STORYTELLING

ARTS FOR HEALTH

Series Editor: Paul Crawford, Professor of Health Humanities, University of Nottingham, UK

The *Arts for Health* series offers a ground-breaking set of books that guide the general public, carers and healthcare providers on how different arts can help people to stay healthy or improve their health and wellbeing.

Bringing together new information and resources underpinning the health humanities (that link health and social care disciplines with the arts and humanities), the books demonstrate the ways in which the arts offer people worldwide a kind of shadow health service – a non-clinical way to maintain or improve our health and wellbeing. The books are aimed at general readers along with interested arts practitioners seeking to explore the health benefits of their work, health and social care providers and clinicians wishing to learn about the application of the arts for health, educators in arts, health and social care and organisations, carers and individuals engaged in public health or generating healthier environments. These easy-to-read, engaging short books help readers to understand the evidence about the value of arts for health and offer guidelines, case studies and resources to make use of these non-clinical routes to a better life.

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United Kingdom – North America – Japan – India
Malaysia – China

Emerald Publishing Limited
Howard House, Wagon Lane, Bingley BD16 1WA, UK

First edition 2022

British Library Cataloguing in Publication Data
A catalogue record for this book is available from the British Library

ISBN: 978-1-83909-759-1 (Print)
ISBN: 978-1-83909-756-0 (Online)
ISBN: 978-1-83909-758-4 (Epub)

Certificate Number 1985
ISO 14001

ISOQAR certified
Management System,
awarded to Emerald
for adherence to
Environmental
standard
ISO 14001:2004.

INVESTOR IN PEOPLE

DEDICATION

For Matthew, Rosie and Rebecca

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SERIES PREFACE: CREATIVE PUBLIC HEALTH

The 'Arts for Health' series aims to provide key information on how different arts and humanities practices can support, or even transform, health and wellbeing. Each book introduces a particular creative activity or resource and outlines its place and value in society, the evidence for its use in advancing health and wellbeing, and cases of how this works. In addition, each book provides useful links and suggestions to readers for following-up on these quick reads. We can think of this series as a kind of shadow health service – encouraging the use of the arts and humanities alongside all the other resources on offer to keep us fit and well.

Creative practices in the arts and humanities offer a fantastic, non-medical, but medically relevant way to improve the health and well-being of individuals, families and communities. Intuitively, we know just how important creative activities are in maintaining or recovering our best possible lives. For example, imagine that we woke up tomorrow to find that all music, books or films had to be destroyed, learn that singing, dancing or theatre had been outlawed or that galleries, museums and theatres had to close permanently; or, indeed, that every street had posters warning citizens of severe punishment for taking photographs, drawing or writing. How would we feel? What would happen to our bodies and minds? How would we survive? Unfortunately, we have seen this kind of removal of creative activities from human society before and today many people remain terribly restricted in artistic expression and consumption.

I hope that this series adds a practical resource to the public. I hope people buy these little books as gifts for family and friends,

or for hard-pressed healthcare professionals, to encourage them to revisit or to consider a creative path to living well. I hope that creative public health makes for a brighter future.

Professor Paul Crawford

PREFACE

This book was first conceived prior to the COVID-19 pandemic outbreak of 2020, but was largely written during the series of extended lockdowns and other restrictions on social activity that followed. Acknowledging that context is important because it was during this time that both elements of this book, health *and* storytelling, were cast into a new light because of the new circumstances under which we were living.

Health experts and immunologists, in particular, had been predicting a pandemic of some sort for many years, but when the first cases began to emerge in late 2019 and its rapid spread around the world realised in early 2020, it still seemed to take politicians and the wider general public by surprise. We seemed woefully unprepared for what quickly became the largest public health emergency in more than a generation.

Health and, in the UK at least, the healthcare system became headline news, but this did not restrict itself simply to the steady advance of coronavirus. There were (and continue to be) concerns around other areas of healthcare. If the healthcare system were overwhelmed, or even stretched, by cases of COVID, how would this impact on other areas of care? How would it affect those patients on waiting lists for important operations? Influenza vaccinations were offered free to all over 50s and other vulnerable groups in order to try and mitigate for the anticipated additional burden on hospitals during the critical winter flu season. Later, it was the vaccination roll-out that dominated the collective consciousness.

