The sources of such neglect can be overtly malign or destructive, like bullying cultures, but the very scale, industrialization, technology, bureaucracy and routine of the enterprise can itself drive out the human.

In reality, effective healthcare depends on the humane, the compassionate, the mindful connection between staff and patients as much as on technical skill. Research and practice shows that staff working together in healthy 'kinship' groups, and meeting patients and their families with 'intelligent kindness' are more resilient, attentive and effective in their efforts. Patients who experience such care, in turn tend to trust, cooperate and benefit more from the work of the staff.

This 'argument for compassion' is now frequently made to promote change in the culture of healthcare organisations and the attitudes and behaviour of their staff. Too often, it is framed in checklist, demanding, even mistrustful ways. There is a danger that the solution becomes another part of the problem.

We believe that it is important not to leave out the human within healthcare and medical humanities. And we are exploring, with a number of hospitals and like-minded colleagues, how this might look in reality. As part of this we will work creatively and with the arts (in their broadest sense) to capture, assert and illuminate this human dimension. The arts can engage, delight, surprise, disrupt and challenge. They have a unique role in telling stories, allowing us to step into other people's shoes, challenging our prejudices and attitudes and helping us imagine a different future.

In time, we hope to paint a picture of what a 'kind system' might look like, to test out new approaches, and tell a story that speaks to patients, clinicians and managers.

Happiness – the case for re-infection

Tom Scanlon
Director of Public Health, Brighton and Hove City Council

Happiness is transmitted by contagion; something akin to a virus or prion: an organism not yet identified and one we may never discover. This is not an unusual situation: many of the great epidemiologists who described infectious disease – Panum and measles, Semelweis and puerperal fever, Snow and cholera – were operating in the dark, facing complex symptomatology with little concept of microbiology. This did not however deter them from shedding blinding light on the nature of infection. Nor indeed did it prevent them from taking action to improve health as John Snow demonstrated when he publicly shut off the Broad Street water pump in Soho – a gesture that has come to symbolise decisive public health.

So it is today; we find ourselves in a state of partial darkness. We may not have discovered the transmitting agent of happiness, but the epidemiology is compelling. Infection generally occurs early in childhood, and with little resistance, most of us grow up laughing and enjoying life. Then, as we reach middle age – occasionally sooner – our immune systems mature and we start to become resistant. We develop

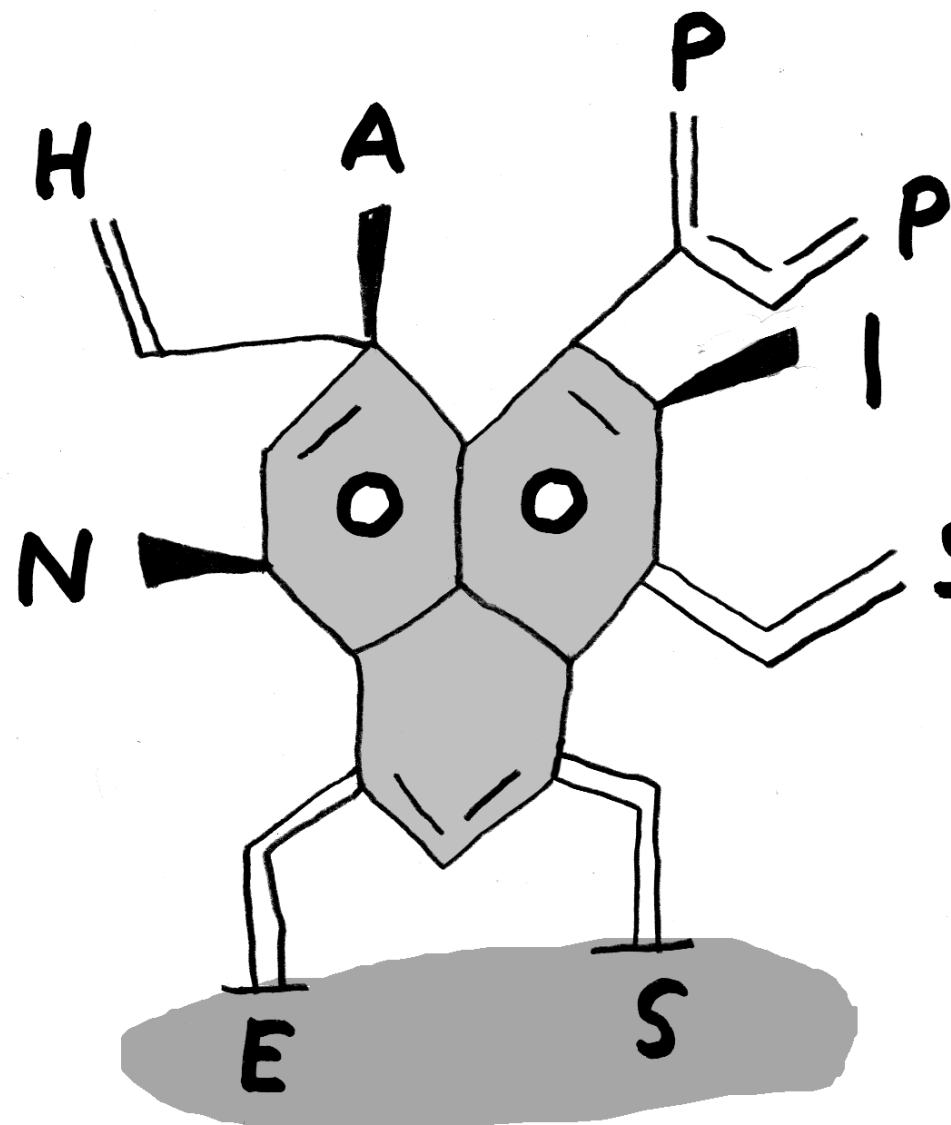
powerful antibodies: distrust, weariness and cynicism, which target happiness, and sometimes the immune response is so overwhelming that we arrive at a state of all-resilient pessimism, apparently impervious to re-infection.

