

Tapping Curiosity

reflections on spirituality, dementia and ageing

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A heartfelt thank you...

In the tradition of Aboriginal people I acknowledge and thank my elders from the past, present and future for my voyage of discovery, enchantment and enlightenment. I thank them for letting me ask difficult questions, inspiring me with beautiful responses and being very generous with their time.

As a member of the next generation of elders I accept responsibility for holding the wisdom, lore, law and cultural and spiritual values for a future global family.

I would like to thank The Winston Churchill Memorial Trust and The Baring Foundation for enabling my learning and my new found friendships.

To new friends a heartfelt thanks for supporting my adventure: Martha Pollard, Faith in Older People, Melanie Henwood, Anne Basting, Robin Mello, Susan McFadden, John McFadden, Lynden Esdaile, Arts Outwest, Christine McMillan, Tracey Callinan, Aleshia Lonsdale, Jimmy Beale, Aunty Gloria Rogers, Warranha and Meg Hegarty.

To very dear old friends, Spare Tyre Trustees and colleagues, and of course my family - your excitement has been inspirational. So you will not be surprised to learn there will be more adventures in due course.

Arti

Introduction

This paper consists of my reflections on spirituality, dementia and ageing. I want this paper to be thought provoking, raise questions, encourage risk taking, creativity and solutions.

The reflections in this paper can be summed up in three words:
Imagination. Compassion. Stillness.

I have always considered imagination to be vital to creativity, without tapping into this curiosity I would not have achieved what I have. I consider all individuals that I encounter as creative, passionate beings.

I acknowledge that compassion is a vital component of connection and collaboration with people, artists, participants and colleagues. It goes a long way to understanding the strength in difference.

Stillness and its importance is the greatest discovery I have made over this past year or so. It's influence and power needs better acknowledgement in our lives today and especially at end of life.

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Imagination



Swastika found in many ancient beliefs including Native American tribes and Hinduism

Setting the scene

I guess you call it serendipity when your world begins to collide with an organisation - in this case Winston Churchill Memorial Trust (WCMT) - and leads towards you putting in an application for a travel bursary to explore your chosen area. Yes it was serendipity, my fate, my destiny.

It began in 2012.

A minute before the deadline I pressed the send button with my application whilst in the sticks in Scotland with everything crossed that the wifi would work and whisk my wants and wishes to London.

It did.

At that stage I had decided to go to the USA and Australia and research care facilities that specialized in 'person-centred' care, namely The Eden Alternative¹ and Spark of Life². The values of these two agencies echoed my own at the time. I wanted to experience the approaches in action from original organisation in the USA to interpretation in Australia.

It was empowering and a very welcome relief to discover that WCMT were supportive of personal growth through world travel that would inform my future practice without focusing on clearly stated outcomes or key performance indicators (KPIs).

Arts practice in the areas of ageing and memory loss in the UK is exploding because arts, health, wellbeing are very current areas especially in the participatory arts sector and it is where there will be future growth in funding. There is already much good practice in the UK that deserves better recognition like Equal Arts, Collective Encounters, John Killick, FACT to name but a very few³.

During 2011 I met Martha Pollard at Edinburgh University, who in turn introduced me to ministry, spirituality and dementia in Scotland whilst we (Spare Tyre) were researching 'Still Life Dreaming' to perform at the Edinburgh Fringe Festival. The themes for this new play

¹www.edenalt.org

² www.dementiacareaustralia.com

³The Baring Foundation is a good source for good arts practitioners

were cognitive ageing, IQ testing and the Wellcome Trust. It was a challenging project but resulted in many new partnerships and connections, and perhaps more importantly made the dreams of several older people come true by enabling them to perform at the festival.

I had spoken with Martha about Spare Tyre's dementia programme **Once Upon a Time**. She became an advocate for our work in Scotland and remains a friend. This programme was a part of the Luminate Festival 2012 and toured around Aberdeenshire, and further inspired me to continue with developing projects for people with advanced dementia and their carers.

My focus became ageing and memory loss. And to tap some of this curiosity I went to Bristol⁴, Derby⁵ and Edinburgh⁶ to begin the background research.

My curiosity began to have a focus on memory loss and the issues that surround it, namely that we seem to value the mind over the body and spirit/soul. We seem to accept an ageing body better than an ageing mind.

Why are we - in the developed world - so afraid of forgetting? Why does witnessing our parents loss of inhibitions make us uncomfortable? What is the role of acceptance?

I had been told on numerous occasions that it was not going to be easy to contact Aboriginal artists, to meet and talk with the community...but I have patience and I come from a place that understands displacement as an East African Asian.

Early 2013 at the Cultural Health and Wellbeing conference in Bristol, I came across presentations from people in New Zealand and Australia. A quick five minute chat connected me with visual artist Christine McMillan, Arts and Health Co-ordinator for Arts Outwest, which in turn connected me to Aboriginal artists.

In Australia I visited a community that had intentionally been decimated, one that was now searching for its identity and culture and trying to slowly reclaim it; re-awaken it without anger and with much humility. I met individuals from 'The Stolen Generation'. They have inspired many of my reflections in this paper. The Stolen Generation are children who were taken away from their Aboriginal families and given to white families to bring up without acknowledging their traditional, cultural or linguistic backgrounds. They have suffered what I call generational memory loss.

2013 I attended the Faith in Older People conference in Edinburgh and presented 'Once Upon a Time' under the broad theme of giving and receiving gifts.

Again call it serendipity but I met lots of likeminded people there like Susan McFadden and Meg Hegarty. It was like coming home. Conversations did not start with explanations about arts and dementia; they began with a shared language.

I met many experts, academics, peers, charities all deeply involved in arts and dementia, ageing, palliative care, theology and philosophy. Critically I received understanding and

⁴Cultural Health and Wellbeing Conference 2013 www.ahsw.org.uk

⁵www.wirksworthfestival.co.uk

⁶5th International Conference on Ageing and Spirituality www.fiop-mha.events-made-easy.com

respect for my own arts practice in this area and the cultural and political perspectives that comes with it, namely Hinduism, East Africa, India and its sense of theatre and ritual.

I was overwhelmed with excitement by these few days. I was amongst very learned people, eating, drinking, laughing and dancing. This experience focused my future travel plans and as time passed I decided that my interest lay in ageing, collective memory loss and its expression as a creative force. And I wanted to investigate this with indigenous people in the USA and Australia.