There were also serious concerns relating to mental health. As we entered lockdown, large numbers of people suffered a significant

loss of income, as jobs were lost, furloughs were introduced and businesses ceased to operate, all adding to personal and family stress levels and affecting mental well-being. The Occupational Health departments of large businesses were kept busy supporting those people who were having to transition to homeworking, often whilst trying to home–school children and work from the kitchen table. Most of all, people were confined to their homes, placing a severe restriction on social interaction and it became increasingly difficult to maintain one's network of social relationships outside of the immediate family, never mind establish new relationships. People became increasingly disconnected from each other, as studies suggested that society was suffering from social isolation and experiencing rapidly rising levels of mental ill health. Particular groups of people were especially vulnerable: the young, who were denied contact with their peers when schools, colleges and universities moved to online delivery; those living alone, or in cramped accommodation; the elderly in residential care homes, who were particularly at risk from the virus and were denied visits from family. There were fears that the measures that were being put in place to tackle the spread of the virus were, in fact, contributing to a mental health crisis.

All through this time, the press, the airwaves, social media and the conversations in family sitting rooms were filled with stories about health and we acquired a whole new vocabulary for telling our health stories. 'Social distancing', 'PPE', 'flattening the curve', 'contact tracing', 'herd immunity, 'the R number', 'superspreader' and 'zoom fatigue' were amongst the plethora of new words and phrases that emerged during 2020 to support our pandemic storytelling. But, leaving the specific area of pandemic-related stories to one side for a moment, a lockdown that limits the degree of social engagement and interaction will inevitably have a detrimental impact on the amount of storytelling that can take place. Storytelling naturally emerges from social interaction and is, indeed, its very glue, so any curtailment of our ability to socially interact will reduce opportunities for storytelling. If we subscribe to the idea that our collective health (in particular our collective mental health) is to some degree dependent on our social well-being and

the good functionality of our social systems and networks, then we will also be concerned about the impact of a decline in what we might call our 'story health', that is our ability to take advantage of opportunities to tell and listen to stories.

There is nothing new, of course, in any of this. In Shakespeare's time, when the plague arrived in sixteenth- and seventeenth-century London, as it periodically did, the first action the city authorities took was to close the theatres. This limited the spread of the disease, but at the same time, closed down the primary popular form of public storytelling. Writing in the middle of the fourteenth century, Giovanni Boccaccio (1313–1375) set *The Decameron* in the context of the 1347–1349 Black Death outbreaks in Florence. In the book, a group of young men and women decamp to a villa outside of the city to wait out the plague, in an act we would now probably call social isolation, or 'forming a bubble'. To pass the time, they take it in turns to tell each other stories, 10 stories a day for 10 days. However, it more than passes the time; in extraordinary circumstances it allows them to maintain the health of their social relationships – it is literally an act of survival and protects them as much from the effects of the plague, as the act of quarantine does.

If necessity is the mother of invention, then the COVID-19 pandemic has likewise presented us with opportunities to innovate and find new creative ways of telling each other our stories. Creative arts professionals have been at the forefront of this innovation and, in particular, storytellers and theatre-makers have exploited the new 'Zoomiverse' to experiment with storytelling forms. In our own work at the Storytelling Academy at Loughborough University, we were forced to postpone the International Digital Storytelling Conference that we had been due to host in April 2020, so instead we created our own 'Digital Decameron' (http://stories.umbc.edu/index.php/2020/03/24/the-digital-decameron/) with colleagues at the University of Maryland Baltimore County, whereby we hosted 10 digital stories per week over 10 weeks, with a different curator for each week.

Nevertheless, these kinds of initiatives were often only substitutes for the real thing. As the lockdown continued, people craved

human contact and it became clearer than ever that Boccaccio's Florentines had one major advantage over us – they were able to gather together to tell their stories in the same shared space, hearing each other's non-mediated voices, occasionally touching each other and feeling each other's breath on their cheeks. For storytelling is less about what is being told and more about the act of telling. It is an intensely human experience and being together in the same space and sharing our stories remind us of, and confirm, our very humanity. Quite simply, storytelling is a statement that confirms that we are alive.

Given the ubiquity and centrality of storytelling in our lives, as I've just argued, one might reasonably ask why we need a book on storytelling for health at all. It is so fundamentally necessary to our existence, in that we are storytelling animals, I might as well propose a book on *breathing* and health. Well, as easy and natural as storytelling might seem, 'storytelling work' can be deceptively difficult, complex and varied. It is the intention of some of the chapters in this book to explore those difficulties and complexities, but it is through the case studies, which deliberately make up the very core of this volume, that the variety of practices that constitute storytelling is represented. This includes workshops and performances, stories from patients and stories from healthcare professionals and medical practitioners, some aimed at the medical establishment and healthcare system and others at patient audiences. Others advocate to a wider public audience. I have tried to include as wide a range of projects and practices as possible, but it is in the nature of a book of this kind that there will also be huge gaps. This is not intended to be an exhaustive, or even fully representative set of examples. Like storytelling itself, it is simply a modest demonstration of the possible.