This then was the task facing the Public Health team of Brighton & Hove City Council. In a city with longstanding high levels of population mental health need, we posed the question: just how happy are the people of Brighton & Hove? Furthermore, could we make them any happier? This was no frivolous endeavour. A considerable body of evidence, collated by the Harvard School of Public Health has detailed how the biological ‘wear and tear’ of negative emotions harms the body, and results in higher rates of stroke, heart disease, diabetes, mental illness and premature mortality. By contrast, optimism, a positive mood and community trust are associated with the converse, and with better lifestyle choices, which in turn foster a virtuous circle. Interventions that promote wellbeing, and tackle co-morbid states associated with unhappiness: such as unemployment, crime and marital breakdown, can improve happiness and

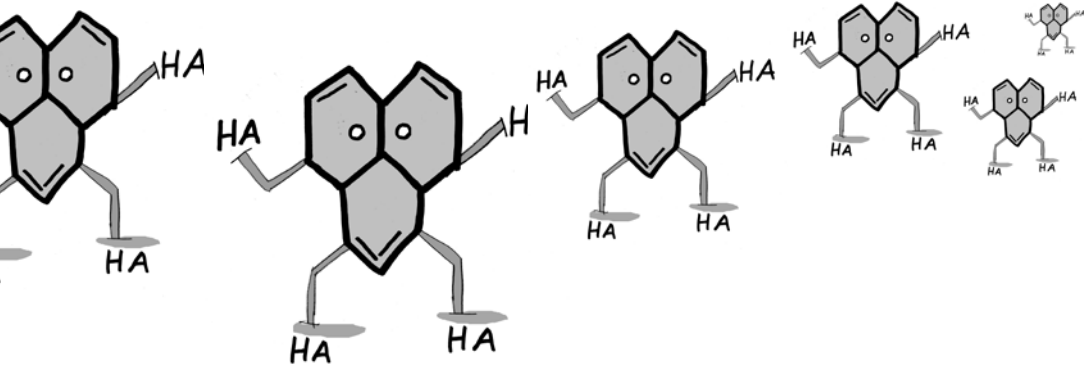
health. It may all seem a little circular but that is the nature of happiness; it is self-fulfilling and crucially it is democratic – we need others; we need herd susceptibility to the infecting agent.

So, in the 2012 Brighton & Hove Health and Wellbeing Survey we explored how satisfied residents were with life, how much they thought the things they did were worthwhile, how anxious and how happy they felt. Sub-analysis by age, gender, geography, affluence, ethnicity, sexuality and religion produced a city map of happiness. Further cross-tabulation explored the relationships between happiness and smoking, drug and alcohol use and sexual activity. The survey, fully described in the 2012/13 Report of the Director of Public Health, threw up some surprising results.

Men and women were equally susceptible, and although levels of happiness fell in middle age, they picked up again in early retirement – suggesting some re-infectivity – perhaps due to contact with young grandchildren. Poverty was toxic, and the affluent were happier than the poor. Heterosexuals were happiest among sexuality groupings, black



Happiness – the case for re-infection Continued



residents happiest among all ethnic groups, and Buddhists happiest among religious groups; Muslims scored significantly lower on all wellbeing measures. Tobacco, drugs and alcohol were associated with resistance, and people who used drugs or drank at high risk levels were unhappier than those who did not, as were smokers. Frequent sexual activity was associated with the acquisition of several viral and bacterial conditions, which in turn seemed to eradicate any happiness contagion as those who reported just one sexual partner in the previous year were much happier than those who reported several.

Of course, in ecological surveys there is no proof of causality, however, the

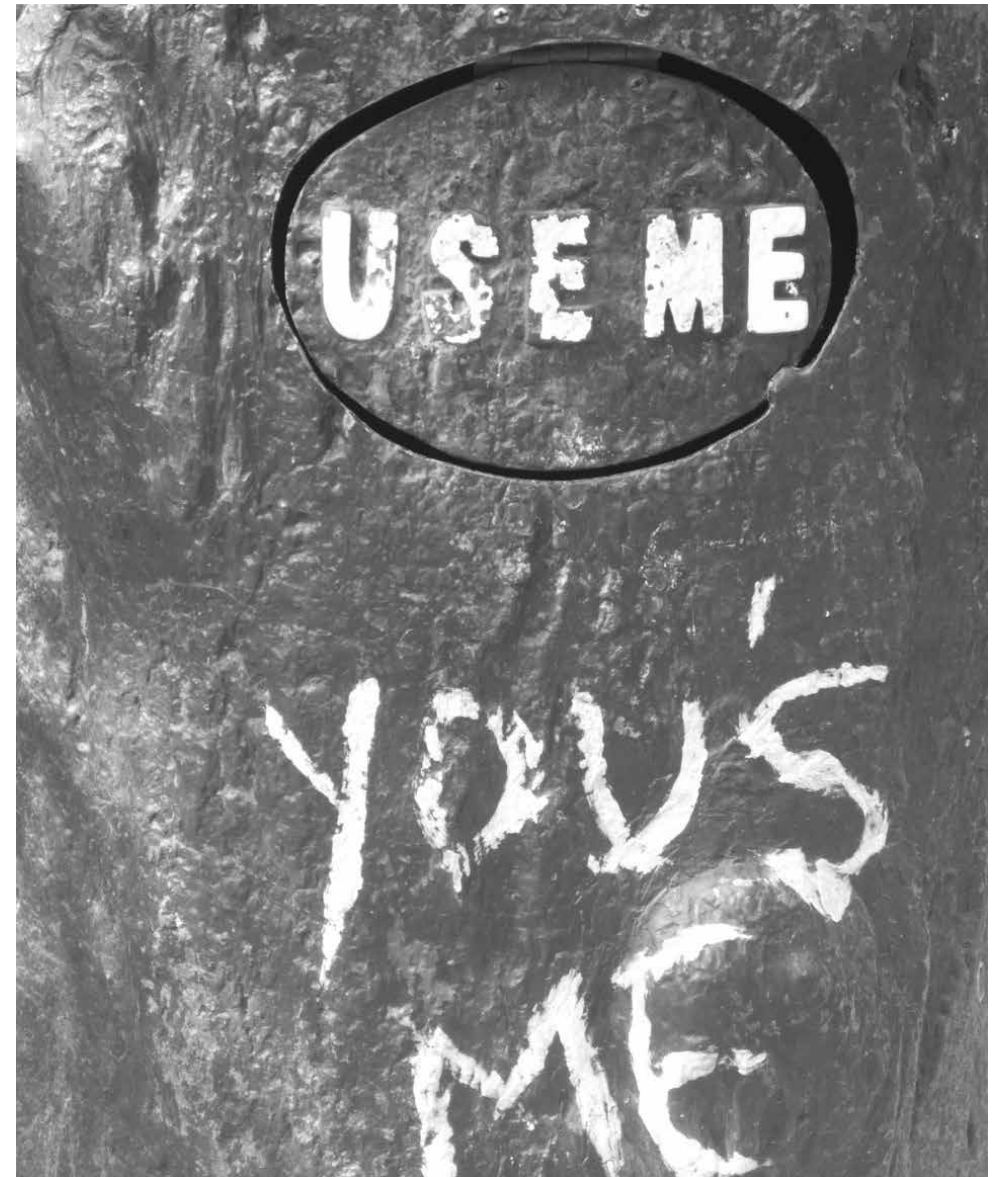
associations were often very significant. Hence, we adopted a Happiness Strategy led by the city's Director of Arts and Culture – the remedy is after all unlikely to be clinical – and we have appointed Happiness Champions across the city, including in the Police and Arts, and debated the concept with the Business Forum. A small grants scheme distributes funds to communities to promote the New Economics Foundation's 'Five Ways': Connect, Be active, Take notice, Keep learning and Give, with diverse initiatives ranging from food growing to singing, and a mental wellbeing arts festival programme 'SICK!', also supported by the Wellcome Trust, is in its second year. Happiness and mental

wellbeing are now key components of city strategies on housing, education, transport, and planning as well as commissioned programmes on tobacco, drug and alcohol and sexual health.

