

Toward Sentience

CLIVE PARKINSON

If you are given the diagnosis of cancer or dementia, the likelihood that this news is given to you in a clinical environment is high, as is that it will be given by a highly trained clinician. That you'd be concerned either for the design of the environment or the integration of the arts into this space would in all probability be an irrelevance. Given a diagnosis of any serious disease, we cling to the professionalism and speed of a responsive health system that will act in our best interest and provide treatment that is well-considered, timely, and effective. In fact, considering design and the arts seems ridiculous in the face of illness and our own mortality. Yet there is movement that bridges the arts, health, and well-being that asserts there is a place for design and the arts alongside medicine. Moreover, there is a growing awareness among clinicians that in the face of illness and mortality, the arts offer medicine something other than scientific reductionism. Added to this, the UK think-tank demos conservatively estimate "that at least a fifth of NHS spending goes on end of life care and the cost of that care will rise from about £20 billion today to £25 billion in 2030... yet 40 per cent of people who die in hospital do not have medical conditions that medics can fight."¹ In the United States, the burgeoning cost of health care is potentially "the greatest threat to the country's long-term solvency, with twenty-five per cent of all Medicare spending is for the five per cent of patients who are in their final year of life, and most of that money goes for care in their last couple of months which is of little apparent benefit."² It seems that scrutinizing the way healthcare is delivered has never been more important.

This chapter will focus on the seemingly tenuous relationship between design, the arts, and health and argue that their potential impact on future patients is far reaching.

Much of the literature in this fast-developing field plots a neat line from the revelations of Florence Nightingale on the impact of improved sanitary conditions on Victorian public health,³ to the not too surprising revelations of Roger Ulrich that, among

other things, tells us that pleasant hospital environments reduce hospital stays.⁴ We're not going to start our journey there, and although we may make passing references to eminent figures from history and contemporary research, much of this chapter will be focused on the here and now and the reality of diverse twenty-first-century life.

The idea of the patient journey is a useful place to begin because like it or not we are all consumers of health services at some point in our lives. Even for those of us in robust health, the likelihood of our final moments of life taking place inside a hospital intensive care unit (ICU) is far more probable than gently slipping away in the comfort of our own bed surrounded by those we love.

In an article for *The New Yorker*, the surgeon and writer Dr. Atul Gawande, through a first person account, painfully illustrates how modern medicine often focuses on aggressive interventions to stave off death while losing sight of the patient and of ways we can improve quality of life in people's final days. In his unflinching narrative echoing early descriptions of health services as "warehouses of the dying,"⁵ he paints a picture of a health system that in its attempt to prolong life takes medicine and surgery to its furthest limits. Whist the goal of medicine and surgery is to prolong life, it runs the risk of sacrificing quality of life by pursuing every available intervention, however traumatic, for the possibility of extra time. This chapter will argue the case for more domestic-scaled care and support that enables the fullest of possible lives in the here and now.

Charles Leadbetter and Jake Garber in their report on how people die in the twenty-first-century United Kingdom, "Dying for a Change," illustrate this issue with clarity:

Hospitals' main weaknesses... are their lack of privacy and personalisation; they are designed around professional, medical procedures and hierarchies rather than to accommodate social relationships; they deliver services for and to people but are less adept at working with them. Patients and families often complain that staff have not got the time, knowledge or skills to communicate effectively.⁶

It is my assertion that in considering all aspects of health and well-being, from the clinical setting to the communities that we live in, we must explore the extremes of the human condition to better understand how to achieve long-term cultural change in the way we design, deliver, and value public health.

Of course, any writing on healthy environments that focuses solely on clinics and hospital settings is missing the point: healthy environments are all those places that life takes place in—the streets, markets, schools, workplaces, and homes that we all inhabit. It is blindingly obvious that the environmental factors that impact on our well-being underpin everything, so a literal approach to this chapter would be to work from the crisis at Fukushima⁷ outward, taking in fundamental human rights and inequalities along the way, but this is too large an area to consider here. Other more intimate factors within this spectrum might be usefully unpicked here though, ranging from patient choices to innovative partnership approaches to addressing complex health needs.

Describing how "more and more of life's inevitable processes and difficulties—birth, sexuality, aging, unhappiness, tiredness, and loneliness—are being medicalised,"⁸

Dr. Richard Smith, one-time editor of the *British Medical Journal*, argues that “medicine alone cannot address these problems and that common values and attitudes towards the management of death, while well known about in scientific circles, have yet to be acted upon because of lack of imagination.”⁹ While the modern version of the Hippocratic Oath¹⁰ urges clinicians to avoid the “twin traps of over-treatment and therapeutic nihilism,” it also stresses that “there is art to medicine as well as science, and that warmth, sympathy, and understanding may outweigh the surgeon’s knife or the chemist’s drug” and urges a focus on the human being, not the illness. Smith suggests that the arts might just be the vehicle to address these points.