Tapping curiosity

*“Where the hand goes there is the eye,
where the eye goes there is the mind,
where there is thought there is emotion”*
- Bharatnatyam saying

My curiosity took me down this path: to investigate memory and the impact of loss of memory for the person, the family, the community, and across generations.

Another question arising from working with people on the advanced dementia spectrum was the question of spiritual pathways and experiences towards end of life. What do we mean by pastoral care and ministry? And what is the role of the arts in this environment?

My creative practice uses rituals taken from our everyday lives, culture, religions, families and social conventions. It questions, challenges or embraces our sometimes-shared morals and values. It asks for openness of mind, appreciation and eventual understanding. It seeks empathy in artist, audience and participant and is designed to make you feel the spectrum of emotions: anger confusion joy love sadness. It awakens the senses by intense interaction with smell, sound, taste, sight and touch and the use of new technologies to enhance the moments of what is increasingly being termed as meaningful engagement. It is about being there, being still, listening, and not fearing silence.

This practice asks you to learn different languages - the language of stillness, the language of words, gesture, eye contact and physical contact. It asks you to be thoughtful and mindful of ‘the other’, and of letting go of self.

It is well expressed in the Te Ngakau Waiora Mercy Spirituality Centre core values in Auckland, New Zealand:

“te tapu o te tangata”	respect for human dignity
“aroha”	compassion
“aroha kit e rawa kore”	concern for the poor and vulnerable
“tika”	justice
“manaakitanga”	hospitality
“mana whakahaere”	mutual empowerment

This form of practice relies on collaboration, being open to question and investigation, generous with ideas without ego. It asks artists to be highly alert to all around them and respond and engage with that, learning and understanding the language of the other without dismissing it as unimportant. Enabling the voiceless to be listened to and heard no matter how difficult the story, paying attention to body, gesture and tone of voice rather than the words. As humans we communicate and connect in many different ways, there is no one way, there is only our imagination and how it can impact on others.

My favourite memory from my travels is this: I ordered a latte on Sydney's Harbourside, AU, it was pouring with rain, a barista gave me my latte and said 'walk between the raindrops and you'll stay dry'. A simple verbal connection brought a huge smile to my face - my imagination went into overdrive as I tried to walk between the raindrops. I don't remember getting wet.

Unfortunately so often our imagination is stifled. A young Dutch Egyptian/Algerian artist friend of mine states 'I am a young European woman with an interesting cultural background'.

Wishing to make no assumptions about culture, age, gender, sexuality, and travelling without expectation many of my conversations led to the following question: what makes an elder?

So what makes an elder?

*"We are such stuff as dreams are made on, and our little life is rounded with a sleep.
Sir I am vexed. Bear with my weakness. My old brain is troubled"*
- William Shakespeare

For Aboriginal communities it's not about age but about experience and what someone has done for their community, their tribe, their mob that gives an individual the mantle of elder - that of Aunty or Uncle. They hold and pass on women's business or men's business and the together business. They carry their lore, culture, language, law and spirituality.

In Hinduism a sage is an older person, to be revered and respected: the younger bows and touches the feet of the older - it is a sign of respect for the older person. There are four stages in life: Brahmacharya (the child), Grihastha (the householder), Vanaprastha (the retired), Sanyasa (renouncing life) each of about 25 years. At its heart there is a collecting of knowledge and materials and then a gradual process of de-cluttering, prayer, cleansing and finally letting go to achieve nirvana and moksha (enlightenment).

I was told a story in the USA of first nation tribes in Wisconsin and how the women go through a very tough ritual to attain elder status and to be able to wear the 'jingle dress'. Women walk around Lake Superior, without food or water, reaching a state that induces visions. To us it may seem extreme as it is a near death state but at its heart it's about meditation, mindfulness and unlocking a higher self: enlightenment.

We are all supposed to gain better wisdom through our experiences in our lives - so depending on your life experience you could be an elder at age 30. In Aboriginal communities an elder is

given that status based on integrity and honesty that is respected by peers or a community. It is a gathering process that brings with it responsibility. I heard many times Aboriginal people say 'you have to earn it to learn it' - there is no automatic right to respect, knowledge and understanding simply because of your age.

My conclusion is that being an elder cannot be assumed and nor is it as simple as a number. It is about having humility, compassion and integrity on a foundation of profound understanding and openness to carry on learning. It is about carrying memory and passing it on through thought, word and action.

*'learning to see – habituating the eye to repose, to patience,
to letting things come to it; learning to defer judgement to investigate and
comprehend the individual case in all its aspects.
This is the first preliminary schooling in spirituality.'*
- Nietzsche



Compassion

Memory (loss)

The questions that I have asked myself are why is it so hard for us to accept personal memory loss? Why do we want to hold on to our past? Who is it important for to make people retain memory? What is its historical value? How does it affect our being? Who holds the memory and can we agree to have different memories?

As time has passed I have become more and more intrigued by our current fascination to 'remember'. Grief, rejection and unresolved emotional issues within relationships all surface when we are experiencing the forgetful nature of loved ones or when their general health declines. Moreover we experience guilt, remorse and regret. We can get so involved in dealing with their practical or medical needs that sometimes we forget they also need pastoral care, being touched, or listened to, or just having a moment of connection.

We should better accept frailty: physical frailty as well as frailty of the mind. But we fear the latter. We believe the mind to be superior over the body, but in many philosophies and theologies harmony is required: for the mind and body to have equality and thereby achieve balance and wellbeing that eventually impacts on our spirit.

My early/romantic memory thinks that not so long ago when the world was not 24/7, people were not so busy, and families lived together or closer by, people of age and people that had memory loss were just accepted within the family and wider community. They were able to wander, or sit, shepherded back to their family after a while, or were looked after by the women at home. But as we have moved towards urban communities, where neighbours don't know each other, loneliness and isolation grows despite social networking via the internet, where everyone has to work to keep the family financially viable, we have forgotten how to have moments of meaningful engagement with our families and friends, older people with dementia, those with mental health needs or disability.

We should not forget compassion in the policies that governments develop. We are dealing now with several different generations from age 60 - 100+, as well as complex language, cultural and religious needs especially in the UK. And our solutions will have to respect and respond to individual and spiritual needs not just medical ones.

