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this is not a piece of research

I need to say this –
make it **crystal clear** –
start as I mean to go on.

this is a minor celebration,
a cause for concern,
maybe a call to **action.**

This is an account of people, wonderful people, interacting. It's a story of sorts, so read it as you would your newspaper, like an account of a royal wedding, or the latest saga in a celebrity relationship (though perhaps with less of the superficiality), and read it with an eye to the future – your future, all our futures. Maybe, just maybe, it's that little bit more important than celebrity culture, because it's about us – you and me – everyday people, and how we live and die.

But, wait a minute, better still, imagine the person you love the most –

your best friend,
your lover,
your brother or sister,
your father or your
mother.

Yes, that's it, let's say this is a story of your mother.

Just think of her name: whenever I use the name Jenny, think of your dear old mum... but remember, it's not research, this, but it is real life, so Jenny is a name that is nothing like the woman I have in mind, the real flesh and blood woman who sometimes cries at night as she tries to find her way home, tries to crawl away from a hospital ward, back to her family. In part, this is the story of a woman who has apparently lost the ability to find words and is just waiting – waiting for what?

Don't think too hard about this waiting, though, it will torture you. OK, you've got it. This is not a piece of research and it's not a hospital report on waiting times, cost efficiencies and targets, but it is real life, wrapped up in a story – the story of one person from a group of men and women I've had the pleasure to meet and work with. A woman affected by memory loss in the later years of her life, living with that thing we call

dementia.

I work with artists and designers – people with big imaginations, sometimes with preposterous ideas and other times with real vision – conceptual and practical, challenging and empathetic.

I want to share my thoughts on why art, design, culture, creativity – whatever we want to call it – is relevant to us when we think about our health.

More than this, I want to share why I think it affects people's wellbeing – even with a diagnosis of a serious illness, or disease, like dementia. So, art and dementia – or, in this case, design and dementia.

First, a memory of my own.

As a child, I witnessed my grandmother slowly changing as she got older, and she was always old – really old – to me. She was Edwardian. She had dressed in dark clothes since my grandfather had died, long before I was born.

Her hair was silver and always scraped tightly into a bun on top of her head. I saw her most weeks, and, over a very long period of time, she started to forget, she'd pluck at her skirt and say the funniest of things. As a boy, I'd laugh nervously, but say daft things back. We'd often laugh together. I started to hear the term 'senile' being used, and, once or twice, she'd remonstrate with other family members about not wanting to go 'up there', to the Victorian asylum that overshadowed the town from the top of the hill.

As her health deteriorated and my family could no longer cope, she was, indeed, admitted to the Lancaster Moor Hospital,¹ and, over a short period of time, her transformation from matriarch to patient became complete. Weekly visits saw her incrementally stripped of her individuality – the most potent images, for me, being the removal of her teeth, and her hair, her beautifully long hair, being freed from that tight bun. Wild and shocking, I'd never seen it loose, and now there she was, sat in a large and damp, ox-blood vinyl Buxton Chair,² apparently lost to the world, speechless, crying and so, so tiny.

Out of the blue, my parents were advised that she was very poorly and we should see her as soon as possible. We all went and visited her, now confined to her bed, and, underneath the starched, white sheets, she appeared smaller than ever, her hair fanned out around her face like a silver halo. She seemed calm but utterly confused and, in a bid to make light of a situation that unnerved me, I played the fool – singing and dancing, insensitive to the gravity of the situation.

My parents tutted and asked me to stop, but, from some distant place, my grandmother opened her tired, grey eyes, fixed me with a steely stare and, with a hint of the naughty smile I knew, she said, as clear as glass, "Give over you daft beggar." These were the last words she ever spoke, when all word-finding had apparently long-gone. She died a few days later. What had happened in those moments when the nervous boy had entertained her like some court jester?