Jonah Lehrer in his book *Proust was a Neuroscientist*¹¹ usefully expands on this theme, suggesting that creative minds might shed new light on complex scientific problems. Citing the work of, among others, Gertrude Stein and Igor Stravinsky, Lehrer uses Marcel Proust’s discovery in *A la Recherche du Temps Perdu*,¹² that smell and taste produce uniquely intense memories which are dependent on moment and mood. These remembered sensations are often selective, changeable and subject to fault: “to remember is to misremember.” Current scientific research shows that memories are indeed stimulated by both smell and taste, which have hard-wired connections to the hippocampus. Lehrer suggests that the artistic enquiry has preempted the scientific understanding. While there is evidence to suggest that loss of olfactory function is an indicator of dementia, smell is a neglected sense that designer James Auger suggests has a low status because of the “re-evaluation of the senses by philosophers and scientists of the eighteenth and nineteenth centuries. Smell was considered lower order, primitive, savage and bestial. Smell is the one sense where control is lost, each intake of breath sends loaded air molecules over the receptors in the nose and in turn potentially guttural, uncensored information to the brain.”¹³

Auger explores our relationship with smell through his challenging “speculative design proposals” around sexual selection, health, and well-being and places it alongside the higher senses of visual and aural perception; observing that “scientists continue to study the ways that smell might have developed to warn humans of the harm of decomposing food or an approaching fire; it is up to designers to encourage people to think about what is lost when we have ‘fire alarms and sell-by dates and fridges’ and, for that matter, deodorants and perfume.”¹⁴

While Lehrer doesn’t manage to show that artists have consistently influenced the research direction of scientists, he does illustrate that through creative inquiry there have been dual approaches to questions of profound human interest. This parallel thirst for understanding or making sense of the world is nevertheless mired by the “mutual incomprehension”¹⁵ between the arts and science, as writer and scientist C. P. Snow asserted in 1959, and is still an area of some difference.

Snow described this potential for the coming together of science and the arts as the third culture,¹⁶ but much of what we describe as third culture is frequently the superficial co-opting of the other’s language, symbols, and style. Often it’s as obvious as a design agency co-opting imagery and words associated with the latest scientific breakthrough to inform the logo of a corporate client, or perhaps a useful sound bite from Shakespeare or Shelley is used by a scientist to make their advances more accessible to the public.

The Wellcome Trust,¹⁷ using the profits of its pharmaceutical legacy, is a major funder of innovative projects that bridge biomedical science and public understanding through the arts. From its pioneering days in the United Kingdom in the 1980s, Arts for Health¹⁸ has influenced integrated public and participatory art alongside design intended to humanize clinical environments. Awareness of the potential of healing environments¹⁹ has grown exponentially, as has the call for evidence of the impact of the arts on health outcomes. An early study conducted by Roger Ulrich in 1984 suggests that surgery patients with a view of nature suffered fewer complications, needed less analgesia, and were discharged sooner than those, unsurprisingly, with a view of a brick wall.²⁰ Studies also exist about the psychological effects of lighting, carpeting, and noise on critical-care patients, but for Ulrich, it is the view of nature or naturalistic art that, he suggests, has the biggest impact on patient outcomes.

In a number of papers however, Ulrich consistently suggests that it is only art that reflects nature that will benefit patients and that, conversely, “inappropriate art styles or image subject matter can increase stress and worsen other outcomes.”²¹ Similarly, he describes the “pitfalls of displaying emotionally challenging art in (the) healthcare environments... of psychiatric patients,” commenting that, “patients indicated strongly negative reactions to artworks that were ambiguous, surreal, or could be interpreted in multiple ways.”²²

Isn't this a paradox? Aren't the arts supposed to be ambiguous and open to interpretation, and is this research asking the right questions? What on Earth was this abstract art that so offended, and what will the bland compromise be: a heady mix of Soylent Green²³ and *Hay Wain*?²⁴ Perhaps if Tracey Emin's Turner Prize–losing *My Bed*²⁵ were to be exhibited on a mixed-sex, multioccupancy ward, there might be room for some concern, not least on the acquired hospital infection front! But even a work as contentious as this might have a place in the atrium of a large hospital because perhaps it may just stimulate a little conversation; after all, aren't we a bit sick of those anonymous lumps of badly conceived corporate art in these cavernous glass-and-steel warehouses? At least you could curate it, change it, and move it on. Or perhaps like the inspiring education staff at the Museum of Modern Art in New York (MoMA),²⁶ you could work with people marginalized by illness and engage with contemporary and sometimes challenging work specifically to provoke a response. In the United Kingdom, United States, and Australia, curators and educators from galleries and museums are increasingly bringing objects to the beds of patients to experience handling the bizarre, alien, and potentially transcendent, but more of that shortly.