So while like our epidemiological forebears we grope around in darkness, we are intent on a state of enlightenment and, mirroring John Snow, we are turning on the tap of happiness contagion. Our approach is to marry science with art, evidence with conjecture, the physical with the metaphysical, and in doing so to make Brighton & Hove a happier – and consequently healthier – place.

A lost and found poem

Astrid Alben
Poet and Creative Director of PARS arts and sciences initiative



Museums: tonic for the soul

Yasmin Khan
Curator and writer

It has long been said that the arts nourish the soul; fuelling our imagination and quenching our curiosity whilst nurturing a sense of belonging and interconnectedness in our world. Museums, usually side-lined as cultural heritage, can embody these attributes too. Yet the existential value of museums is often overlooked. We undermine their capability if we seek to define museums as secular temples of knowledge for the modern age. Museums today transcend their origins as repositories for showcasing objects; now the object back-story is the lynchpin, empowering museums to function as cerebral gyms that can stir our moods and exercise our emotions. Museums have become a communal sanctuary for us to reflect on the big questions such as: 'Who are we?', 'What's out there?' and 'Where did we come from?'.

A well-designed exhibit can be a springboard for a numinous moment that can endure in our memories for years. So it is not surprising that museum objects are now being used as a tool to rehabilitate impaired memory function of those suffering from dementia. Could museums do more to investigate the relationship between physical, mental,



emotional and spiritual wellbeing in their displays? The growth of diverse cultures in our national community ought to give the impetus to explore the intersectionalities between our hybrid identities through more ground-breaking programmes and displays. An enduring challenge is how to frame the contextual significance of objects. Seyyid Hossein Nasr, a historian of Islamic science, laments the profound psychological effects of 'cultural dislocation' manifest in museological representations:

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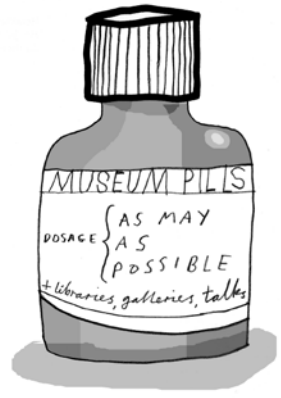
Do not think that a science museum is simply neutral in its cultural impact. It has a tremendous impact upon those who go into it. If you go into a building in which one room is full of dinosaurs, the next room is full of wires, and the third is full of trains, you are going to have a segmented view of knowledge which is going to have a deep effect upon the young person who goes there, who has been taught about Tauhid, about Unity, about the Unity of knowledge. About the Unity of God, the Unity of the universe. There is going to be a dichotomy created in him. You must be able to integrate knowledge.

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Paradoxically, if museums have contributed to the fracturing of our mind-sets, they can also be a source for restitution. Initiatives like the Happy Museum project are paving the way to reimagine the purpose of museums and cement the linkage between wellbeing and environmental sustainability.

We are leaning back towards more holistic frameworks of healthcare that encompass all the different facets of our daily life. The movement towards 'wellbeing' and 'social justice' in museums, can be paralleled with the evolution of hospitals; one of the earliest known hospitals was built in Damascus in 706 CE, becoming a model for more advanced hospitals that emerged later in Baghdad and Cairo. By the 12th Century these sophisticated hospitals were multidimensional in outlook – not just dispensing medicines and treatments but also considering the aesthetics in all its aspects, as documented in 1950 by philosopher and historian, Will Durant.



“

Within a spacious quadrangular enclosure four buildings rose around a courtyard adorned with arcades and cooled with fountains and brooks. There were separate wards for diverse diseases and for convalescents; laboratories, a dispensary, out-patient clinics, diet kitchens, baths, a library, a chapel, a lecture hall, and particularly pleasant accommodations for the insane. Treatment was given gratis to men and women, rich and poor, slave and free; and a sum of money was disbursed to each convalescent on his departure, so that he need not at once return to work. The sleepless were provided with soft music, professional story-tellers, and perhaps books of history.

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Nowadays, our national hospitals routinely exhibit art work in situ as part of a 360-degree therapeutic package for in-patients. On the flipside, as public health is becoming more decentralised in the UK, NHS primary care services are starting to trial 'museums on prescription' referral schemes.

Of course, museums cannot be the panacea to all our mental ailments – perhaps they are at best, a much-needed pressure valve for our society? But we should not underestimate the ability for museums to play a more active role in healing. We must tap the further potential for museums to be a tonic for the soul.



The power of the written word word word word word word word word word word word word word word word word

Callie Clapp
Clinical social worker and writer

Cancer can be insidious. It creates despair and self-doubt. You can't help but think: Why me? Will I die? How will my children and husband cope? These questions creep into your mind and can be as dangerous as the rapidly multiplying cancer cells. Despite the ever-present message to think positively, it's hard. I know. I am a clinical social worker and a woman living with breast cancer—a breast cancer that doesn't want to stay away.

I was first diagnosed with breast cancer in 2011. The process, from detection to treatment, took a month. Meeting doctors, taking tests, talking to family, helping our kids understand the process and course of treatment became a second job. Once we had a medical treatment plan, though, it was time for me to take a more active role in my healing. I started asking my doctors, what else can I be doing? How can I be a part of the team? Some of the answers were obvious: sleep, eat a cancer fighting diet, exercise and seek support. Sleep, diet and exercise were easier to do than seeking support. It's embarrassing to admit because of my vocation, but I'm excellent at giving help—I'm not good at asking for it. But this time I needed

it and, ironically, I wasn't sure how to do it.

I knew I was sick, but I didn't want to act sick. My clinical life has centered on promoting wellness and health and helping folks find empowerment within their own lives, yet trying to implement it personally was daunting. I have the good fortune of having an amazing support network of women. These women emphasized and reminded me that I needed to turn my considerable powers of healing inward. They gave me inspirational books by Pema Chodron. They became part of my team of 'chemo buddies' who accompanied me to infusion and made me laugh so hard the nurses would ask us to quiet down. The support didn't end there though because I chose to write.