So imagine, it's almost 30 years after that event – an event that's been lodged in the back of my mind all this time – and I'm with a group of men and women at very different stages in their lives and with a variety of dementias. I am sitting with a woman; we are holding hands briefly, and we are working very closely. She's looking a bit concerned, and I put a small and delicate object in her hands; I cup her hands around this seemingly precious jewel; her frown fades, and she begins to talk – to ask questions. "What is it, what's it for?" She holds it close to her eyes, rotates and manipulates it in her fingers – cautious at first, but increasingly confident. "Who made it? Oh, it's beautiful, you could put it in a gallery – you should sell it."

this is Jenny, the small dignified woman with silver hair who spends much of her day fretful, wanting to go home and increasingly

lost for words

my time with her, over four separate days, sees her animated and engaged for well over an hour each time.

Let me tell you a little about my time with Jenny, how we got to that moment and what it was that fired up her imagination. A few years ago, Derbyshire Community Health Services NHS Trust (DCHS)³ approached my organisation, Arts for Health at MMU,⁴ to explore how the arts and creativity might be used within their Trust.

By meeting patients and staff across the organisation and community, I built up a picture of how culture and the arts might support the health and wellbeing agenda. Some of those early ideas were about creating calmer and more welcoming hospital spaces; some were about delivering health messages in more appealing and engaging ways, but one of the first things we explored was how we can think differently – be a little more creative in the way we work with people, and focus more on wellbeing and less on sickness.

At the same time, I was supporting clinical staff on wards, thinking about translating some of the ideas we were sharing into reality. There was a culture of wanting to try out new ideas and a can-do approach to salutogenesis, or health-creation. Nowhere was this enthusiasm in more abundance than on Riverside Ward – a dementia assessment unit, where staff always welcomed new ideas to support the care they offer to their patients.

Over the same period, I was approached by the designer, Darren Browett,⁶ who wanted me to help him identify ways of testing his work within a health context. Darren was creating a range of objects that acted as a way of triggering memory and engagement – a kind-of memento mori. In particular, he was exploring the relationship between the elements of the natural world, of the circle of life, of seeds and regeneration, and he had created small articulated wooden shapes, rather like seed pods from a tree. Think of shiny brown conkers, hidden inside their spiky protective casings, only in this case, the outer layer hides embossed, shiny, coloured plastic ‘seeds’.

The diagnosis of any life-changing condition is always going to knock us for six, and living with an often uncertain prognosis seems to result in the slow diminution of opportunities as those around us focus more on what we can't do and less on what we can. What had happened to my grandmother all those years ago and what was happening to Jenny now? How had a woman who had supposedly lost her word-finding capabilities suddenly become animated, asking questions that were entirely appropriate? Not only had Jenny seemed somehow transformed, but all the other members of this small group found themselves deeply engaged in something that was a million miles away from daytime television, more sociable than communal lunch-times and far removed from the potential distress of routine medical examinations.

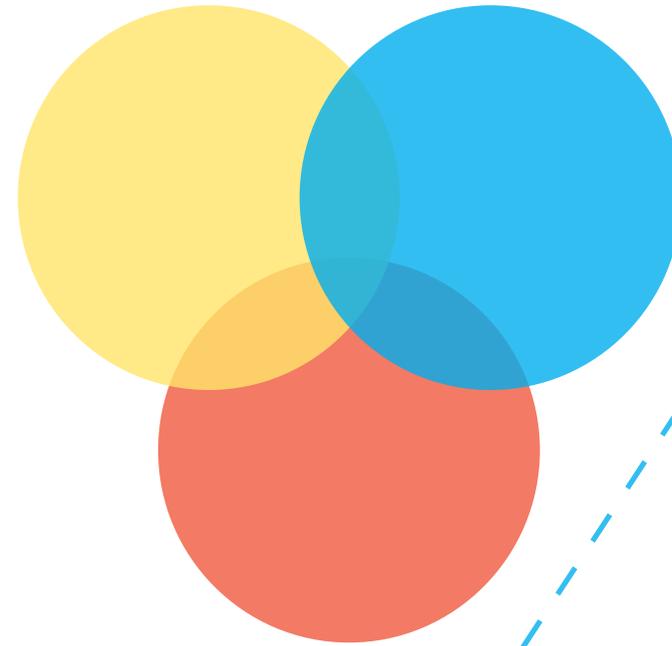
Darren had an opportunity to share this work with people staying on Riverside, and with the support of the forward-thinking Occupational Therapy team, he was able to experience how a well-designed but simple idea can have a profound impact on the most vulnerable people: people who are disabled by their health, who are losing their confidence and living out their diagnosis:

no longer an individual,
but a patient –
someone we pity or fear,
knowing that there is no magic
cure for memory loss.

It would be easy to assume that it was this level of physical engagement alone which had provoked a response, but I want to suggest that it's a lot more than this. I want to suggest that this object offers an Aesthetic Third,⁷ which has mediated a far deeper interaction.

Aesthetic Third?
Sounds mysterious, doesn't it? It's not; it's just a useful way of thinking about how the arts – in this case a beautifully designed object – might be a potent resource for creating conducive time and space. And it may just have an impact on quality of life that goes beyond disease management – to promoting our wellbeing, beyond prescriptions and sedatives. Let me explain.

So what was all this about? What was happening? Most certainly, the sessions that I'd been involved in were warm and engaging; people were given attention, gently and calmly. When we shared these three-dimensional sculptures, we often helped each other, cupping hands around them, encouraging exploration. More often than not, we were physically close to each other, curious about these precious little objects. Perhaps that level of close interaction helps, because, as we get older, we tend to lack the physical contact associated with intimacy, with youth, with vitality.



through active creative engagement,
people had been given time and space to be
more than the symptoms of ill-health
by which they had become defined – they had been
enabled to be themselves.

Imagine the person you love – imagine yourself – tired, anxious, bored or angry, all these things and more. Day in, day out, a deepening restlessness – less and less is interesting, more and more is disconcerting, sometimes frightening. You feel patronised, embarrassed and so, so frustrated. Imagine too, that in these dark moments, someone occasionally takes you by the hand, away from the inane chatter of the TV, from your fitful drifting sleep, and shares something with you – something like jewellery – it looks so fragile, you're a bit nervous to touch it. But then it's in your hands, and it feels different to anything else you've ever touched. And something's happening; you're curious about this thing – you're not sure what it is, whether it might break – but people are reassuring you that it doesn't matter. Perhaps it reminds you of something – or maybe not – but it's certainly intriguing you. And someone else is passing you another one, but this one is different, a different colour and a different smell too. There are one or two other people sat around with you, and you're swapping these rattling, beautiful things between each other. There's a gentle buzz of excitement in the room, and one of the other

women, who's been turning it over and over in her hands, peers deeply into the little cage, holds it close to her face and tells us, after a moment's contemplation, that it's like a "bird in a gilded cage." This is a pivotal moment, rich and pregnant with meaning, shared and exciting. We look at each other and all know that this is some kind of poetry. Then we laugh. In fact, there are peels of laughter about an old music hall song,⁸ but people like this image, and they are scouring their imaginations for other ways of describing this object. It is this object that sits between you, the person living with memory loss, and you, the carer, the clinician or friend – this is the Aesthetic Third, the 'thing' that offers a space, or a moment between other realities. It can be a loaded moment to focus down into meaningful conversation or, as in this case, a moment of liberation and escape from fear and worry and into a moment of deep, imaginative engagement and pleasure. Watching this happening from the outside is moving, perhaps because you'd given up hope that you'd see your partner laugh again, or perhaps because your mum had been ill for a long time, but then, here she is, connecting with you, connecting with the world, delighting in the moment. Transformed for a time.

keep this idea in mind:
transformation.⁹

Here's the nub, then.