Typically though, hospitals get lumbered with some semipermanent prehistoric mural like the recently unveiled Michael Craig-Martin *KIDS*²⁷ at the Oxford Radcliffe hospital. Doubtless conceived with good intention and planned to inspire and uplift the poorly children of Oxford, in its conceit this will become a fast-ageing, five-story memento mori to the artist. Interestingly, this is one of the few arts/health stories to make it to the prime-time UK news, and an informed reader might presume the working of the celebrity artist publicity machine.

In 2003, Rosalia Staricoff published research undertaken at the Chelsea and Westminster Hospital²⁸ exploring the effects of “bold, challenging works of art and high

quality live music and performing arts,” which found that the length of stay of patients on a trauma and orthopedic ward was one day shorter when they experienced visual arts and live music, and their need for pain relief was significantly less than those in a control group; live music was very effective in reducing levels of anxiety and depression; visual arts and live music reduced levels of depression by one-third in patients undergoing chemotherapy; and staff recruitment and retention were improved.

Of course, a rational approach to integrating design into healing environments should take into account the use of natural light, noise reduction, layout and ergonomics, single-occupancy rooms, ideally with windows on a pleasant aspect and with considered way-finding. In fact, the much-lauded Evidence-Based Design (EBD) seems nothing more than a common-sense approach to design that buys into the vernacular of EBD. Some of the objective truths behind pharmacological gold standard randomized controlled trials, however, defy belief and would warrant a more rigorously forensic level of scrutiny.

Much research around EBD has time and again told us that its rigorous implementation will

- reduce staff stress and fatigue and increase effectiveness in care delivery;
- improve patient safety;
- reduce stress and improving health outcomes; and
- improve overall healthcare quality,²⁹

Given the surge of interest in EBD, there are grotesquely different approaches to commissioning artists and designers in health settings. I have been involved with a number of UK NHS (National Health Service) Trusts whose approach to integrated design or inclusion of the arts amounts to a tick-box exercise; in one case, a chief executive officer demanded complete control over color schemes, way-finding, and furnishings. The resulting aesthetic, while complying with health and safety legislation, looked like an industrial-scale IKEA remainder store. If EBD is in place to reduce the likelihood of ill-formed hospital makeovers, it has to be a good thing, but if it standardizes and reduces hospitals to a corporate aesthetic, we should be skeptical.

What is apparent in much of this field of enquiry, and considering the notion of a third culture, is that the artistic element of this work is often subservient to a broader prescriptive health agenda, potentially reducing it to gloss and decoration—or as former prime minister Tony Blair described it in a Kings Fund report on Healing Environments, “the Wow Factor.”³⁰

One thing that’s certain is that EBD and a broader understanding of the potential of integrating the arts into new healthcare buildings has spawned a range of self-styled consultants, training, accreditation, and glossy websites, all inviting you to buy into the meme that theirs is the solution to all the burgeoning health issues out there: that art and design have all the answers.

Increasingly, designers and artists are thrown a tasty challenge: redesign the hospital patient gown, encourage us all to wash our hands thoroughly, and show us how to

navigate this maze of corridors and clinics. Yet research undertaken by Mary G Lankford and colleagues shows that the most influential factor on hand washing in a clinical environment wasn't the design of the facility but the behavior of senior peers in a clinical team, suggesting "that health-care worker hand-hygiene compliance is influenced significantly by the behaviour of other health-care workers."³¹

While there are examples of inspirational practice, it's critical to note that one size doesn't fit all, and where signage in a large hospital may be crucial, in a smaller setting like the Bromley by Bow Centre,³² signage is an irrelevance: the hospitality, reception, and human interaction are the most powerful means of facilitating the patient journey and potentially affecting change—in other words, interaction and behavior are the significant factors.

I started this chapter imagining the delivery of news of a serious illness—which will in reality affect us all in some way throughout our lives. Bringing this chapter full circle leads me to two such, very real stories: that of Maggie Keswick Jencks³³ and that of a small group of people affected by dementia, who I've had the good fortune to be involved with. Jencks has been the inspiration and motivating factor behind much of my thinking for this chapter, and although I never had the good fortune of meeting her, her experience of being diagnosed with breast cancer and her personal journey perhaps best illustrate the potential of art and design as means of transformative change and the numinous potential of the built environment.