As we move towards an ageing society in developed nations, we are faced with very hard questions about home care or care home, dying in dignity or living with dignity, and how we are going to face the financial burdens for care in a compassionate society that wants to be person centred and meet the needs and demands of individual.

It will demand sacrifices of individual family members, it will demand a slowing down of our own wants and wishes, it will impose a financial burden on state, society and family, it will ask us to acknowledge spirituality when people are frail of mind and body, and its possible role at end of life.

'...now live in the land of shadows, where the light of the memory is dimmed, where the familiar lies unknown, where the beloved become as strangers...'

- RA Horton

There is a story I was told about the different tribes and countries of the Aboriginal communities. It's an image of waiting: 'A man walks, and never in a straight line but always a zigzag, windin' path. He walks and when he knows he has reached a water hole, a scared place or the edge of his country, he stops. On reaching the edge of his country, he knows and understands the law and abides by it, he stops, lights a fire and waits for someone to come by from the other country to guide him across. It doesn't occur to him to just rush over, to break convention or ritual but to be patient and wait for the moment when he will be able to cross the country boundary.'

It teaches us that there is a time and a place for everything.

There is something very powerful in that image: that we should wait, wait for the right moment, respect that moment and patiently trust it and work with it.

I am struggling to retain all the wonderful moments that have happened to me during my 6 weeks of research. There have been many encounters that were joyous and thought provoking, many that were just ok, but my personal memory only remembers fragments as time passes. When given the right environment my imagination awakens a fragment of memory to surface - an experience that is locked in both the body and mind.

Perhaps rather than just worry about loss of memory it is more important that we experience and gather, that we acknowledge distress and loss of communication as we knew it. If we all lived our lives in the present would it make us more content?

Aware Communities



In Appleton Wisconsin USA I was invited to attend a **Memory Café** a run by Rev John McFadden and Professor Emerita Susan McFadden. The venue was beautiful, an old paper mill that had been fittingly and beautifully revived as a creative space, with the river gushing passed outside. It was a cold, snowy day and to our surprise about twenty people attended - people with dementia, their carers and family, volunteers and a few others interested in opening their own **Memory Café** in other towns. The theme for this session was books, any book that you wanted to bring: albums, cook books, quotation books, books of personal letters. John chose to read passages from Mark Twain about ageing and growing old, about treating dementia as a disability like any other disability, thus making it acceptable and not something to be ashamed of. Susan

had chosen to talk about an Atlas which opened up more stories about places visited, holidays done or planned.

It was lovely to watch John read, to see the response from people and to see how gently and easily both he and Susan were talking about dementia being normal - being dementia friendly I guess you would call it, but I would like to suggest that they were creating a feeling of the end of life as normal too, an environment that said that it was alright to acknowledge and accept this very natural event in our life. The two hours were warm and supportive. Everyone shared and spoke about their book. It was especially lovely for family and carers who enjoyed the socializing, being heard and listened to, laughing and meeting friends. A community was establishing itself, and slowly recreating values that were acceptable for a community that lives with dementia.

The afternoon was centred around set rituals; a welcome song that introduces everyone by name and encourages everyone to exert their lungs and voice, a moment to tell jokes - bad jokes but they help set a mood, a tone that it's alright to be silly or just to be yourself, a moment to share the theme of the day, a moment to eat together fruit, biscuits tea and coffee, and to end with a raffle with very bad fun prizes. It was a simple idea that facilitated very complex social engagement that was mindful and meaningful. You don't need it to be big and fancy. The simplicity of these few hours enabled us to connect with our emotional and spiritual being and nurtured the soul.

When the atmosphere is so warm, welcoming, open, fun and generous why would you not want to attend? It had at its heart compassion.

This **Memory Café** is a good model but essentially it relies on understanding what is essential to achieve a supportive environment: the individuals who run a **Memory Café** will need to understand the concept of friendship, the power of imagination and repetition, and be willing to take risks - large and small - like John and Susan - if they want big return.

The Dementia Challenge in England is creating dementia friendly communities and perhaps regular mentoring and training should be offered to retain the integrity of initiatives like the **Memory Cafés**.

The Islands of Milwaukee is an inspirational project developed by Anne Basting and her teams. She is based at the University of Wisconsin Milwaukee, Professor of Theatre, Peck School of Arts. The project is looking at making older people visible to their community. It 'is a team of artists, volunteers, older adults, care providers and researchers.' It has 3 phases and is a multi year project.

When we met we talked about the work we do with people with dementia we agreed it is about being in the moment. Anne talks of 'shift' in time, space and mood. She talked of her use of folklore, myths, and sacred scripts, 'because it provides metaphor, parallels, character types and debate'. I agree with her.



Anne Basting in Milwaukee Town Hall

The Islands of Milwaukee⁷ has many strands to it but its strength is in engaging with different generations via meaningful quality arts practice. The project is exploring safe and unsafe road intersections for older people, their opinions and thoughts are recorded and put out on local radio, the power of hearing older voices is immense. Its use of multi platforms has made its impact. Older people are very visible on the community radio, skilled artists work with and respond to people with dementia using dance, song, storytelling, and the project is providing data from diverse communities of the city that will impact future provision in many different sectors: health, arts, education and planning to name some.

I was also privileged to meet Tom - who has Parkinson's Disease and whose passion is rocks. His laboured words and pauses make beautiful

poetry allowing the imagination to roam. What the final creative response to Tom is, will be interesting to see, hear or read about. This is a massive project that has basic trust in the artists and institution delivering it, and because of that it's able to be organic and respond to its many participants in an organic yet highly creative way which will I'm sure honour all perspectives that have been involved from the older people to the theatre students.

Associate Professor Robin Mello's master-classes on storytelling were just brilliant. She is a colleague of Anne's and they work closely on projects. The classes were with young people from very diverse cultural backgrounds and Robin explained the power of story clearly in very non theatre terms, demystifying by using non theatre terminology that teachers, architects, mathematicians could identify with and then appreciate the power of conversation, face to face communication. Robin is a strong advocate for Karen Armstrong and her Charter for Compassion:

'If we don't manage to implement the Golden Rule globally, so that we treat all peoples, wherever and whoever they may be, as though they were as important as ourselves, I doubt that we'll have a viable world to hand on to the next generation'.