Someone with memory loss is going through something that unquestionably changes them, changes you and alters the way we all relate to each other. Inevitably, we all want to find ways of treating dementia. Neuroscience and medicine offer us tantalising glimpses of what might be possible, but they are some distance from that elixir, that magic bullet we crave to know exists which will 'cure' dementia.

We know, too, that, as we survive more and more of life's diseases, we inevitably live longer, so the way we live healthily with dementia – the way we maintain our wellbeing and are personally fulfilled, regardless of our diagnosis – is of profound importance.

Pharmacology, surgery and talking therapies have had a huge impact on our lives. Our understanding of disease and trauma is also expanding exponentially, with near-global eradication of diseases like polio symbolising the potency of mass immunisation, and people's survival of, and with, cancers steadily improving. Antipsychotic medication has had a powerful impact on the lives of people experiencing extremes of mental ill-health, but its overuse in attempts to manage difficult behaviours, sometimes associated with dementia, has contributed to a reduction in quality of life for those it's intended to help...

something popular culture
calls the chemical
straight-jacket.¹⁶
you are right to shudder.

This arts and health story is about how we might live well, regardless of our diagnosis, and, whilst we might easily understand the relationship between science, medicine and health, the relationship between culture, the arts and wellbeing might not be as readily obvious. It's a story made more difficult to tell because of the desperate aspiration of some to slavishly apply scientific criteria in a bid to understand the impact of interactions like the one experienced by Jenny.

Such a clinical way of attempting to understand Jenny's fleeting moments of sentience runs the risk of forgetting who we are as people, reducing her to cold analysis.

wouldn't this undermine everything
we have been doing?
The arts cannot cure dementia.
I'm not saying they can.
I'd never suggest such a thing.¹¹

Those who argue that we need to understand cultural interventions only in the language of pseudo-science or through cost-benefit analysis-

weighing out human life

in pounds, shillings and pence – are missing the point. If we aspire to have this kind of arts-based intervention understood as a clinical process, we're confusing things. It's not clinical, it's cultural; and it's complimentary, adding to clinical care, rather than undermining it.

The arts aren't a cure-all, and it's not always relevant to be thinking outside the box – there are times when only professional, clinical judgment and compassionate care will do. This is what the NHS does so well. But, in light of the seemingly growing number of national complaints about unacceptable care and neglect, the time is right to focus on the quality of the lived experienced in NHS and other care settings.

If any of us observe these moments of what I call transformation, in which someone who has apparently become so confused by their illness – lost for words and utterly depressed – is lifted by this creative engagement, isn't it essential that artists and health professionals work more closely to enable these moments?

When we see imagination opening up and people engaging in deeper conversation – becoming sentient – we should explore and understand, but in ways that respect those of us who are most vulnerable, and in ways that allow us to explore our values without undermining the cultural engagement.

In the UK today, we are told that we are all equal. Yet, when disease takes away our ability to make decisions about our day-to-day lives, it's difficult to really achieve equality. Rather distressingly, we take inequalities for granted. We accept that the rich are rich, the poor are poor and we all (more or less) crave the same things in life – the giant flat-screen TV, the latest well-marketed gadgets. But inequalities affect our health, our education and our opportunities in life, and this includes our access to culture and the arts. A civil society can be evidenced by the way it cares for its most marginalised or vulnerable members, by how it cares for those we love towards the end of their lives. If deep creative engagement improves the quality of this stage of our lives, shouldn't this opportunity for deep cultural engagement be available to all of us, regardless of our economic status?

So let's not think about what I'm sharing in terms of singular clinical measurements. Let's begin to think about new ways of understanding how these kinds of opportunities add to the quality of the lives of people we care for, the most vulnerable and isolated. Yes, let's think in terms of care and quality. Artists, designers and all those artisans too numerous to name, what they do is maverick; what they do can challenge, comfort and provoke.