As a caveat, it is important to note here the emerging twenty-first-century secular concept of numinous, as implied by Christopher Hitchens et al.,³⁴ which I define as that feeling of awe, wonderment, or transcendence in the presence of natural beauty or art, or better still, the flow state we enter when we are fully engaged in creative activity. We have ample evidence of the impact of participation not only in the reduction of symptoms of ill health but, pivotally, in increased environmental mastery, personal autonomy, and civic engagement—the very factors that underpin well-being.³⁵

In an article for the *Observer*, Kate Kellaway describes how Jencks, accompanied by her architect husband, Charles, recounted her experience of being given her prognosis by a consultant in an Edinburgh hospital in a way we are all too familiar with: waiting in an "awful interior" with neon lighting, and when asking the consultant, "How long have we got?" being given the reply, "Do you really want to know? Two to three months." Then, ushered into a windowless corridor because of the queue of people waiting to see the consultant, she and Charles were left to deal with these harsh facts.³⁶

It was this experience, however, that set a chain of events in motion and saw Maggie and Charles exploring notions of time, space, and respect: after all, weren't these some of the most crucial needs when facing your own mortality? Maggie clearly "understood the need to feel in charge and not be a helpless passenger in a hospital production line" and devoted the remainder of her life to envisioning how this might happen.³⁷

Over the last decade, the result of this experience has seen one woman's vision articulated into seven Maggie's Centres up and running and seven more in the planning with architects, including among others, Zaha Hadid, Frank Gehry, and Kisho Kurokawa.³⁸



AQ1

FIGURE 54 Nestling in the shadow of Charing Cross Hospital, the roof of Maggie's London, can just be seen. Photograph by Clive Parkinson.

The principles of the centers are very simple, based on what Charles Jencks describes as “the underlying notion that active involvement by patients in their own therapy can make a difference: to their attitude, to their family and friends and perhaps, even their health and outcome.”³⁹ The design of the service and the mixture of architecture and art with the input of influential designers and architects offers the main focus, with four overarching goals:

- lowering the stress levels of patients;
- providing psychological and social support;
- helping navigate the information and treatment overload; and
- offering peace and stimulation.

Writing about her experience of treatment, Maggie describes how “at the moment most hospital environments say to the patient, in effect: ‘How you feel is unimportant. You are not of value. Fit in with us, not us with you.’ With very little effort and money this could be changed to something like: ‘Welcome! And don’t worry. We are here to reassure you, and your treatment will be good and helpful to you.’”⁴⁰

Maggie’s Centres, largely funded by donations, offer exactly this support and care alongside a mix of the imaginative and the domestic, but crucially they place the



FIGURE 55 The fragrant gardens of Maggie's London. Photograph by Clive Parkinson.

individual at the center of the innovation. Visiting the award-winning Richard Rogers–designed Maggie's Centre in London best illustrates how these environments impact the well-being of people affected by cancer and address by proxy some of the concerns highlighted by Abdul Gawande.

The center is hard to spot in the shadow of the 1970s modernist eyesore of Charing Cross Hospital in which it nestles on the permanently grid-locked Fulham Palace Road. Ironic, too, as the hospital's designer, Ralph Tubbs, was responsible for the stunning Dome of Discovery⁴¹ at the Festival of Britain (given free reign with design, what might he have produced for Maggie's?).

Low-level and surrounded by lush foliage, the only sense that you get of this modest-sized building is the flashes of bright terracotta against the harsh backdrop of the hospital. Indeed, it's that startling Mediterranean palette that signals that you are somewhere completely different. The meandering pathway that leads you to the building is less concerned with signage (I don't think there's one in the building at all) than with coercing your curiosity. Your senses are bombarded with fragrances of lemon and rosemary, and the subtropical foliage provides shady nooks to contemplate your arrival.

This path has been taken by over sixty thousand people affected by cancer since it opened in 2008, and I wonder how typical my first impressions were. You enter the building through what feels like a domestic library, lit by the bright summer sky, and emerge straight into a large welcoming kitchen, with a giant wooden table and a fragrant



FIGURE 56 A wood-burning stove at the heart of the center. Photograph Maggie's Centre.

wood-burning stove. Didn't Frank Lloyd-Wright talk about the fire being the heart of any home? And Maggie's Centres certainly make a feature of this communal table, but this isn't a home, and its most definitely not a hospital, but the domestic is central to how this place feels, albeit on an aesthetic spectrum that many of us could only aspire to. And this is exactly what drove Maggie toward this vision—a place where people



FIGURE 57 Maggie's London. Photograph by Clive Parkinson.

facing the hurdles of serious illness would be given reassuring space, away from the harsh machinery of the clinical environment. No smell of detergent here; no clinical edge or staff separated by walls and signs. This is an open-plan space with movable walls, and as I enter, what greets me but the sound of laughter from a support group taking place. Laughter! I spend an hour or so in the center and observe people reading quietly or sitting in huddles deep in conversation. This building is modest, humane, and anything but intimidating. Importantly, it doesn't feel like a pristine space, where you can't relax, but critically (and as highlighted in the Maggie's Architectural Brief) "a calm friendly space where each individual can decide what strategy they want to adopt to support their medical treatment and their overall welfare." This might be managing stress and anxiety; it could be one of the many creative activities, or it might be getting advice with the practical, not least guidance on welfare benefits. In short, it is a place where you can engage deeply in conversation that's appropriate to you.