- Karen Armstrong

This is reflected in the way she teaches with empathy, intuition and embracing the Quaker belief that everyone is a divine being. All these experiences were full of enchantment, magic, intuition and empathy with a big dose of play, laughter and fun.

Giving creative participatory projects the chance to grow, learn from risk taking is essential for long term impact and implementing a culture change in how we accept an ageing society:

⁸Anne Basting in Milwaukee Town Hall

⁹Not his real name

that we see it as integral to our future, a useful resource of gathering experiences and knowledge rather than a financial burden.

Care homes

I visited care homes and day centres in the USA and Australia, they were very similar to those I visit in the UK, dependent of course on individual managers or care staff for their progressive or not so progressive attitudes. The vast majority of private/state owned care homes or day centres still operate on the medical model of care, and see the arts as 'passive entertainment rather than vital engagement' as Elizabeth MacKinlay so eloquently puts it. She also states "Humans have not changed, cultures have changed, pastoral care needs to ask what it means to be human"

Cultures are changing, but many still remain fundamentally the same. Elizabeth Mackinlay's statement is provocative. But I would suggest that we re-evaluate the culture of care and the role of arts within that culture.

Meaningful person centred engagement is what we all desire from when we are born to the day we die. We want to be touched, spoken with and included. We want to love and be loved, we want to share joy and sadness. When creating with and for people with dementia and their carers, our imagination has to take us to a place of truth, so that the moment of connection is sincere and not impatient or imposed - that it is of a spiritual nature as we connect better with people who are on their pathway towards end of life even if it's just for a moment.

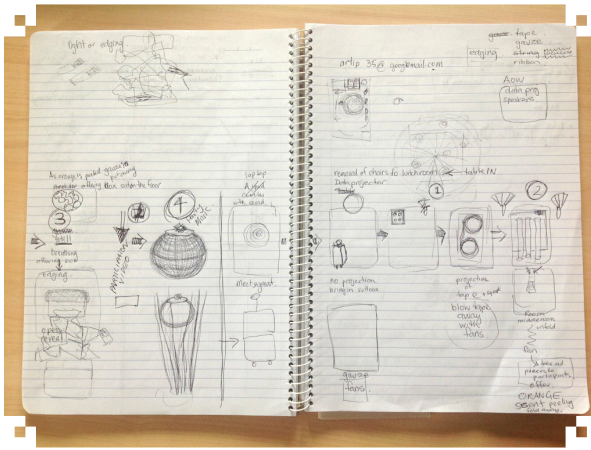
Spirituality and compassion can be supported by a combination of creative interaction with nature, their environments, belief systems, and relationships. Meaningful, person centred engagement requires a holistic approach. Trying to respond to individual wants, needs, and beliefs is not going to be easy but to be a compassionate society we have to strive towards it and start delivering it fast.

Perhaps if we said 'homes for later life' rather than 'care homes' we could shift our perspective of older people and see them as resilient and useful rather than in need. Many older people with dementia - can still do, can still give. They can prune plants, lay the table, give a massage as I experienced very recently. There is no quick fix to ageing. Science and technology might be able to assist practically or creatively if we wish it but they cannot assist with our need for compassion enlightenment atonement on our pathway towards end of life.

Open the Box

I overheard an older man say after a very dry summer in Australia followed by the rains: "the plants were sleeping, and they were awoken from their dreaming and into life". It was poetically put and just added to my experience of Australia, ageing and spirituality.

Whilst in Bathurst, NSW, Australia visual artist and Arts and Health Co-ordinator for Arts Outwest, Christine McMillan asked me to share my practice with her. It was an easy request - I



Open the Box photos by Christine McMillan
our ideas.

moved easily from theory to practice and vice versa. I had offered to share my practice by running workshops with artists when I had made initial approaches to people I had contacted. We were spending much time together, discussing arts and health projects for student doctors and indigenous young people in Australia and projects like MOMA's *Art in a Suitcase*. So when we started talking about dementia one thing led to another. It's not just the talk that led to the creative collaboration but sharing food, drink, nature and a comfortable home that acted as a studio space for

Christine wanted to learn about my sensory approach, I was interested in trying out ideas I had been toying with for a little while about working in a less intimate space - almost the opposite of *Once Upon a Time (OUAT)*¹⁰. OUAT uses a story structure to enable moments of interaction with people with dementia. It uses non verbal communication: body language, facial gesture, sounds and sensory stimulation to awaken imagination that can take us anywhere. It is not about awakening memory but about awakening imagination. It makes no assumptions about the individuals we collaborate with in that moment but enables uncensored creativity and honours everything that we are given from one moment to the next. Once imagination is awakened we are led by the older person - whom we respect as the expert and the elder in that interaction, working at their pace to understand their method of communication and accept their delight joy anger or sadness.

Christine approached St Catherine's Care Home and I approached the Seymour Day Centre in Bathurst. To both we were at pains to say it was a workshop in progress, but we ensured all the safeguards were observed for working with vulnerable adults.



Open the Box photos by Christine McMillan

Christine and I called our little experiment: 'Open the Box'. The whole premise of this exploration was based on my practice of non-verbal communication. Person centred meaningful engagement would rely on gesture, copying, and open body language. It would rely on eye contact and touch, as well as very good listening and interpreting skills. At its heart is the practice of being present and in the moment and being able to improvise: accept what you have been given and add to it without blocking imagination or contradicting/censoring the thought process of the participant. When working creatively like there can be no boundaries. This way of working requires bravery and risk taking but they are small risks if the safe environment has been set up well and ritual is observed: a gentle way in, and gentle way out, repetition,

¹⁰<http://sparetyre.org/watch-and-listen/video/once-upon-a-time4>

slowness and allowing time and stillness.

Christine and I worked easily together, bouncing ideas, playing with a range of materials, discussing my approach and tested concepts, layering it with her great visual eye. We delivered two workshops: one was for people with advanced dementia in a residential setting, the other was for a mixture of adults with learning disabilities and dementia and was in a day care facility.

This is Christine's evaluation of the collaboration:

Introduction to centres

A sensory experience for people with advanced dementia and their carers.