ACKNOWLEDGMENTS

In spite of what it says on the cover, this book is, of course, not the work of a single person. Various people have contributed in myriad ways and it would be unfeasible to mention them all by name, but I hope they know who they are and that I am grateful.

Specifically, I would like to thank Professor Paul Crawford from Nottingham University and Professor Emeritus Alan Bleakley from the Peninsula Medical School in Truro, whose extensive knowledge and wisdom concerning the role of the arts in healthcare have been freely and generously given over many years.

I would also like to thank the many colleagues and partners from other universities, organisations and communities across the world, who I have been fortunate enough to work with on various storytelling and health projects and whose company and conversation I have always found enriching.

Special thanks should also go to my colleagues and doctoral researchers at the Storytelling Academy at Loughborough University. I learn from them every day, more than they probably realise.

And finally, I would like to thank my wife, Jayne, for her unconditional support throughout, and my black Labrador, Izzy, who has selflessly kept me company by spending most of the pandemic asleep on the armchair in my study, whilst I tried to write this book.

Loughborough, November 2021

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INTRODUCTION

It would make sense to begin all of this with a story. This is actually a story about a story and it was told to me about 15 years or so ago by someone who worked for the UK National Health Service (NHS). He was not a doctor or surgeon or nurse, but one of the universally hated band of administrators whose job it was to improve quality of service in the hospital for the patients. We were talking about the value of storytelling as a tool for evaluating and improving service delivery and he offered me this anecdote as an example of why he thought we should listen to patients' stories if we were serious about making improvements in all aspects of the NHS.

He told me that the aspect of service that patients complain most consistently about is the quality of the food in hospitals. This is a concern on many levels – not least because encouraging patients to eat a healthy diet in hospital is often critical to recovery – but imagine the effect on the morale of staff who go around cooking and serving food in hospitals under very difficult conditions, if all they hear is a round of never-ending complaints. He told me that they decided to conduct a survey amongst the patients in a particular hospital and asked them to rate the quality of the food on a scale of 0–10. Unsurprisingly nearly everyone gave ratings towards the bottom end of the scale. However, they then went round asking people to tell them of their *experience* of hospital food. The first person they asked was an elderly woman and she told them that whilst the food left a lot to be to desired, she always looked forward to mealtimes because the woman who brought it round was so lovely and would always stop for a chat and ask her how she was.

There are many points to this story – and, of course, every story has to have a point. It ably demonstrates that statistics and questionnaires never tell the whole story. If you ask people to evaluate something on a straightforward numerical scale, you will get a straightforward, simplistic answer that misses the nuance and complexity of the human experience. You will miss important information about how the staff of the hospital are positively contributing to the experiences of those in their care, how they are striving, in small ways, to make their lives better during the chaos and uncertainty that illness brings. In fact, you may well end up falsely concluding that the patient experience is fundamentally broken.

The story also makes an important point about storytelling. Not only does it allow the service evaluator to gain a more textured and complex view of the service that is being evaluated, but it also demonstrates the criticality of storytelling to our well-being. The patient in the story mentioned that the woman who served her food actually made time to have a conversation with her – in very small ways, perhaps, but to engage in an act of storytelling, a fundamental act of humanity.

I have, however, told this story to begin this book for another reason. Very often when we are talking about patient stories (and very often when we are talking about storytelling and health we *are* talking about *patient* stories), we are talking about what are generally called illness narratives. I'll talk more about these later, but essentially these are stories that are usually told by the patient to their doctor, a nurse or other healthcare professional, that outline their experiences of and feelings about developing a particular medical condition. The field of Narrative Medicine makes a convincing case that these stories ought to be part of any medical diagnosis and that any healthcare professional needs to acquire both a scientific and narrative competence in order to make an accurate diagnosis and prescribe an effective course of treatment. So far, so good, and I would not wish to argue with that at all.

Nevertheless, it is worth pointing out that the story I've just told you is not an illness narrative. I have no idea what the woman in the story was in hospital for. I said she was an elderly woman, but I don't really know how old she was. I may even have just made that bit up because as I was told the story I had the picture of an elderly

woman in my head. But that isn't important to the story and her illness isn't important either, because it's not a story about illness, but a story about human beings and how small acts of social kindness are important to our well-being. And that's the point – it is – I think undeniably – a story about health and well-being. It's just not focussed on the patient's illness and their identity as a patient with a condition.