When I leave the center, I'm told I can take one of the fat, ripe figs growing up among the grapes that I've been eying up while we talked. A truly delicious gift alongside the warmth, exchange, and laughter.

My second story, about dementia, promises for me a more personal journey perhaps of relevance to us all, given our ageing demographic.

I was recently approached by a post-graduate student in three-dimensional design who as part of his master's, wanted to test a product he was working on. Darren

Browett⁴² had been experimenting in new materials creating a range of small, hand-held objects that explored the notion of memento mori: objects loaded with memory, both literal and metaphorical.

Over the same period, I was working with occupational therapists and nursing staff on an NHS dementia assessment unit, exploring ways of engaging with the client group that went beyond reminiscence and singing old-time songs. I'd hoped to build on emerging activity taking place in Milwaukee, Wisconsin, led by Dr. Anne Davis Basting⁴³ and the public engagement work of MoMA: both furthering the work of the psychiatrist Professor Gene Cohen⁴⁴ and the belief that in working with people affected by dementia, we're wrong to focus on the deficits of the person and the symptoms of the disease; we should instead focus on their assets rather than getting bogged down with memory, as singling out the failing aspect of the person will ultimately frustrate and depress them, as Basting puts it in her book *Forget Memory*.⁴⁵

Cohen took this argument further, positing that it's the symptoms of this disease that give us a potential new palette to work with, and when a person affected by dementia displays disinhibited behavior, it is in fact this disinhibition that gives rise to creative potential, often for the first time in a person's life. In short, this step-change in mindset moves away from the signs and symptoms of a disease to a focus on the individual's assets, strengths, and satisfactions—what Cohen referred to as the “four S approach.”⁴⁶

Western culture seems over-reliant on a well-marketed pharmaceutical approach to ill-health and well-being, with an ever-increasing range of preventative medications for those at risk of disease. In the United Kingdom, people with dementia have been routinely prescribed antipsychotic medication as a method of controlling behaviors associated with the disease including wandering aimlessly, aggression, and displays of sexual promiscuity. Although the National Dementia Strategy⁴⁷ aims to address this institutional prescribing, there is an underlying concern that while these behaviors are symptomatic of the disease, they also reflect boredom, lack of liberty, frustration, and fear.

It is within this context that Browett and I tested his design to explore the possibility that his work could elicit conversation and stimulation—bearing in mind the potential of the arts to engage at a deeper emotional level rather than focusing on the intellectual. Browett was initially particularly interested in the potency of relational and shared souvenirs and memory, belonging not solely to one person but existing between people.

Building on the work of Constantin Boym,⁴⁸ investigating moments of collective memory around tragic situations, Browett produced a series of mnemonic devices which, he hypothesized, people could put their feelings into and somehow make memories more permanent: objects that could be loaded with meaning and act somehow as a catalyst to conversation and debate.

Browett took the view that “it is the personal moments that provide the measure and meaning to life, and are the events that shape us. The rights of passage of birth, childhood, love and partnership, old age and death are the emotional milestones making human experiences that are the common properties of mankind across time and culture. Objects that mark out these life events,” which—he suggests, “become personal memorials and reminders of our shared humanity.”⁴⁹

Early on in his exploration, Browett investigated the complex structures of pollen and the “powerful symbolism of seeds as a metaphor to re-connect us with the natural world [representing the] beginning and end of the life of plants, and the rebirth... of seeds and fruit and the endless and ever repeating cycle.”⁵⁰

From this idea of seeds and nature, he crafted prototype designs combining new technologies and handcrafting. From his experimentation, his desire to create beautiful, high-quality, and challenging objects that were loaded with imaginative potential, he created what became known as, his “seedpods.”

The pods are small articulated objects, far more robust than they look, that turn inside out on themselves. Each contains a thermoplastic seed with an embossed design of a domestic object, person, or pet. These objects, no matter how precious they may appear, demand a sense of inquiry through handling and play. I would suggest that these loaded objects offer something very different to a memento mori and possibly offer a powerful vehicle for facilitating difficult conversations akin to a secular *Ars Moriendi*.⁵¹

Using a participatory action research approach to his work, Browett worked with patients, family, and staff to test his design. They had a profound impact on engagement. Here’s what one occupational therapist said:

The patients were fascinated by the shape of the outer object and they shared what they thought the object was, or what it reminded them of, which encouraged thought