This pilot project offers opportunities for participants to interact with a range of materials. We will use the senses of sight, hearing, touch and smell in a playful, fun series of activities which will employ non verbal communication. The materials will be accessible and safe. Participants will be photographed and filmed while involved in exploring the materials as a part of our project documentation and evaluation. We would request signed consent forms which we can provide.

In preparation of this pilot project we would like to spend time in your care centre to observe clients and how the spaces in your care centre are used.

Discussion with staff

Was there any positive change as a result of this project?

Residents seemed more alert, calm, relaxed and happy, there were no dramas in the afternoon.

Everyone was very settled even those who are not usually settled in the afternoon. Art and music re activate the senses, touch, hearing, smell which is positive.

Were there any unexpected outcomes?

Surprised and overwhelmed when taste was aroused by smell.

Most people joined in.

The feeling of being cold was created by both the fan and the blue light, one of the participants rubbed her hands together warming them under the orange light.

The bird calls had a wonderful effect.

What would you do differently?

Liked how the workshop was executed, would do nothing differently.

I was worried about people bending over further than their knees and losing their balance while reaching for the floor.

It would be interesting to do workshop at tables with the projection on the table.

It was good something different.

Do you have suggestions for future projects?

Get people up dancing/ music/ more body movement/ a daily activity

An activity like this once per month

Has the project assisted you in the delivery of health services? How?

I could see how everyday objects could be used in an activity that we could run in the dementia unit.

Cloth and food, connecting music and food. There is no need to buy expensive things.

Did the project help to reduce stress levels?

It worked for the moment. People were really relaxed afterwards.

Did participation in the project assist in connecting with others?

It helped me connect to a couple of the new residents. I think they are warmer towards me smiling when I pass them, like there is a memory of the emotion, having fun while we were dancing.

Quotes

One of the residents who does not normally participate in group activities but removes himself from the space sat in the workshop. Didn't physically participate. When the workshop was over he commented 'They were pretty good weren't they'.

What did you gain from the workshop experience with both groups?

I very much enjoyed preparing the workshop with Arti Prashar because I was reminded of the delight of exploring ideas which bridge gaps between medium and the application. The parameters set were guided by Arti's experience with people with dementia.

I was amazed at how the 'Open the Box' workshop stimulated touch, hearing, smell, taste and sight, awakening the mind, stimulating in a gentle and supportive way. It was also fun. Presenting with two people made it easier to step back to view how individuals were responding and how the overall choreography of the presentation was working. The performance aspect, the flow, the different opportunities for engagement, building the activity, the rhythm and speed were all elements that I would consider in the future.

How will this influence future work?

I had the opportunity to learn from Arti's expertise while working together to design a sensory experience for people with dementia using visuals that had been created for her project in the UK combined with a variety of materials chosen from my collection of materials and objects. It was very rewarding to work with another creative artist.

This inspired me to suggested to one of the other Arts OutWest project manager, who has a creative arts practice, that we get together to work on a project with people with disabilities. A project has been suggested and we plan to begin to work on the development of this project in May.

After talking to staff at St Catherine's I am also thinking of presenting other workshops on a regular basis.

Anything else?

Working with Arti has prompted me to think about developing an arts and health project as part of my own practice as an artist. I would like to investigate what sounds, images, smells etc. enliven the senses but are still calm while being stimulating and interesting. As part of this investigation I will create digital art works that can be used by health workers to de stress. The space I will use to project the images for this work was identified by Arti as an area that is unused and an ideal space to change within the hospital buildings.

I hope the two centres will be able to follow through on some of the ideas, and keep their imaginations open. I would also hope to return to work with Christine and Arts Outwest within the next two years.



Open the Box photos by Christine McMillan

Open the Box was a great success as a work in progress. Two artists - from two very different backgrounds and experiences - who had never worked together but were able to respect what each brought to this collaboration and responded to the participants within the structure of the workshop concept. I want my future dementia work to be virtually non-verbal and in a less intimate space.

Identity

I spent a few days in Holdfast Bay, Adelaide Australia. At the local museum I picked up a leaflet. It said “Marni naa putni Kurna yarta-ana - welcome to Kurna country” Today the City of Holdfast Bay acknowledges Kurna people as the traditional owners and custodians of the land. They respect their spiritual relationship with country that has developed over thousands of years, and the cultural heritage and beliefs that remain important to Kurna people today.

In 1836 the first Europeans arrived to claim it as their own. The traditional hunting grounds, camping places and ceremonial and sacred sites were overrun by Europeans who destroyed the Kurna people’s culture.

Today across Australia there are many indigenous people trying to re-discover their identity, language, and culture. There are many who want it to remain secret and there are some who are willing to be open about it.

As a displaced person who understands that much of my cultural referencing stems from being an East African Asian living in Britain, I have often asked myself the questions where is my home, where am I from, who am I? Am I African, Indian or British? How important is historical memory, family memory, personal memory? Do I live in the past, present or future?

I met with several Aboriginal individuals - from a leader to elders in care to artists to care worker - from the tribes of New South Wales, Australia. I asked them all if I could record their words, I asked them all if I could use their words and asked what I should say. They showed their trust in me by saying I would know what to say, write, reveal.

I have spent a large part of my life honouring other peoples’ stories. I hope they approve of this telling as I feel I have been given an immense responsibility to share their thoughts and

words, and perhaps write the new myths and legends for future generations.

The Stolen Generation (Aboriginal children taken from their families) wants respect and reconciliation, to discover their total identities and then choose how they want to express that memory and identity. Memory and identity go hand in hand. It helps us understand who we are and the road we travel.

'It's important to know who I am' Bruce Wilson from Catholic Care said. I agreed with him. When we know about ourselves we can make choices for ourselves.

People with dementia often revert to an identity early in their life, often they revert back to their first spoken language, they may even change their dietary habits like adding sugar to tea or eating meat. I often say we are witnessing the rebirth of another person - which we should celebrate. Yes mourn the person who has gone but accept the new being and celebrate them.

Certainly for those with dementia trying to make them remember can be a frustrating or a negative experience. We should simply be led by them - the elders of dementia. We have to learn to trust in the moment, by being very present and accepting.