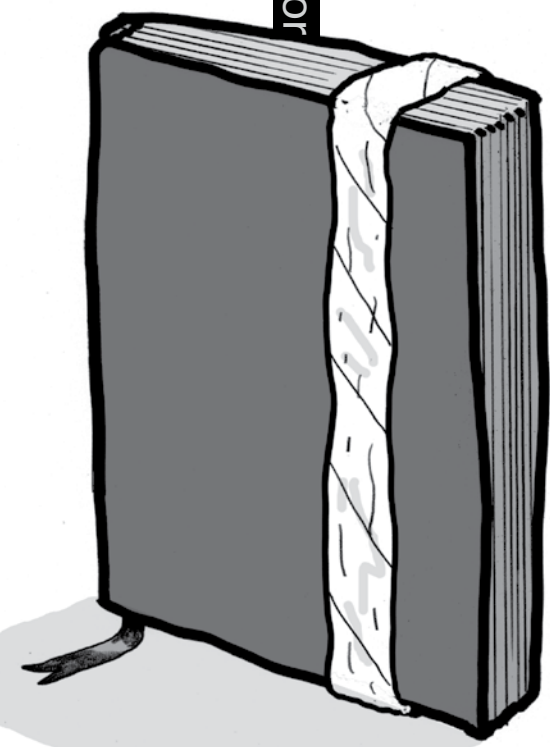
Novels have always played an important role in my life. For years I have turned to Jane Austen's books for inspiration and a good laugh. I have even kept a journal periodically to make note of my children's developmental milestones or vacations. But I did not understand the emotional power of the written word and its ability to heal until I began writing a blog on the website CaringBridge.org. I began using the website so that

family and friends from away could follow my progress and not have to call. These calls in which my husband and I talked repeatedly to others about my disease and its treatment were hard for my kids to hear. So...I began to write. Initially I wrote about being diagnosed and the treatment plan we chose. But each blog entry took me farther away from this original intent. I began to write about the fragility of life and the despair of physical pain. I wrote about the absurdly funny situations in which I would find myself: like having to buy a prosthetic breast or traveling in elevators at The Dana Farber Institute with tubes sticking out of my chest. The writing became less informational for others and more transformational for me. Cancer took so many things away. Writing gave me a voice and the blog gave me the platform in which to express it. The blog became the place where I could process, take stock and make note of how hard the journey was and how far I had come. I shouldn't have been surprised by how powerful this tool became, but I was. Writing made me action oriented—I stopped waiting for healing to happen to me and took responsibility back into my own hands.

The responses people wrote to me were even more surprising and meaningful. My CaringBridge.org blog became its own entity. As soon as I posted an entry, readers— even people I hadn't met—wrote back to me. They inspired me. They bore witness to my pain, accepted it and sent it back to me in lovely wrapped packages of acceptance, understanding and empathy. I can't emphasize enough the power this means of communication offered me. CaringBridge.org's smart phone app was particularly helpful. Each time I wrote an entry, within minutes dozens of people would respond: encouraging me and virtually connecting with me. I literally carried my support network in my back pocket. When I needed it, I could pull out my phone, read the comments, feel lifted up, transported and loved.

Writing taught me I was capable of transcending cancer beyond pain, worry and hopelessness. It connected me to my loved ones and gave me the gift of inspiration and support. It made me part of my own treatment team but, more importantly, it helped me bridge the difference between surviving cancer and living beyond it.

word word word word word



words Writing helps people to heal words words words words words words words words words words words words words words words

Ainsley Clapp, aged 12

Sadness grips me like a rope as the tears drip down my pain-stricken face,

I squeeze my brother's hand

We share the worry that the shadow of death may linger behind her

Many a time I hide in my room or bathroom and the tears come unexpected or not

They hit like a tittle wave of despair

I stagger back to regain myself and get up

At times it's hard, even harder to put on a happy face

I grope in the darkness of depression

And try to find the happiness I once always had

Weeks pass like the pages of my book being read

And a change happens not emotional but physical and visual

As I see the picture, sadness strikes like an angry cobra consuming me in a whirl of questions,

Why her?

Why my family?

Why did this happen?

This change will take some getting used to

This is bad change unwanted and different

She's at the hospital

Grandparents here

She's at the hospital; I was told I couldn't come

Worry holding me in a grieving embrace

They take us out trying to force the joy to take the worry away

Worry wins that battle

She's back from the hospital we put on smiles for her sake

She's uneven

That large scar

Painful to look at

I cringe from this difference and the pain it must be causing her

Like tightening zipper

I silently scream for this to all go away

Time passes, the books being read

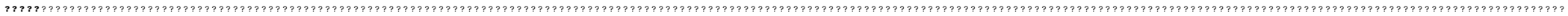
I try to ignore it but the daily check ups are constant reminders said so casually

Despair squeezes through a happy time as I realize this is my crutch

My secret excuse for everything

My own reason to duck out: shy away from new things

But what I need to do is let go of that crutch



Not merely the absence of disease

Nils Fietje and Claudia Stein
Division of Information, Evidence, Research and Innovation,
World Health Organisation

The World Health Organization (WHO) isn't known for being lyrical. We doubt anyone who reads our contribution to this book will be surprised to find that it's not a poem or a fairy-tale. Guidelines, statistics, and health-related evidence are what WHO is known for. The mere fact that WHO is represented in this book at all could well raise an eyebrow or two. And yet, the medical humanities (if not lyricism) are central to the work of the Organization.

WHO was founded in the post-Second World War global public health vacuum, which had been inadequately filled by several international and regional health and sanitary organizations whose mandates were all limited in 'space, time or function'.¹ The Organization was formally established on 7 April, 1948 when its Constitution was ratified

by its Member States. Enshrined in this Constitution is WHO's definition of health, which, even if it might not be exactly lyrical, has nevertheless often been praised for its visionary inclusiveness.

WHO defines health as 'a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity'. It's a short, but powerful statement, one that has often been quoted, certainly within the public health sphere. But it didn't originate with public health experts, or epidemiologists, or even doctors or other health care professionals. Instead, the sentence can be traced back to the work of the pioneering medical historian Henry Siegerist, who wrote in 1941 that "health is not simply the absence of disease; it is something positive [...] A healthy

individual [...] is well balanced bodily and mentally, and well-adjusted to his physical and social environment".²

If Siegerist were alive today (or conversely, if the Wellcome Trust's Humanities and Social Science programme had been around then), he would probably have drawn his funding from the Trust. As an individual who worked tirelessly to situate medicine "in a matrix that is at once historical, social, political, economic, and cultural"³, he became not only a founding father of the study of history of medicine, but also one of the distant pioneers in medical humanities.

The definition of health from WHO's constitution is so recognizable to anyone who is interested in medical humanities precisely because it was inspired by a medical

humanities thinker. Of course, like any unifying definition of a complex topic, it has also proven to be problematic. Critics have claimed, for instance, that it is aspirational, rather than operational. But as such, it fulfils an important role in periodically reminding us that health cannot simply be the pursuit of a disease-focused, vertical model; that it is instead a complex, integrated, often conflicting and always subjective experience that defies the mere collecting of mortality data or the articulation of nutritional guidelines.

Over the past decades, the emphasis in global public health has begun to shift from looking purely at pathogens and risk factors, towards a more holistic understanding of health and well-being. This new values-based public health approach, which advocates people-centred health systems, which promotes health throughout the

- 1 Development and Constitution of the WHO. Chronicle of the World Health Organization. 1947;1:1.
- 2 Siegerist HR. Medicine and human welfare. New Haven: Yale University Press; 1941:54.
- 3 Gregg A, Henry E. Siegerist: his impact on American medicine. Bull Hist Med. 1948;22:32.

life-course and which strives to achieve equity and health for all, is putting the full complexity of the human experience squarely in the centre of its focus. Many of the activities within WHO, whether they have to do with the Healthy Cities programme or our work on tackling social determinants of health, acknowledge the multi-dimensionality of health. That is why WHO has much to gain from medical humanities research and insights.