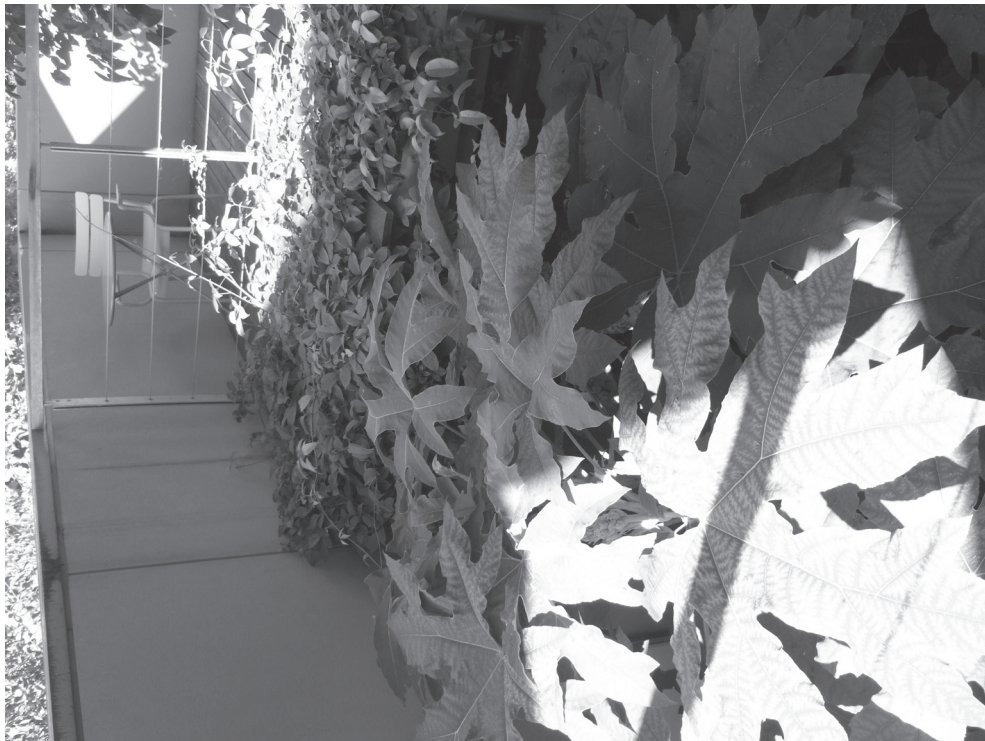


FIGURE 58 Maggie’s London. Photograph by Clive Parkinson.

and communication. They then worked out how to extract the centre... and were drawn to it by the bright colour... and the image etched onto the surface sparked off a whole new set of questions. The objects, stimulated speech, thought and communication... during this session one lady who had significant word finding difficulties, was free of her symptoms.⁵²

This work did impact on memory in the sense that Anne Basting illustrates, where memory is not only an act of retrieval but an act of creative storytelling using imagination based on the here and now, emphasizing that memory is relational and does not belong