When I was told the following anecdote it made me stop and re-assess my views and assumptions. One of the homes I had visited was originally the convent for the Sisters of Mercy. With their natural ageing came dementia and a need to care for them. So we would assume -or at least I did - that they would be compliant, gentle and calm but they were not. Having spent a life in strict discipline, and with some having been forced into the sisterhood, in the state of dementia they became disinhibited and another 'self' emerged, one that happened to be stubborn, angry and demanding. For me this is simply a pathway towards end of life. Consciously or sub-consciously we begin a process of cleansing and letting go of our self, preparing for death or passing over. I use both terms as it depends on your belief system as to whether or not your journey is final or the beginning of something else.

The following transcripts are voices of two Australian Aboriginal men who are in the process of re-discovering their identity, culture, language and heritage. They have experience of loss which has impacted on their sense of themselves.

*'If we forget these moments we will forget tenderness and compassion.
There is wisdom in vulnerability and sharing struggle, disinhibition and laughter'*
- Meg Hegarty 2014

Brian's story¹¹

'Some people don't want me to know they have dementia in a small community. Dementia equals mental health issues in the old days. Now we support, run diagnosis.

When dementia happened their story would have got lost, due to our history - The Stolen Generation - people lost touch, it makes it hard, lost cultural identity, language in New South Wales, wiradjuri language.

It's only because of people like me who will say tell your story. The Aboriginal community is in a moment of redefining itself, getting language back into schools in the curriculum. We learn French why not teach Aboriginal?

In the Northern Territory you still see the culture, it's still alive - the tradition carries on.

I have it (the language) in some words.

To be Aboriginal is a 'very special feeling' for me. There is conflict about who holds the memory. Spiritually it's a special feeling, really special.

If you question why we need policies and money from government then you don't understand.

I am proud, a very proud aboriginal person, my heritage. I can live in this society but also in my culture. With the Stolen Generation some elders are asking are they really Aboriginal, but people have lost their roots, identity.

Smoking ceremonies take the bad spirit away, at work a room was smoked, to get rid of bad vibes and infuse positive attitudes - as a part of reconciliation.

I had a Sorry Day. The funeral was so cultural - walking through smoke. A very beautiful service.'

¹¹Not his original name



Jimmy Beale's story¹²

JB: I have come back through rebirth, recalling of our culture. Sometimes you have to be careful what you say to some people they might think you are mad or stupid. But for me I'm proud of being Aboriginal.

Age is related to the passing of the moon: or on the bark; I don't know how old I am - could be hundreds of years old. Whiteman's terminology it's a birth certificate.

Eldership comes from community and how they accept you as an elder and how you do things in your community. Amongst your people doing things.

To have stories come through to you from beyond - that's magic, that's magical. Grassroots feel the same way.

All Aboriginals are the same across the world. Who are we, where did we travel from? They found boomerangs in Tutankhamun's tomb.

When a white man is arguing with me I say he is trying to find his way home, cos we are quite happy cos we belong, we belong to the earth.

Finding your way home - we belong to the earth and the land - the spirit goes back into nature, trees, birds. I've journeyed probably many moons. I have three totems, three tribes, languagesI was called in Bathurst. My three totems are kangaroo, emu, and guana.

AP: What happens to collective memory that's disappearing?

JB: I have a friend with dementia memory lapses, geeze it's hard for him. It's a hard question.

AP: Or is it important? If it's your spirit that moves on then is it important to worry about memory?

JB: It's a want and need for that memory to stay with you. For forty eight years I was in another wilderness, until my spirit found me. It was my dreamtime, it's about my culture and feeling proud. Walking and talking. Brought community together. I am tired of living in another world; I need to be with mine. I have had enough of pretending of being someone else. I have a shift in me - and that's a spirit shift and I'm proud of that. Not afraid to tell people that - if they think I'm a strange person then it's their problem.

We can't walk the land like we used to but I am still in my dreamtime mind.

I need to be me. I am in my dreamtime mind, collecting these stories as I go along. I'm the engine and they are driving me to tell the stories of the past.

AP: Is dreamtime shared?

JB: I tell stories, write poems, once you are in the zone it surfaces. We have a huge identity crisis.

Should never lose sight of your grassroots, where your family came from, how they journeyed around

¹²Jimmy discovered he was of Aboriginal descent late in life

this countryside, how you came to be who you are today, but a lot of these children are old souls coming back. And this is where the shift is, a lot of our young ones have old souls in them. We try and explain to the young ones it's about being yourself, find your identity, trace your family tree back, you will find yourself.

I have a special place, I went to a special place out in Blackfella's Hand cave. I went out swearing and cursing, asking who am I in this white skin, my father's dream was stolen, my mum's is intact, who am I? Things started to shift, now I know the spirits are walking with me.

AP: I really like that image of the spirits having always been here.

JB: They are asked to be re-awakened again. Always been there. They are coming out of their own sleep just as you are.

It's dreamtime sleep. There's an awakening - gomarra - the awakening.

Musicians want to take the stories on the road, I said spirits are not ready yet to go on the road, when they are ready we will go. Don't rush. Engage young fellas first, history is hidden.

When I am called back home, spirits will leave the body - this vessel. When I'm called back home to dreamtime in death. When I paint or tell poetry I'm in dreamtime - its just flows. It's oral, when the spirit comes you have to write it down quickly, paper is our new bark now. Same thing it comes from the tree.

Feel that it comes from that bark. People can feel it. Spirits put things into me, they seen a need in me. My mother will see this in the spirit world. My mother came to a girl in a dream. She brings her tribe and my birth tribe to the gathering, all those spirits will be there.

AP: How is community that is not awakened going to deal with all this? All these people in institutions?

JB: Elders can't tell stories like they used to, some of them are even afraid to do that.

Local council trying to understand, they talk about the Stolen Generation, but they really don't know how much they have destroyed in our culture. Elders separated from young, men's business, women's business. All this has disappeared, elders don't know how to talk to young people.

AP: So there is a lot of fear - so perhaps you need to ask the spirits how to overcome this fear. And open these pathways.

JB: This is my care of duty. I have started this with the council. Men's group, women's group. It's not just stolen generation but a stolen culture, stolen dreamtime minds. We had it all, we had a perfect world but it was destroyed.

People like myself who have been sent back, are trying to heal these pathways. Helping these young kids. Got to wait for these old guys to die. This young generation have open minds, open thoughts, since Sorry Day our people are walking these streets with their heads held high.

AP: Can you explain dreamtime?

JB: Dreamtime is here with us everyday. I have two old fellas with me always. It's the awakening. It will always be there, every day.