This is important because one of the key experiences that people have when they go into hospital is that they lose their identity to their illness. They are no longer John the Teacher or Mary the Farmer, or even Susan the Doctor, but they are now the cancer sufferer, the cardiology patient or the stroke victim. Their illness or condition comes to define them and they suffer a potentially devastating loss of identity and control over how to define themselves. We know that, amongst other things (and again more of that later), storytelling is the way in which we build and create our own identities and then present them to others in order to negotiate our social, professional and personal relationships.

Back in the early 2000s, there was some talk of the need for a dignity agenda in healthcare provision in the UK, a need to consider how we are able to preserve and respect people's dignities when they are at their most vulnerable, physically and mentally. That issue has not gone away, although it may have slid down the political agenda, but ensuring that people have the time and opportunity to share stories – for example to stop and shoot the breeze *en route* to delivering hospital meals to the bedside – is one very important step towards addressing it. Of course, storytelling is such an everyday activity that we hardly even notice it when it is happening under our very noses. We all tell stories all the time and we take it for granted. But perhaps that is why it is so important – enabling a healthy storytelling culture is as fundamental to our well-being as clean air and water. It is our cultural oxygen.

So, this book – importantly – is called *Storytelling* in the context of the series 'Arts for Health'. There is no shortage of literature on stories and health and/or medicine, but most of that literature – and as important and brilliant as much of it is – largely takes health as its starting point. It is written by researchers and practitioners who have come to this field from medical practice

or enquiry. In other words, they are health service practitioners who see in story a tool that will help them become better health service practitioners. I offer no criticism of that – in fact quite the opposite. It is all very essential. This book, however, comes from a different starting point. It begins from the study and practice of storytelling and from there ventures with some trepidation into the field of health and well-being. It also takes a particular interest in storytelling more than story. That is to say, that unlike much of the current literature, it does not assume that the primary value in a storied approach to health is that stories are simply repositories of experiential knowledge that are of added value to the medical practitioner. That may be true, of course, but this book asserts the importance of storytelling as a practice in relation to health and well-being. Moreover, it also does not simply propose storytelling as a therapeutic practice (although it may, of course, have therapeutic value and outcomes), but rather as a process where knowledge is explored, interrogated and tested in a social exchange, whereby knowledge is *collaboratively* produced between doctor and patient. It also does not assume the patient in the role of storyteller and the doctor, or other health professional, such as nurse or psychotherapist, as listener/interpreter. Instead it argues that all actors in a storytelling event are simultaneously tellers and listeners in a moment of improvised co-creation. This is storytelling not only as a knowledge system but also as a thinking system. Storytelling is not only a way of knowing the world but also a way of thinking about it. As Alan Bleakley argues (2005), storytelling research is not just about thinking *about* stories, but also thinking *with* stories.

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WHY STORYTELLING?

As this is a book about storytelling, let's begin with one.

A man in his mid-50s walked into his doctor's surgery …

Actually, no, let's stop a moment. This is not just any man, this is a particular man and unless we know the name of this man, unless he publicly declares his identity to us, then the story loses its specificity and with that its meaning. It would be reduced to something general and vague and would lose much of its potency. We are made up of our stories, so our stories are as much part of us as we are of our stories, and so unless we know the identity of the storyteller, then we lose much of the story itself, which is why the automatic anonymisation of stories is problematic for the researcher of storytelling. So, let's start again …

I am in my mid-50s and one day, earlier this year I walked into my doctor's surgery …

You see, this story is about me. It is *my* story. But I need to start again because the story doesn't really begin when I walked into the doctor's surgery. The story could start at any point. It could start in 1930s urban Manchester, where my parents grew up. It could start in 1970s Bolton, where I grew up. It could start in 1999, after my mother died. The point is that where the story starts is not an arbitrary decision, but it is a decision that I, the storyteller, am charged with making. And depending on to whom and for what purpose I'm telling the story, I may choose a different starting point. Choosing

the right point for the start of the story is my first responsibility as a storyteller and it will lay the ground for a series of further decisions that I will have to make over the next five minutes as I tell my story. But more of that later, let me get on with the story, which for the purpose of this particular re-telling, begins about a week before I walked into my doctor's surgery.

It was shortly after New Year and I was spending a week in Cochin in southern India, as part of a research project I was involved in on using theatre and storytelling to help address issues of mental health literacy in Kerala. So, by coincidence, a storytelling and health project. The journey there was long and involved overnight travel, so I arrived tired and jet-lagged into a polluted environment (Cochin is not as polluted as many Indian cities, but the air quality is still not great) and temperatures in the low to mid-30s (having left behind an English winter).