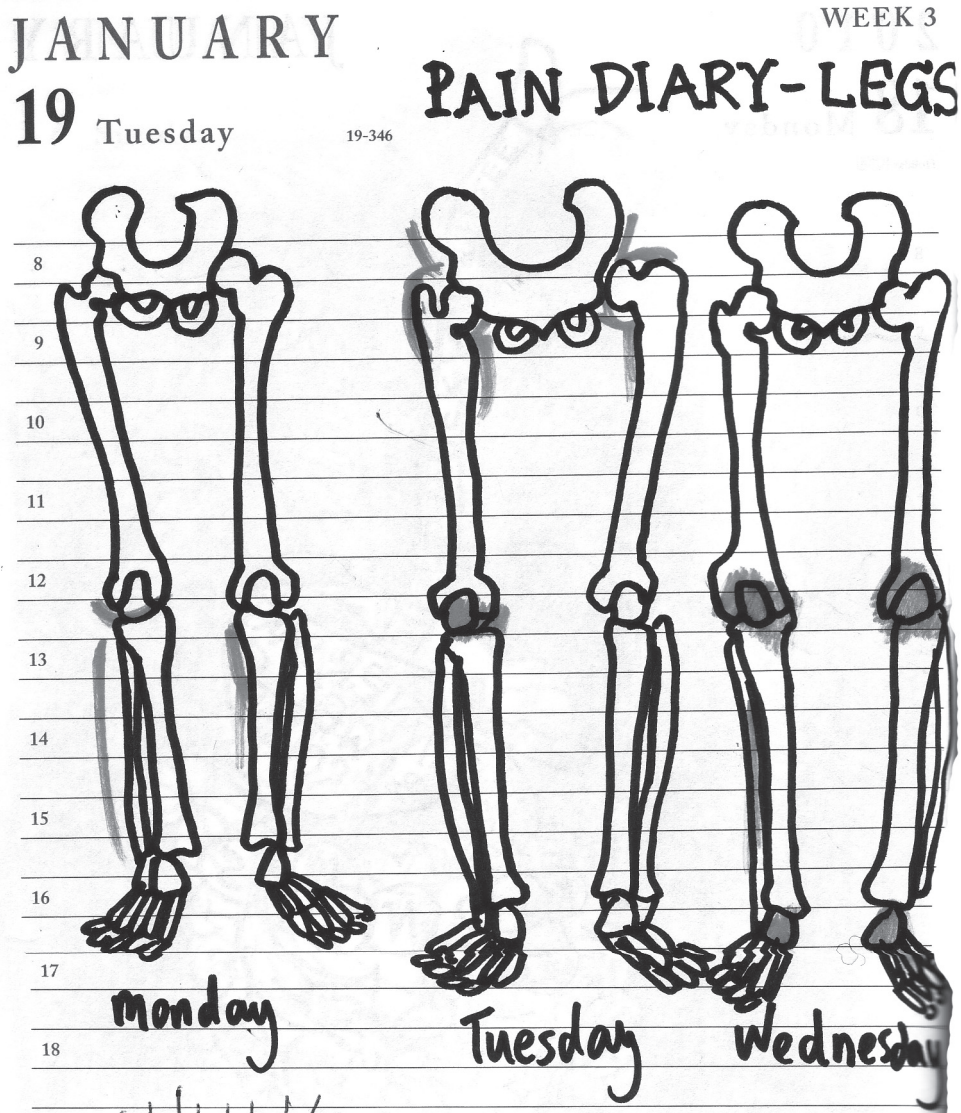


FIGURE 59 Pain Diary Legs. Photograph by Lois Blackburn (Arthur and Martha).

to one person. This small-scale research has established that through challenging design Browett's intervention has enabled

- the making of connections between personal stories and the world at large;
- exploration and exchange of ideas;
- intellectual stimulation and engagement in imaginative activity;
- participation in an activity that fostered personal growth and a wider understanding of the individual; and
- being fully absorbed in the present moment.

It is perhaps this idea of being actively absorbed in the present moment that has the most significance: the potential of regaining part of yourself. Through his practice, Browett aimed to create meaningful objects that aimed to be “cathartic in situations that are considered to be a crisis.”⁵³ He succeeded, with many of the people involved engaging in the activity way beyond the normal few minutes, up to well over an hour—time in which the participants experienced real sentience.

Globally, health services typified by the United Kingdom's fragile NHS are, in very real terms, geared toward the diagnosis and treatment of sickness and not to the promotion of health and well-being. Imagining ourselves, or our loved ones, receiving a diagnosis of a serious illness is useful in beginning to understand the relevance of design and the arts in relation to the condition of being human.

I have suggested that in the face of serious health crises, the arts offer a key to making sense of our experience of being human, and contribute to humanizing the procedures and



FIGURE 60 Wood-burning stove. Photograph Maggie's Centre.

processes of treatment. Research suggests that EBD has some very real impacts on patient outcomes and, by proxy, the potential to impact on economic factors. The temptation of focusing on savings and profit for health providers leads, however, to the old trap of market forces, rather than the ethical context, being the dominant factor in healthcare delivery.



FIGURE 61 Marjorie Raynor. Photograph by Lois Blackburn (Arthur and Martha).

Conspicuous consumption and selfish individualism brought on by a belief in the free market and all that it offers have fed a culture of greed and materialism, which has, in part, led to the current global recession. This same consumer culture has had an insidious effect on health services, which have become target obsessed, competition driven, and rife with inequalities. Design is widely associated with beauty and aspiration and is a potent symbol of celebrity-obsessed superficiality: for whitened, straightened teeth and flawless bronzed skin. Well-being is increasingly associated with the appearance of health, and a burgeoning high-street cosmetic industry is ready to suck out your fat, pump up your lips, and take away your lines. Added to the rise in preventative health technologies, we are witnessing what the general practitioner Iona Heath describes as “a new arena of human greed, which responds to an enduring fear.”⁵⁴ Our selfish individualism may also enable us to take the notion of interior design to its inevitable limits through customized DNA profiling, sex selection, and shopping list kit-formed children of the future.

We have bought into the consumer myth of our own invincibility wholesale, and our relationship with clinicians reflects this “customer is always right” retail market reality. Because I have succumbed to male-pattern baldness and the inevitable macular degeneration associated with my long years, should I treat these as disease or an inevitable consequence of ageing? Clearly I can buy eyeglasses, probably one of the most successfully designed and marketed medical devices available; I could even go the whole hog and have a hair transplant. Here then is my plea to designers, scientists, artists, and philosophers: as future patients, we must collaborate around our often divergent vision with one another to affect a paradigm shift in the way health is perceived and well-being is nurtured. There are enormous and challenging ideas to test, and the ways in which we support people toward the end of their lives should be central to this conversation.