This is particularly evident in WHO's new European health policy framework, Health 2020. The framework, which is putting citizens at its centre, has taken a proactive stance on well-being, having made the enhancement of well-being one of its six overarching targets. Of course, if well-being is to be improved, it must be measured. Since it must be measured, it must be defined. And now that

WHO has defined it, and Member States have even agreed on the necessary indicators, we will need to find a way for that definition to make sense on a social as well as a personal level, objectively, as well as subjectively, across a WHO European Region that, from Iceland to the Russian Federation and Kyrgyzstan, has enormous cultural diversity.

The cultural determinants of well-being are still relatively uncharted. Mapping them will no doubt present a substantial challenge. Health 2020 is a formidable start and has put the European Region on the right trajectory, but we also recognize that this is only the beginning of a difficult and immensely worthwhile journey. It's a journey on which we will be looking towards some of the most promising and innovative work from the medical humanities to help us along the way.

Hearing voices

Angela Woods and Charles Fernyhough
Hearing Voices Project, Durham University

Hearing a voice no-one else can hear. Hearing the voice of your partner of fifty years, six months after they have died. Hearing a constant commentary on your every action. Hearing the voice of an abuser, decades after the trauma happened. Hearing God speak to you in your hour of darkness.

What's normal?

Our project Hearing the Voice begins by bracketing assumptions: about what counts as a 'hallucination', about the status of auditory hallucinations as 'symptoms', and about the rights and wrongs – conceptual as well as ethical – of distinctions between 'normal' and 'pathological' forms of voice-hearing.

Our touchstones instead are the 'what is it like' questions. Hearing voices is, above all else, an experience – something that registers in an individual's (consciousness of) body, self and world. We know that up to thirteen per cent of us will hear voices at some point during our lives and that there are fascinating connections with the inner speech and inner hearing of the everyday. And yet auditory verbal hallucinations are commonly regarded as the signature symptom of psychosis, poorly understood and horribly stigmatised.

Scholars and practitioners in the clinical disciplines are deeply invested in delineating the aberrant, diseased, dysfunctional or distressing from what we might call 'normal'. We believe that it's precisely by taking seriously the diversity of voice-hearing experiences – now and in the past – that we can move forward in supporting people for whom voices are distressing and who find themselves in clinical care. Stigma, secrecy and shame may be part of many voice-hearers' reality but there are powerful ways to make sense of and explore these experiences—not as something inherently pathological and frightening but as a meaningful and potentially even valuable part of what makes us human.

How, then, should you set about investigating voice-hearing? What would a medical humanities approach to the study of inner experience look and feel like?

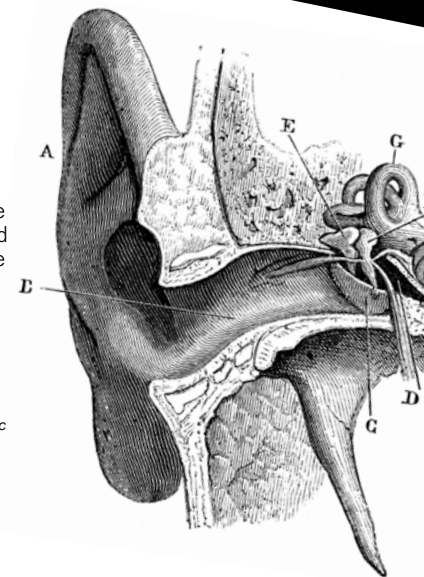
The short answer is: exciting, risky and highly interdisciplinary. Our project

harnesses a whole range of methodologies – from the study of modernist literature to in-depth qualitative interviews with voice-hearers to studies in transcranial direct-current stimulation. And through processes of critical reflection, cross-fertilization and collaboration, Hearing the Voice seeks to develop these methodologies in new and creative ways. For example, we've run experimental design hackathons in which members of our Voice Club sit down to hunt out new scientific protocols, drawing on the techniques of philosophical phenomenology to develop new tools for the empirical investigation of experience, using approaches from the visual and performance arts to facilitate conversations among researchers, bringing our team together in regular, intensive research meetings which allow those conversations to flourish and – crucially – to be sustained over time.

While there are many styles and flavours of interdisciplinary research, for us there is something distinctive about situating our work in the medical humanities: the people. From the earliest stages of project design to our most ambitious plans for making a difference, we've listened to, learned from, collaborated with and endeavoured to empower people who hear voices. "Your project is certainly of interest to voice-hearers, but how will it be of benefit?" That question was posed to us by Jacqui Dillon, Chair of England's Hearing Voices Network, and it is one to which we keep returning. It's not that we insist that all research must be immediately applicable, instrumental, or operationalisable.

But Jacqui's question is a reminder that working in the medical humanities gives us the opportunity and the incentive to dismantle what's left of the walls of the ivory tower and engage with people whose lives, experiences and values lie beyond it.

Hearing the Voice is an interdisciplinary project on the experience of auditory verbal hallucinations based at Durham University and funded by a Strategic Award from the Wellcome Trust.



Human technology

Ceri Batchelder, Business Development Director, HMA Digital Marketing
Peter Cudd, Senior Researcher, The University of Sheffield

The University of Sheffield and HMA Digital Marketing, a Barnsley-based creative and digital agency, have formed a special collaborative partnership to develop mobile healthcare solutions for vulnerable people. This includes people who may have failing memory or other conditions such as visual impairment or hearing loss, where quality of life is very dependent on receipt of care and support from others. Through the expertise within the University's Centre for Assistive Technology and Connected Healthcare (CATCH), all projects are centred around the needs of the user and people involved in their care. Members of the public and patients are consulted in all the Centre's work, some becoming part of the team.

There are five key elements to our vision to improve quality of self-care and professional care for vulnerable people:

- Promote the confidence of the user, and reduce any stigma associated with having a particular condition.
- Provide support in gaining more sustainable access and high quality, expert online services.
- Tailor support and services through personalised digital solutions.
- Reflect that life includes a combination of health care, social care and leisure/social activities (and is not divided into silos).
- Ensure that our solutions are affordable.

To achieve our vision we are developing a tailored suite of Internet services that are friendly and very straightforward to use from portable digital technologies (i.e. smart phones and tablets). The number, content and control of the services can be customised to ensure they are in proportion to the individual's needs and capabilities. By reducing complexity we avoid the situation with current mass market technologies which

are appropriate for the majority but exclude those who struggle to, or cannot, use them. It is forecast that there are likely to be many people in this situation, e.g. people with Alzheimer's, Parkinson's, hearing loss and sight loss – or indeed anyone with a long-term condition who might panic when having a sudden adverse health episode.

If a person is diagnosed with dementia or another condition, they can find that they are suddenly 'labelled' as such, and it can be this categorisation as much as anything that can knock confidence and affect independence. As a result, we are choosing hardware that looks and feels like other devices on the market that everyone is using.