This work is not about morbidity and pathology – the things that are going wrong. This is about who we are, as humans of flesh and blood, emotion and imagination. Don't think for a moment that this is a prescription for a benign, nostalgic singing of songs from our youth.

Whilst, for some, such engaged moments will instil relaxation and calm, the transformation I allude to can also provide some home truths. When any of us are deeply engaged in something – involved in that story, moved by that music, engrossed in that film – more than this, when we are in the moment, in that flow state and alive to our feelings, this is more than some cultural sedative; this is a powerful stimulant.

this isn't simply a question
of added value; this is a
question of our moral
values in contemporary
society.

Over the past decade, the NHS has invested in new buildings and the appearance of a sophisticated 21st century health service.

The time is now ripe to look beyond the gilded facade to the quality of care that it offers.

This is art in the public realm, but in the most critical of environments and contexts.

this is about our most vulnerable people, and how we contribute to lives fully lived.

It is incumbent upon us to provide the most sensitive, skilful and compassionate support to those most in need.

Let us re-imagine our lives, yours and mine and those we love, in ways that move beyond the purely functional – beyond the endurance of the waiting room and well-marketed dream of immortality – and let us enable small opportunities to flourish in the here and now.

some thoughts to ponder:

how do we round off a life well lived?

can we experience wellbeing towards the end of our lives regardless of ill-health?

we are bombarded with stories of neglect and, worse, abuse.
what are our values?

what are these waiting rooms, these gilded warehouses?

that television switched onto daytime tv no longer makes sense –
its white noise and poisonous ambience are pernicious.

making conversation with someone you care about is so,
so difficult when they are very poorly;
how many times must we talk about the weather, the tv or the food?

when memories are confused or faded, imagination is possible.

how can we provide windows of opportunity – moments to flourish?

Footnotes

1 Lancaster Moor Hospital was opened in 1816 as the 'County Lunatic Asylum for the County Palatine of Lancaster'. It closed in 1999.

http://www.asylumprojects.org/index.php?title=Lancaster_Moor_Hospital

2 Buxton Chair

The House of Commons Health Committee, second report on Elder Abuse, Ordered by The House of Commons and printed 24 March 2004 (page 22) described the Buxton Chair as "a chair that is used to restrain patients and restrict their movements. It can be tilted backwards to prevent attempts to leave it and also has a table which can be locked across the patient's lap". The report states "...that inappropriate management of behaviour or inappropriate forms of restraint were a form of physical abuse and might constitute criminal offences. (including) Misuse of equipment or furniture beyond its intended purpose (for example, misuse of bedrails or 'Buxton' chairs)."

<http://www.publications.parliament.uk/pa/cm200304/cmselect/cmhealth/111/111.pdf>

3 DCHS

Derbyshire Community Health Services NHS Trust is a large and complex organisation employing more than 5,000 staff with an annual income of approximately £148 million.

It is one of the largest NHS provider organisations in the country, offering a range of different services, including Riverside Ward, which is part of older people's mental health services. <http://www.dchs.nhs.uk/>

4

Arts for Health at Manchester Metropolitan University is the UK's longest established arts and health organisation, specialising in research, advocacy and development. Following the *Invest to Save: Arts in Health* research project that unpicked the relationship between environment and culture on wellbeing. Arts for Health at MMU has continued its strategic partnership with the Department of Health at local, regional and national levels. It continues to work with and support the strategic vision of Arts Council England. Arts for Health is currently engaged in a number of research, evaluation and advocacy projects and is about to embark on a multi-disciplinary research project, funded by the Arts and Humanities Research Council's Connected Communities stream. This work will explore Dementia and the Imagination asking, in particular, how can visual arts interventions change, sustain and catalyse community cultures, beliefs, attitudes and behaviours to create dementia friendly communities?