It's an aura, it's life with the spirits, it's with us always.

It's a need in people. I walk in a sea of colour of rainbow. I am a part of everyone. We are a part of everyone.

Passing over - rebirth, not death. It's not part of us. We will be recycled. Old souls will return in our children.

(Jimmy then tells the story of his mother's spirit in his grandchild)

It's a never-ending story, for each and every Aboriginal.

Who would believe a little old white aboriginal like me from a reserve, would be addressing these issues today. Pushing forward not reconciliation but building bridges with that other world I've lived in, building a community. I came to Bathurst playing rugby league. One of my elders told me I was on a spiritual journey but I didn't realize... Dreamtime is my life.

Because we are fair skinned, people don't believe you are who you are but spirits tell you a lot of things. They choose you. Some elders think I am the chosen one. I will do this quietly because dreamtime wants me to walk this pathway.

(Jimmy tells the story of an elder who saw two old aboriginals (spirits) throw a cloak over Jimmy)

JB: She says you can't run from this, I say I won't. It makes me feel proud, I will follow their guidance. I will do whatever they want me to through dreamtime, we will create a new dreaming. We did that on Saturday 15 February (2014) created a new dreaming.

Our sacred day is Saturday, the spirits still with us. I'm rich inside. How they have recalled me, sung me back. They have seen something in me to help bring us together. So I'm happy with that. So dreamtime is always here until I pass over and come back and start a new dreaming.

AP: It's a very profound acceptance of nature, of the earth - it's asking for us to be accepting of that. You have described us not fighting it -it's a flow, you have to go with the flow.

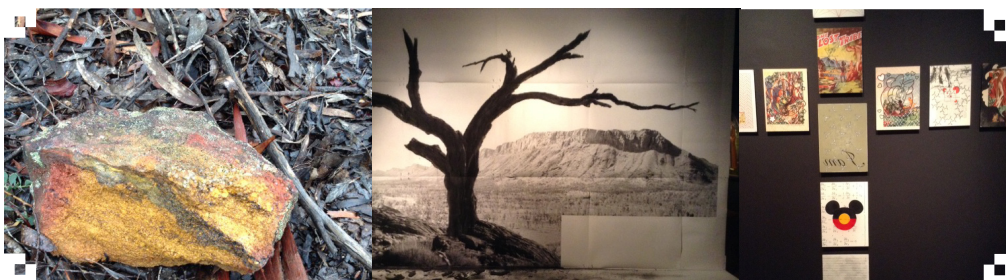
JB: You have to go with dreamtime.

AP: And that's what it is! (penny dropping - dreamtime = flow)

JB: My relationship is with Mother Earth - she's the one who provides and yet we keep digging into her.

'The use of folklore, sacred text, myths are powerful forms of narratives and wisdom which we are in danger of losing because their wisdom is deeper than merely rational knowing or information that is most respected, trusted and believed in in our societies today.'

- Meg Hegarty 2014



Artwork by Aboriginal artists: Warwick Thornton, Tony Albert

Stillness

*'we need to slow down our thought processes, to become inwardly quiet,
and to have a kind of poetic awareness...'*

- Kitwood 1990

Slowing down

Nomadic people are at one with their land, they understand its power, the strength of nature and the elements that dry the land or keep and make it wet. It feels that as mankind ails with diabetes, dementia, heart disease and cancer so does the earth with drought, flooding and extreme weather conditions. So what will cure both?

If we take a leaf from nomadic ways of living then we should seriously consider less consumption and a simpler way of living. We could learn from nomadic ways - use only what is necessary. We can learn from the lessons and stories of old from many cultures as they are valuable lessons or thoughts. Our increasing reliance on science cannot tell us everything or cure everything, it can contribute to a truth but as in all things a balance is required. Technology is not a substitute for connection and empathy but it can assist us and sometimes ease our lives.

And for me a part of the slowing down includes our acceptance of the ageing process. To be open to it and to accept it with grace, apply dignity and understand that decay and death is a part of life - a very natural part of life and living.

'Likewise, human beings, though dropped, crumpled and stepped on during the course of their lives, never lose value. Their worth is determined by who they are, more than by what they have done. This intrinsic value and worth is a large part of how we define spirituality.' Julia Barton

Acceptance of end

I believe in closing one door for another to open or we could call it mindfulness, making space, being still. In all the areas of science, spirituality and creativity silence, rest or pause is a vital ingredient for reflection, for acceptance and for questioning, waiting to see what happens next: imagination, compassion and stillness.

Memory loss - collective, generational or personal- is hard to bear. But from that experience can come a slow process of reclaiming much: roots, heritage, identity, freedom of thought and expression. Memory loss and ageing asks us to see the past in a very different light. It asks us to accept the now and embrace it without question to enable a process of healing, forgiveness, reconciliation and celebration.

For many of us physical degeneration is more acceptable than mental degeneration. Why should we favour one above the other.

Death or passing over is inevitable so perhaps what we also need to consider and accept the spiritual pathways that can bring comfort, and ease us from one journey into the next. Most cultures have stages in life, stages that lead us to death/passing over. There is a process of de-cluttering, cleansing, disinhibition and letting go - perhaps we should trust in these pathways. Some will become more religious or more rebellious, and those with dementia go through much change over their final years, often returning to their original language, change their dietary habits, fall in love again, can be rude, cheeky and sexy. It is a confusing process for those who live and work with people with dementia, it can bring distress, anger and regret but if accepted as a natural pathway towards end of life it becomes easier to witness.

And therein lies the challenge of dementia: how can we celebrate and respond to these changes: watch the birth of a new being whilst still mourning our loss of a loved one? How can we ensure a safe space for calming fears and anxiety towards end of life for all concerned - those dying, their families and care/nursing staff?

“There is no death just a passing over, reincarnation, recalling song and oneness with Mother Earth”

- Jimmy Beale 2014

Respecting different pathways

When we talk of person centred care what do we really mean by it and can we really deliver the multi-faceted demands of person centred care? The demands being made involve personal sacrifice, and a society willing to prioritise its most vulnerable and care for them whatever the cost. It will ask us to slow down to care for loved ones, it will ask us to sacrifice our own wants and respect the needs of the other.