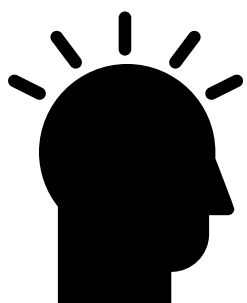
Through the flexibility and adaptability of our user interfaces, we aim to individually tailor access to support and services so that successful use is maintained for as long as possible. Whether users are at home or outdoors, the intent is to improve their ability to live independently, reducing the impact of their dependency on others.

Underpinning our activity is a strong focus on affordability, largely driven by the globally expressed need to have cost-effective health and social care services that maintain citizens' health, wellbeing and independent living. Affordability is essential because the numbers needing daily life support are set to increase significantly in each of the coming decades – while at the same time in many countries in Europe, and the world, the proportion of young people in society is set to fall, the impact being that there will not be enough people to deliver care in the way it is now. If vulnerable people can care for themselves more, it means there should be less frequent need for low level help, thereby reducing overall costs. As a result, when people do need a greater level of support, more professional time and resources can be directed to delivering an improved quality of care.

The mobile healthcare market is growing rapidly and can be challenging to enter, as well as to succeed in. To help manage this, we proactively seek to partner with charitable organisations that have connections with user groups, and healthcare companies with the

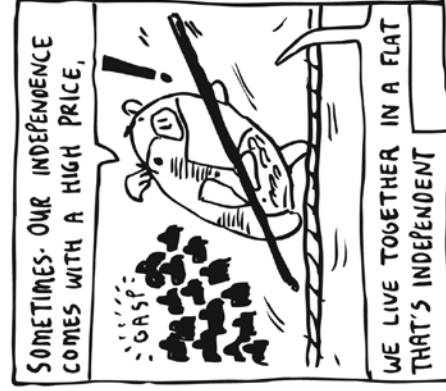
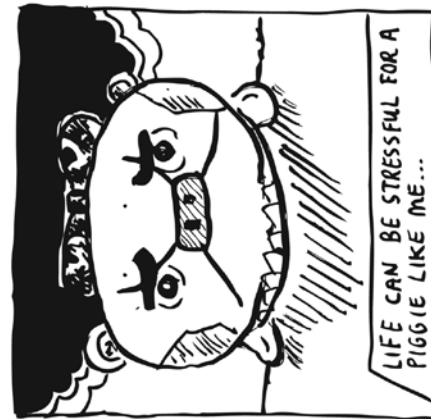
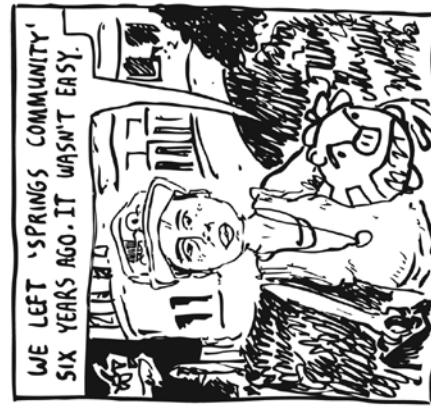
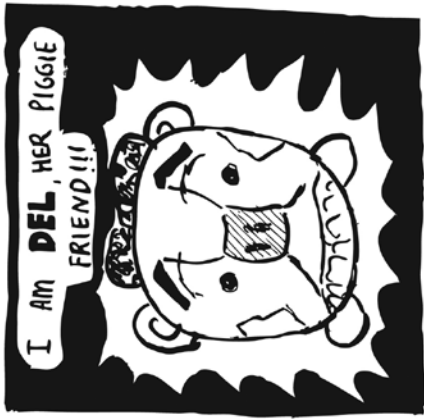
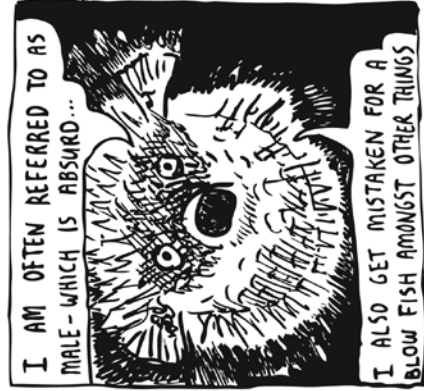
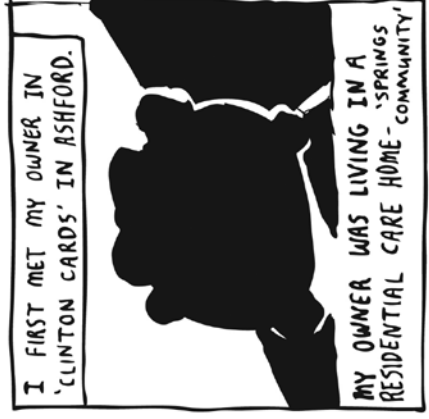
necessary commercial infrastructure and global reach to bring a product to market. Through collaborating over several years, CATCH and HMA have formed an integrated research and development partnership which provides a solid basis for digital healthcare projects. For HMA, this relationship has allowed a digital agency (that typically provides online marketing services) to apply its technical and creative capability to developing its own products and services for elderly and vulnerable people. It brings a new dimension to the team's activities and one that they are very keen to continue.

Our most recent influential project is a collaborative partnership with Tunstall Healthcare, a leader in telehealthcare solutions. The project is funded by the Creative England NHS Digital Fund, HMA and Tunstall, with the purpose of creating a mobile assistive device for vulnerable people to support self-care and independent living.

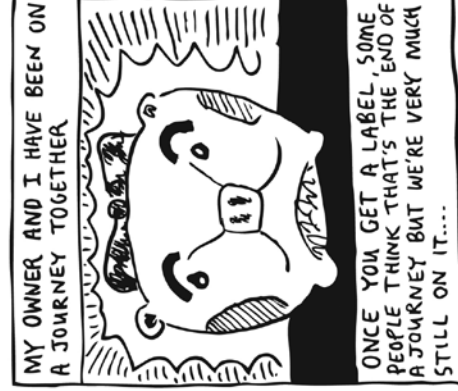
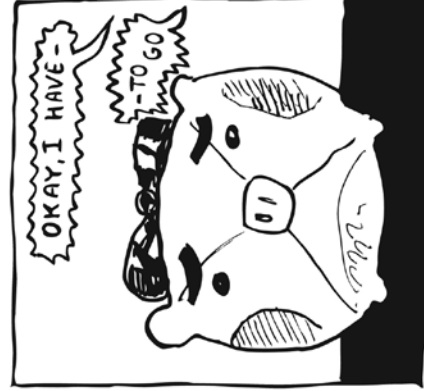


