

2012

Dementia and the use of creative arts to maintain personhood.



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1. EXECUTIVE SUMMARY

- An estimated 670,000 people in the UK live with dementia; this number will reach 1 million in less than 10 years. The estimated cost of dementia care in the UK is £23b.,
- Many people, and their families, exist with dementia rather than live,
- Creative Arts is used extensively in dementia care but appears to lack a logical framework,
- The design of the physical environment supports positive experiences in the person living with dementia,
- Humour therapy does bring fun and laughter to not only the person living with dementia but also the professional care staff,
- Research in Australia shows that a weekly session of 'humour' has the same level of outcome as a daily dose of anti-psychotic medication in the reduction of challenging behaviour incidents,
- Music, drumming and art reaches inside the person who is living with dementia, breaks down cultural barriers and brings together all the generations,
- The *Spark of Life* Program shows real evidence of delivering 'Re-mentia', it enables people living with dementia to come to life with new abilities thought to have been lost to their illness. It does provide a clear framework for both daily and creative interventions,
- Re-mentia does not propose that the physical changes of dementia are suddenly stopped, clearly they are not, but it does claim that by reaching the person using very clear techniques that the essence of what makes a person unique is enhanced, maintained and protected for as long as possible,
- There is a suggestion that the Care Sector needs to challenge the Medical Model of Dementia, to change the perceptions and by so doing positively and actively engage with each person who is living with dementia
- Creative interventions do add depth and meaning to the lives of people living with dementia. The challenge is to be able to deliver those interventions in a consistent, practical way within ever tightening cost constraints
- Care and activity need to be seen as one activity which requires professional carers to either be very creative (and some clearly are) or to give those professional carers a framework that encourages and delivers creative care experiences, *Spark of Life* appears to give that structure and framework.

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3. INTRODUCTION

In February 2009 the Department of Health launched the first UK Dementia Strategy. When the Prime Minister announced on the 26th March 2012 that he wanted the UK to be a world leader in the dementia care and research, he identified some key figures:

- An estimated 670,000 in England with dementia and the figures are expected to double within 30 years,
- In less than ten years, as we all live longer lives, the number of sufferers will reach a million
- The Dementia UK report (2007) estimated that the dementia cost to society as being £17bn this has now risen to £23bn for the UK and £19bn for England – it is higher than the costs of Cancer, Heart Disease or Stroke.
- One in three people over 65 will develop dementia
- 39% of over 55's most feared getting Alzheimer's disease, as compared with 25% who most feared getting cancer.

Hence, the dementia challenge was launched to tackle one of the most important issues we face as the population ages. The challenge states that it is an ambitious programme of work designed to make a real difference to the lives of people with dementia and their families and their carers.

The key aims of the strategy were to:

- Give a boost to dementia research
- Address quality of dementia care
- Increase public understanding of dementia
- Make communities more dementia friendly.

Then most recently on the 21st September 2012, the Department of Health launched a campaign as part of the Prime Ministers Dementia Challenge to encourage people to have that first 'difficult conversation' with a friend or family member when they spot the signs of symptoms of dementia, and encourage them to visit their GP.

Jeremy Hunt Secretary of State for Health, said:

'Our goal is to make this country a world leader in tackling the challenge of dementia. That requires us all to play our part; including being brave enough to start conversations about dementia to get our loved ones the early help we know makes a difference'

Care and Support Minister Norman Lamb said:

'Dementia is one of the biggest challenges we are facing, but while there remains no cure, early diagnosis can help people take control of their condition and plan for the future.'

However, there does remain a fear, a stigma, an all-encompassing dread that perhaps I, or perhaps more poignantly you, will be one of the 1 in 3 suffers, that you will be confined to a Care Home, incontinent, wandering aimlessly asking for your mother! Your family visiting but no recognition of the person you once were, gone, all gone apart from your feeble body that just refuses to die.

In November 2011, Charles P Vega MD, published his research which indicated that a diagnosis of dementia increases the risk of suicide, especially if there are pre-existing conditions of depression and anxiety already present.

Shocking but perhaps not that surprising.

The aim for this report is to evidence that there is a wealth of research and working practices available that can give a very positive outcome to the person living with dementia. Together these principles, practices and ways of working can they give the person living with dementia a future of hope and possibility – a life, which is different, but still fulfilling, rewarding and wonderful.