On my second day in Cochin I noticed that whenever I walked up the two flights of stairs to my hotel bedroom I started to develop a tightness in my chest and a dull pain in my upper left arm and sometimes in my neck too. The tightness and pain subsided within a minute or two of reaching my room. Now, I am admittedly overweight and out of shape, but I also consider myself fairly active, I am a brisk walker and would normally run up a couple of flights of stairs without a problem. At the same time, my mother had died, aged 65, of heart failure, having undergone bypass surgery a few years earlier. Her father, too, died of thrombosis in his mid-50s, and one of her four brothers died of a heart attack in his late 30s and two others survived heart attacks in their 50s. They were all brought up on diets of lard and nicotine in the harsh working class environment of urban Manchester (in Moss Side for those who know it) in the inter-war years, but even so there is enough of a family (hi)story there for me to know that there's a genetic vulnerability I may have inherited. Also, like my mother, I suffer from raised cholesterol (that's another story I won't tell you just now) and have regularly taken statins for the last 20 years. So, although I have never had any symptoms like this before, I have familiarised myself with the classic symptoms of angina.

I took the rest of the week as easily as I could, but the symptoms persisted whenever I exerted myself. But then, on the way home, I had to change flights at Abu Dhabi airport and I had quite a tight transfer time. I was a little worried as a slight delay in my first flight meant that I had to sprint across the airport between gates to make my connecting flight. Of course it left me a little breathless, but there was no tightness in my chest and no other dull pains – all of the angina symptoms seemed to have disappeared.

The day after I arrived back in the UK, I had decided to take as a day off in order to rest and recover from the travel. This was unusual for me – I normally head straight back into work for meetings – but because my diary was clear I thought it was probably worth my whilst just popping into the doctor's surgery for a quick check-up.

It was the first time I had been to see the doctor in about three years – my visits to the medical centre were normally limited to seeing the practice nurse for routine cholesterol tests and travel vaccines – so this was quite a big deal for me. And I shall not pretend that I wasn't a little worried – not that I was at risk of imminent death, but rather that I would be diagnosed with a chronic condition that would significantly impact on my professional life (which involves a lot of overseas travel).

As I sat down in her consulting room, the doctor asked me to tell her what had brought me there that day – an invitation to tell a story. And so I proceeded to tell her the story I have just told you. What took place was probably completely typical of a doctor–patient encounter in a UK drop-in surgery. As I was telling the story I was aware that at times she was listening intently and at other times she seemed less engaged, at times even distracted by signing some paperwork, or dealing with an e-mail on the computer. At these times I was reminded that her time was under pressure and there were a number of factors that might have been preventing her from listening properly (by which I mean engaging in *deep* listening) – I was only one of a number of patients she was scheduled to see that day and no doubt I had been notionally allotted a ridiculously short amount of time that was completely inadequate for dealing with a patient reporting potential first symptoms of heart

disease. But I didn't want to waste the doctor's time and I know only too well what it's like working under those kinds of time pressures, so when I noticed her being distracted, or I read in her behaviour those very small tell-tale signs that indicate impatience, I would start editing the story, being as concise as possible (and concision does not come naturally to me once I have warmed to my theme). Then there were times when she would interrupt me with a question designed to elicit precise information. At these moments, I felt she was more interested in extracting information from me, rather than listening to my story. Or rather that she was only interested in listening to my story in so far as it gave her particular data that was directly relevant to making a swift and accurate diagnosis of my condition.

At this point, I have to admit displaying a certain resistance. I wanted, or rather needed, to tell my story and have it listened to, and whilst I was perfectly happy to adapt my telling to the situation and shorten it, as appropriate, a story also demands its own time and cannot be rushed. Even when there are other patients waiting. Storytelling makes certain minimum demands on our time and will resist strongly attempts to artificially impose a different frame on it. No doubt the doctor found parts of my story useful. She would have understood a little about my family history (and more so than a mere reading of my medical notes would have given) and she would have understood a little about my symptoms and the context in which they occurred. All very helpful to her in making a diagnosis and determining a particular course of action – in this case further tests. But if she had both the time and the capacity to listen more deeply to the story, she may have understood that this storytelling event was much more than giving her some basic diagnostic information. She may have understood that the way I was telling the story would have indicated how I was feeling, what were my fears, my hopes, my expectations. How was I telling my story? What information was I privileging? What information might I have been leaving out and why? Was I presenting a story that was full of fear, or optimism? Was my act of storytelling, with all its accompanying gestures, verbal acrobatics and so on, indicating a patient who was fearful (we're all fearful in these situations