Heart n Soul

Tilley Hughes, Del the Piggie and Ben Connors



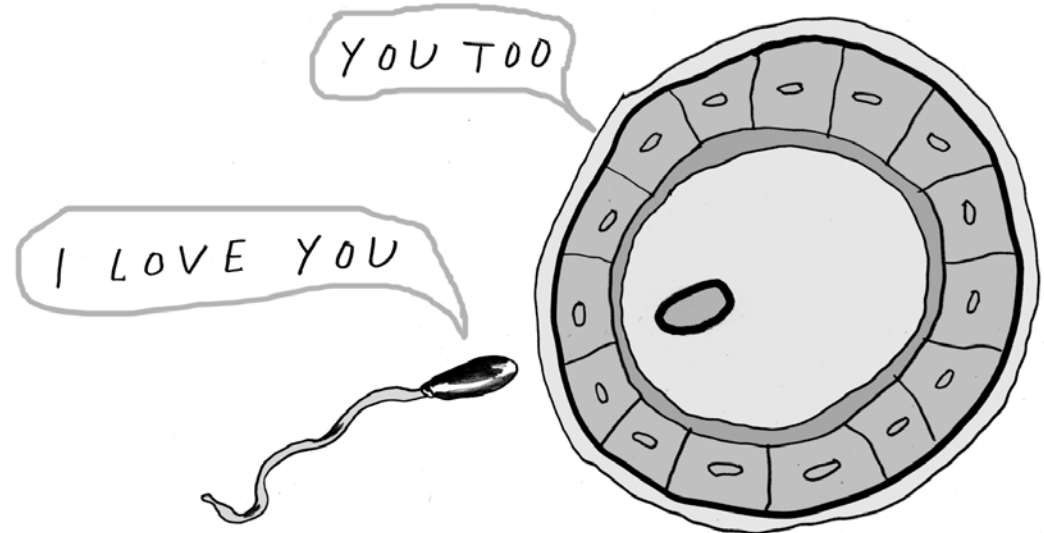
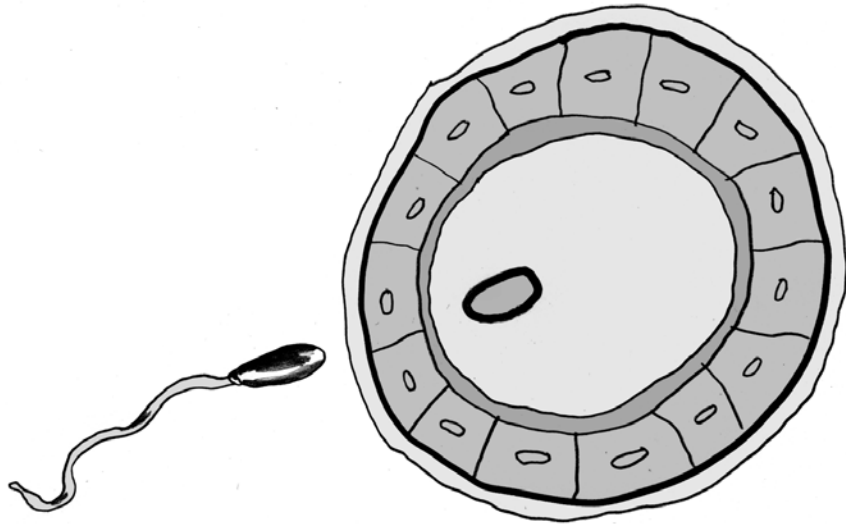
Heart n Soul Continued



A personal reflection on 'medical humanities' at Wellcome

Clare Matterson
Director of Culture and Society at the Wellcome Trust

WHATEVER
WE WILL BE



Henry Wellcome, the founder of the Wellcome Trust was perhaps the first 'medical humanist'. He pioneered the pursuit of medical science to produce new treatments and drugs, but this was far from the whole picture. With an insatiable curiosity and through the amassing of a vast collection touching on every aspect of the human condition, he embraced the idea of human health as having something of the scientific, cultural, religious, societal, personal, historical – much like the modern day 'medical humanities'.

A personal reflection on 'medical humanities' at Wellcome Continued

Henry's vision of using his collection to establish a Museum of Man died with him in 1936. The dizzying collection of over one million objects was never manageable. Although attempts were made to bring it to order, the sheer scale of the collection overwhelmed the Trustees of the day: it was divided, given away and stored. What remained at Wellcome was a library and a research programme on the history of medicine.

In line with Henry's wishes, the history of medicine was supported by the Wellcome Trust for many years spawning great scholars and insights into our understanding of human health. Stand out amongst these was Roy Porter whose prolific outputs showed how, at every stage in history, medical understanding is inseparable from the social and cultural framework of the time.

Seventy years post Henry's death, and with the benefit of the rich corpus of work from the history of medicine, a small band of us created Wellcome Collection. With health at its core and within the building that Henry built, Wellcome Collection set out to explore the human condition through the lens of science, culture,

anthropology, history, art and many more.

The public response to Wellcome Collection's interdisciplinary, often quirky, exhibitions that span themes across dirt, dreaming and death was greater than we dared anticipate. Many more visitors than planned came, and along with returning and loyal supporters they show that our interest in health in culture is as old as humanity itself. Wellcome Collection has become, unintentionally, the venue for medical humanities.

This intense public response coincided with renewed interest in medical humanities as an academic field. At Wellcome, we encouraged the field seeking to support research at the intersection of disciplines that could examine social, historical and cultural determinants and consequences of scientific knowledge, clinical practice and health care policies. Moreover, we were keen to give meaning to personal experiences, narrative and representations of health as a valid form of enquiry.

This resulting research and our experiences with Wellcome Collection suggest three forms

of medical humanities endeavour.

First, medical humanities can be integral to the work of health and medical professions. The role of the humanities to 'humanise' medical students is not new, yet we have recently seen greater innovation. New work is emerging where interdisciplinary teams are opening up new routes of enquiry on questions that directly affect health, well-being and illness. A prime example is the project 'Hearing the Voice' at Durham University. This ambitious research project seeks to offer a better understanding of the experience of voice hearing. As this 'condition' has become increasingly medicalised in today's society, the team contends that there is much to learn from the rich descriptions across cultures and historical eras, alongside the testimonies from current day voice hearers.

Second, the medical humanities can offer an in-depth reflection of medical development, practice or human experience. In one such example, Sarah Franklin's work as a sociologist turned historian explores how the passage of time has made IVF 'routine', yet has also

contributed to some of the more radical changes in our understandings of parenthood, kinship, fertility.

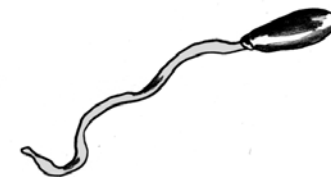
The third manifestation of the medical humanities lies in its ability to create intense and meaningful engagement. Such engagement might be as a visitor to Wellcome Collection engrossed in exploring topics aligned to the human condition. Or, it could be the ways in which artists such as Bobby Baker, who over the course of more than a decade created a personal journal into the misunderstood realities of mental illness through expressive and intuitive visual language. Available as an exhibition and book, 'Diary Drawings: Mental Illness and Me', we are able to gain a deep and intuitive understanding of the experience of mental health.

So what has all this achieved? At a time of increased specialisation, especially in the sciences, work to integrate perspectives from medicine and the humanities has forced us to look outwards, opened up conversations, challenged convention, sparked new collaborations and led to creative and academic outputs. As health and illness have become the preserve of medics and

medicine, medical humanities has begun to redress the balance.