<http://www.artsforhealth.org/>

5

Salutogenesis is a term coined by medical sociologist Aaron Antonovsky in his 1987 book, *Unraveling the Mysteries of Health* which describes an approach that focuses on factors supporting human health and wellbeing, rather than on factors causing disease. More specifically, the 'salutogenic model' is concerned with the relationship between health, stress and coping.

<http://en.wikipedia.org/wiki/Salutogenesis>

6 Darren Browett's *Fortuitous Novelties Seedpods* represent a succinct example of crafted objects in a given context, concerned with an ideas-based approach alongside an investigation of materials and techniques. Exploring human rites of passage in situations of enforced change, Browett creates meaningful objects that aim to be cathartic.
<http://darrenbrowett.wordpress.com/>

7 The Aesthetic Third
[...] contains both something of the individual and something of the world, meaningfully conjoined. It is in the link – the experience of being meaningfully conjoined with a bit of the world that well-being resides. The fact that the bit of the world in question is not only a cultural object or process outside of the self – but an object of wonder, curiosity or delight, can only enhance the pleasure in the link. The sense of discovery is not only the discovery of something new, as is often thought, it is the discovery of a personal relation to something new – an enriching expansion of relational possibilities.
New Model Visual Arts Organisations, Froggett, Lynn et al, Psychosocial Research Unit, University of Central Lancashire, 2011 (page 98)

8 A Bird in a Gilded Cage is a song composed by Arthur J. Lamb (lyrics) and Harry Von Tilzer. The song describes the sad life of a beautiful woman who has married for money instead of love, and was one of the most popular songs of 1900. A 1904 recording sung by Harry Anthony is available at: <https://vimeo.com/64883066>

Here is the chorus

"She's only a bird in a gilded cage,
a beautiful sight to see,
you may think she's happy and free from care,
she's not, though she seems to be,
'tis sad when you think of her wasted life,
for youth cannot mate with age,
and her beauty was sold,
for an old man's gold,
she's a bird in a gilded cage."

9 The term Transformation embodies unproven assumptions about the impact of the arts, and is avoided in peer reviewed journals. As such, I embrace it for what it is – ambiguous, subjective and self-explanatory. Research undertaken by Arts for Health in 2007 explored the relationship between the cultural context and environment in which arts/health activity takes place.

Through a mixed methodological approach, the impact of the arts and cultural interventions on health and wellbeing was interrogated. Gathering quantitative and qualitative data and engaging with project stakeholders through appreciative enquiry enabled rich data collection and a deeper understanding of patient and participant voice.

Crucially, this evidenced reduction in symptoms of stress, anxiety and depression, and significantly, an increase in the mechanisms that enable wellbeing to take place. The concept of eudemonic wellbeing, or ‘active’ wellbeing alongside the idea of personal and group transformation was a strong theme that emerged throughout the research and in particular, the idea of being able to ‘practice being well.’

<http://www.miriad.mmu.ac.uk/investtosave/reports/>

10 Chemical Straightjacket or Chemical Cosh are colloquial names for the antipsychotic sedatives sometimes used inappropriately to control what is regarded as ‘difficult’ behaviour in people affected by dementia.

<http://www.bbc.co.uk/news/health-13698487>

11 Some thoughts on excellence

The links between the arts and dementia are not new, and examples of excellence are abundant, as are more dubious claims of impact. A starting point, for me, was the inspirational Meet me at MoMA project at the Museum of Modern Art in New York. This programme’s inspiring Gallery Educator, Carrie McGee, introduced me to Dr. Anne Basting, author of Forget Memory: Creating Better Lives for People with Dementia and founder of Time Slips and The Penelope Project.

I’m indebted to them both for supporting the artist, Claire Ford, who is ploughing a unique furrow in bringing the digital arts to people with dementia through her iPad engAGE project.

<http://www.moma.org/meetme/>

<http://www.timeslips.org/>

<http://enrichinglifewithcreativeexpression.blogspot.co.uk/>

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