In life there are several pathways, rituals and belief systems that can and are observed. In death there are just as many different pathways: rebirth, reincarnation, passing over, death, heaven and hell. At end of life most of us have an understanding of death and want to depart in peace.

Whilst on my fellowship I wrote a blog¹³. The following three passages are from there:



Lyre Bird by William Barak of Woiworong Group of the Kulin people of South Victoria, Australia 1890's

‘Mid to end stage: Am mid-point on my travels and suddenly hit by a tiredness which came on as I was trying to sort the next two weeks out. Making contact with people, devising a new project for people with dementia, discovering a new town, shall I fly or train? Also aware of the inevitable end approaching - this is an interesting metaphor for end of life, death, passing over - I know the end point but can't quite work out the steps to get there; I could make hard decisions or just bumble along which is what most of us do and hope for the best.’

¹³memorymeanderings.wordpress.com

'Stories: talking with Aboriginal elders makes me reflect on my own cultural, religious, spiritual background. They talk of many notions and beliefs that exist within Hinduism and my understanding of it. But right now the stories that were exchanged will remain our stories that will surface as time passes. The circle of learning, the cycles of life, feeling the earth beneath my feet, the downpour with hailstones, lightening flash. Hoping the Lyre Birds will be signalling that our visit is welcome to the caves, or we may have to turn back tomorrow as we go out to a sacred site.'

'Walking in the bush: It was an extraordinary day yesterday to be taken into the bush and be privileged to experience a smoking ceremony, after the Lyre Bird - the guardian of this sacred site - greeted us and sang throughout.

I feel I cannot say much more than that, it would not be respectful. There are some things that should and need to remain in the realm of personal experience - being still and accepting of the other. As the rains approached the kookaburra began to cry loud letting us know the heavens were about to open and they did without us getting wet!'

An Aboriginal visual artist said: 'Before she starts a new work she asks for the guidance of the spirits.' She was brought up in the Christian faith and late in life learnt she had Aboriginal blood. She is spiritual in her own way and she doesn't want to return and be reborn, once dead she wants to remain dead.

Serenity

What is it to be spiritual in thought and action? I was describing a participatory arts project that we at Spare Tyre are delivering on a London estate. The project seeks to connect a diverse community and find creative solutions and platforms that will assist with connection, communication and community. The response to this project has been that in its concept and approach it is holistic and spiritual. When you receive feedback like that you have very little choice but to reflect on your practice to try and understand where that creativity is flowing from.



When I visited Milwaukee Art Museum, and entered the Quadracci Pavilion designed by Santiago Calatrava its white serenity took my breath away and calmed me in the next breath. It's a fin, a ship, a sail, a temple, a sculpture, a place of joy and rest. In its design nature is at one with a man-made structure. I would have happily taken my last breath there as the sun poured in through the glass that overlooked the blue sky and lake. Its serenity was extremely powerful.

There were many conversations I had with people who work in the palliative care sector. The conversations were deeply moving and the sharing of their stories extremely powerful. I heard stories of change in those dying, of those 'ready to go', stories of acceptance in those watching death, stories of celebration and understanding that the time had come to let go. The stories gently came out as they were given the space to be told in an environment of trust, respect and acceptance.

Below is part of a verbatim conversation I had with Aunty Gloria and Warranha, two beautiful women who are Australian Aboriginal elders.

AP: So how do you see the future? So if I was to equate it (the stolen generation episode) to a kind of a memory loss that has happened within the community, because that is what I think it is. In a way I feel it too, because I feel displaced. I told you about my working life but my origins are - my mother and my father's origins are Indian, but actually we lived in East Africa, I was born in Kenya, we went to London... so actually ... I feel very displaced. There are times when I don't know who I am, (laughs). I'm not quite sure - as you say where is my spirit?

AG: But don't you feel , but don't you feel a connection to somewhere?

AP: Yes I do... Yes I do.

W: Well then isn't that your belonging?

AP: Well I guess that's... you know... it happens to be East Africa. That's where I feel is home. That's what I have to process, because people would have said surely it's India, but actually it's East Africa. (AP laughs)

AG: That's where your spirit comes from. That's why you feel that connection. It doesn't matter that you have a different cultural background. That's where your spirit comes from.

(AP doesn't speak but remembers when the dentist thought she was African because of a tooth lodged horizontally in her lower gum aged 15!!!)

W: In our belief we believe that that's where your spirit will return.

AG: Yes.

AP: I look forward to it (AP laughs)

Conclusion

As an artist working within the participatory arts, dementia and ageing sectors I believe as ambassadors of culture we have a responsibility not only to have fun but to understand the people we collaborate with in a better cultural and spiritual way, to understand them in the here and now, to value and honour their stories, to provide safe environments for them to express their fears and anxieties so that their pathway at end of life and at death/passing over is calm and serene.



McKinlay states 'engaging in creativity is key to resilience in later life' - yes because we - the artists - can create the environments that support the enchantment and enlightenment by employing the imagination of myths legends folklore poetry paintings music dance song. We can facilitate slowing down, we can facilitate acceptance and respect for different pathways.

We can responsibly facilitate a connection so that our spirit can be at rest or be at peace as we age and at the point of death. And we can begin to ease the pain of loss for those left behind. The artist can do all this so well.

I hope we as a diverse society can be better guided by imagination, compassion and stillness.

Outcomes to date

This paper has been read by academics, politicians, people in the care sector and artists. They have all commented that they have been challenged personally and professionally, had their thoughts provoked and have reflected on their own lives and practice.

Anne Basting's Islands of Milwaukee has influenced Spare Tyre's project Roehampton Radio on an estate in south London. We have debated death with a diverse community: young and old and from many cultural backgrounds. Their thoughts can be heard on Roehampton Radio¹⁴.

Arts Outwest from Bathurst NSW Australia have been so inspired by 'Open the Box' that they have applied for funds to develop a multisensory project for people with dementia in Australia with me as consultant.

Whilst on this travel bursary I have acknowledged my own belief system and spirituality: accepting responsibility as a member of the next generation of elders for holding the wisdom, lore, law and cultural and spiritual values for a future global family.

The care staff training offered as a part of Spare Tyre's 'Once Upon a Time' now has reflective practice and mentoring at its heart offering creative and simple solutions based on human contact and need.

¹⁴<http://www.mixcloud.com/roehamptonradio/>