As a mark of this success, it could be time to contemplate dropping the potentially restricting term 'medical humanities'. By doing so we could celebrate the contributions made from all disciplines, and we could draw on the expertise of any scholar, scientist, medic, author, artist as a constituent part of the rich and vital conversation on what it means to be human. Perhaps this was what Henry Wellcome was aiming for all along. It has just taken the rest of us a while to catch up.

Clare Matterson is Director of Society & Culture at the Wellcome Trust. She has led its development of medical humanities, public engagement and Wellcome Collection for the past 10 years.



Some kind of equilibrium

John Holden, John Kieffer, John Newbigin and Shelagh Wright
Editors

Clare Matterson writes “as health and illness have become the preserve of medics and medicine, medical humanities has begun to redress the balance”. In common with almost every field of science and technology, the last two centuries have seen a breath-taking expansion of our understanding about human bodies, how they work, how they fail and how they can be repaired. That, in turn, has led to a bewildering array of professional specialisms which, between them, have colonised our entire lives, not just when we are ill but every moment of our existence from birth to death, tending to reduce the person to the ‘patient’ – a passive recipient of someone else’s expertise. Life events such as pregnancy and adolescence have almost been turned into diseases; and medicine is ubiquitous, a fact wittily reflected in the title of a book by the sociologist of science Bruno Latour: ‘The Pasteurization of France’.

As medical science pushes ahead into unexplored corners of life and consciousness, the need to temper science with ethical judgements becomes ever more urgent and complex. Technology and the application of

technology also need frameworks of value and purpose – otherwise they can produce unanticipated outcomes at best, or runaway monsters at worst.

The complementary – or countervailing – force to the power of science and technology is culture, what Daniel Chua in his essay calls “the medicine of meaning”. It’s the regulator that stops the nuclear reactor of ‘progress’ from going into meltdown. Science and technology address the external world. Culture links that external world to our own internal worlds; links myth with reality; links past with present.

Times of rapid scientific and technological advance must also be times of cultural energy, if those advances are to be of real and lasting benefit. It’s no wonder that there is a growing recognition that the two great branches of exploration and explanation in our civilisation, the sciences and the humanities – or ‘natural sciences’ and ‘moral sciences’ – need to be re-united in some kind of equilibrium which, at the moment they patently are not. That need for convergence, for a more holistic approach to the future, is having an impact

on the medical world as it is in many other spheres, at both personal and social level.

Our reverence for such concepts as ‘personal freedom’ and ‘choice’ (illusory though much if it may be), coupled with the power of the internet, gives us radically different expectations to those of our parents and grandparents with their deference for the medical profession and its institutions.

At the social level, medical advances are generating ethical issues about the prolongation and termination of life. Another set of ethical issues is posed by the uncomfortable paradox of spectacular advances in hi-tech healthcare in the wealthy world, making it ever more impossible to provide equality of access to all, coupled with the dreadful reality of half the world’s population still living in such poverty as to be denied access to even basic healthcare.

At yet another level there’s the plain fact that even in those societies where medicine is at its most advanced and the overall standard of physical health has probably never been better, there are serious cracks developing –

increased levels of insecurity and anxiety, new forms of mental illness, new allergies and phobias, growing resistance to the drugs that have made the world safer for the last few decades and a terrifying increase in such apparently avoidable illnesses as obesity – and its consequences.

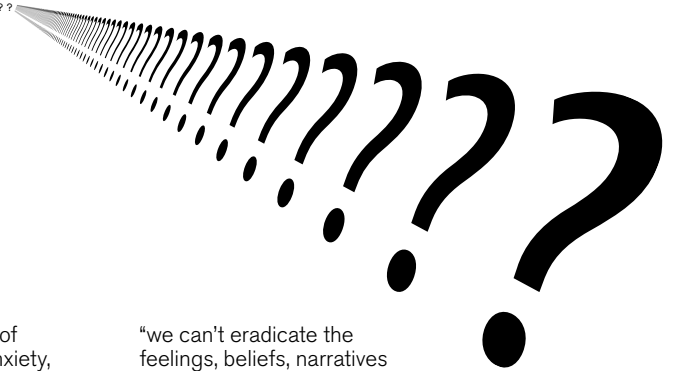
So no wonder medical humanities is of the moment.

This is not just about doctors being given copies of Little Women to read, as Dan O’Connor suggests, tongue in cheek. It’s got to be a proper mutuality of understanding and a parity of esteem. It’s Tom Andrews asking why we have allowed flowers to become taboo at hospital bedsides. It’s Tom Scanlon arguing that public health policy needs to address depression and unhappiness in the same spirit that a previous generation of public health officials addressed cholera. It’s Paul Boross questioning our response to people whose faith in prayer or charms or herbs ‘works for them’, in defiance of all clinical understanding. It’s Ainsley Clapp with her belief that “writing helps people to heal”.

It’s also Louisa Bolch with her observation that

“we can’t eradicate the feelings, beliefs, narratives and prejudices that influence clinicians, patients and policy. But we can seek to make them visible, question them ... change them”. The medical humanities is a conversation in which every one of us has a right to be heard. Many of our contributors allude to the connection between well being and a sense of active participation, ‘substantiating our sense of self’, as Rick Rylance and Adam Zeman express it, helping other people help themselves, as Matt Peacock, Jonnie Turpie and Dan Jones all argue. It’s about not being the patient, but the active participant, summed up by Bob and Roberta Smith with the thought “to be well we must not be pushed around by the world, we have to interpret it and feel confident to contribute to it.”

It’s each one of us learning to work with the messy truth of the human as part of the efficacy of the medicine. Or as Shakespeare put it “Thus policy in love, t’ anticipate The ills that were not, grew to faults assured, And brought to medicine a healthful state Which, rank of goodness, would by ill be cured...”



What's next

Contemporary definitions of medicine and clinical practice occupy just one small corner of a vast field of beliefs, superstitions, cultures and practices across which human beings have always roamed in the effort to keep feeling well.

We asked the contributors to this book to take a walk through that field recognising that it's a space in which artists, poets, historians, film-makers, comedians and cartoonists – in fact every one of us has the right to explore.

It is therefore also an invitation to you to join the conversation.

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What does it mean to be well?
Or ill? And who, apart from you,
really knows which is which?

Contemporary definitions of
medicine and clinical practice
occupy just one small corner
of a vast field of beliefs,
superstitions, cultures and
practices across which human
beings have always roamed in
the search to keep themselves,
and others, feeling well.

The label 'medical humanities'
is the best effort we've made
so far to define the fence that
encloses that very large field;
recognising that it's a space in
which artists, poets, historians,
film-makers, comedians and
cartoonists – in fact every
one of us – has as much right
to explore as any humanities-
schooled or clinically
trained professional.

This book is a walk through
that field, a celebration of its
rich diversity, a dip into some
of the conversations that are
going on within it, an attempt
to get it in perspective –
and an invitation to you to join
the conversation yourself.