Jonah Lehrer describes the tensions between science and art and suggests that building on C. P. Snow’s third culture, in which “scientists and artists continue to describe the world in incommensurate languages”⁵⁵ that we aspire to a fourth culture in which, “art and science can be useful, and both can be true,” with art acting as “a necessary counterbalance to the glories and excesses of scientific reductionism, especially as they are applied to the human experience.”⁵⁶

Writing in the *British Medical Journal*, Iona Heath provides us with some difficult food for thought around this conversation on ageing, illness, and mortality. Heath suggests that as governments strive to reduce mortality, they are ultimately fighting a losing battle, as “the mortality rate for the population will always be 100%, [and if] we continue to fight all causes of mortality, particularly in extreme old age, we have no hope of success, and we will consume an ever increasing proportion of healthcare resources for ever diminishing returns.”⁵⁷

In her paper “What Do We Want to Die From?” Heath describes the natural process of death in old age and the trap that clinicians find themselves in, as their efforts to treat one disease is met by another that takes its place. Despite all the evidence, preventative medicines like statins are prescribed to people over 70, which successfully reduce deaths from cardiovascular disease, only to increase mortality rates through cancer and

dementia. She cites a U.S. study of care in people dying of advanced cancer or dementia in acute hospitals, which found that “for 24% of both groups cardiopulmonary resuscitation was attempted and that 55% of those with dementia died with feeding tubes in place.”⁵⁸ Her explicit question is, “Is this what we want for ourselves or those we love—or indeed for anyone?”⁵⁹

Succinctly, Heath comments, “Authentic health care for the old and frail has much more to do with helping to preserve their dignity, treating them with affection, and supporting their continued involvement in social activities, rather than the pursuit of ever-more elusive cures.”⁶⁰ As I write this chapter, an argument is raging in the United Kingdom about assisted dying: as one of the last great taboos in society, this ethical minefield is one our fourth culture should engage in.

While patient involvement in healthcare is well-established, there is still a feeling of tokenism, lack of vision, and genuine voice. Experience-Based Design, offers something beyond Evidence-Based Design which puts patients’ and users’ experience at the heart of the process, echoing Kath Weston’s call for theory that comes from people outside of the academic (straight) sphere, which she describes as “Street Theory,” and which offers “a wellspring of explanatory devices and rhetorical strategies in their own right.”⁶¹ Experience-Based Design, as Paul Bate and Glenn Robert illustrate perfectly, pushes “to widen and intensify the search for ‘better’ and more effective theories and approaches to transformation, particularly those at the participative end of the spectrum.”⁶²

The UK Alzheimer 100 project has seen codesign put into practice and has involved “stakeholders of dementia to generate ideas and make decisions based on their experiences, rather than focusing on only improving technology and drugs.”⁶³ My own work in the NHS builds on that of Darren Browett and has opened up the possibility of patients, caregivers, and staff influencing the design of a new dedicated dementia treatment center and giving voice to patient treatment options.



AQ2 FIGURE 62 *Fortuitous Novelties* (seed pods) by Darren Browett.

Perhaps Experience-Based Design will enable genuine engagement with civic society, in relation to health and well-being, and the broader conversations around our experience of life care, which while challenging, will present the most innovative of collaborations with the greatest of opportunities.

Gene Cohen reminds us, that “the optimal treatment of the patient focuses not just on clinical problems but also on the individual potential of that person. It’s only when problems and potential are considered together that health is best promoted and illness best cared for. This is the ultimate art and creativity of medicine and healthcare.”⁶⁴

Through divergent thinking and convergent collaboration, the arts and sciences offer us something bigger than our transient individual egos. Designers, scientists, artists, and philosophers can facilitate something profound and nonprescribed. By engaging with wider society and addressing the deficit of imagination posited by Richard Smith,⁶⁵ this fourth culture can inform and influence a generational cultural shift around how health and well-being are understood, and ultimately how we care for each other.

Can the arts cure cancer or dementia? Of course not. But in the face of serious illness and our own mortality, do the arts have any real relevance? I suggest that the connection is profound and yet incredibly subtle. The design of Maggie’s Centres and the craftsmanship of Darren Browett’s seedpods are equally uplifting and life-affirming, and neither were intended as vehicles for discussions on mortality, but both offer new opportunities for deeply meaningful interaction. Our fourth culture dialogue should be less focused on superficiality and gloss and more deeply engaged with a new philosophy of how we live our lives and, explicitly, end our days. A difficult conversation perhaps but one that the arts are best placed to address, enabling a new humanist aesthetic that not only stimulates and provokes our senses but facilitates breakpoint discussion.⁶⁶