So to all those people living in the shadow of a possible diagnosis of dementia, to all those families who dread the thought of watching the one they love disappear and to all those care providers (professional, voluntary and family) who work so hard only to see the person before them become frustrated, angry, confused and withdrawn – I give you the vision of.....

A Wonderful Day.

4. TRAVEL TO MAKE A DIFFERENCE

(i) *What was I researching?*

In January 2012, I was awarded a Winston Churchill Fellowship to investigate:

Dementia and the use of creative arts to maintain personhood.

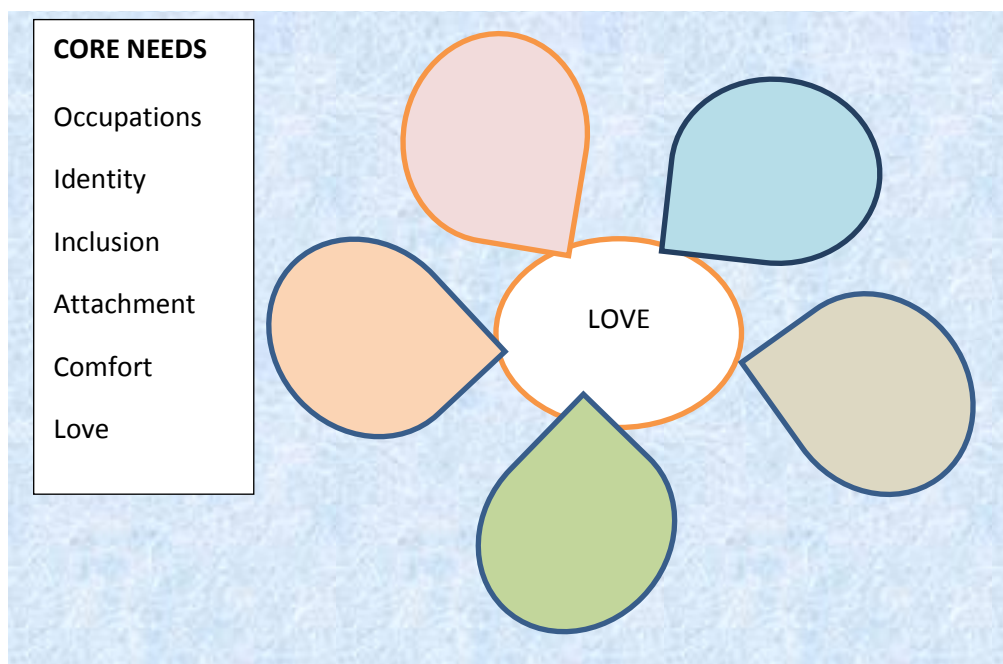
At that time I was the HR Director for a Charity called Brunelcare which is dedicated to helping older people make the most of their lives. I was particularly interested to investigate the possibility that as an older person's dementia progresses their creative abilities develop and grow.

Kitwood (1997) described good dementia care as

- Sustaining personhood for each individual and upholding their personhood in the face of advancing cognitive impairment
- Understanding the wellbeing of people living with dementia relies on everyone within their surroundings to guarantee, replenish and uphold their personhood.

Personhood is described as 'a standing or status that is bestowed on one human being, by another in the context of relationship or social being'.

It is the unique and almost sacred essence of the person; it is maintained, grown and restored when we treat each other with deep respect. The person living with dementia is seen to have 6 core psychological needs, the central need being to love/or be loved.



The primary aim of the project was to investigate and personally experience the use of arts in the preservation of a person's personhood/identity when developing or living with dementia. By visiting the world centres of excellence in various 'art' groupings the aim would be to increase my knowledge in this field.

My aim was to gather a broad range of information that once implemented would help older people make the most of their lives. Specifically to:

- Investigate the various use of the creative arts
- Identify any best practice
- Translate any learning and experience that could support the delivery of World Class Dementia Care in the UK
- To bring together the best practise from around the world into the UK to benefit those people living with dementia now and in the future.

Put very simply, it was to get ideas as to how we could give people living with dementia... a Wonderful Day.

(ii) *Where did I go?*

My traveling fellowship award was for five weeks, the intention was to spend 4 weeks in Australia and then visit Canada for one week. I would visit the major cities of Sydney, Melbourne, Brisbane and Adelaide. However, as will be detailed later I was also able to visit a unique care facility in Auckland, New Zealand. It is also my intention to return to Australia to further investigate some of the concepts detailed in this report. It was a great privilege to be able to visit the organisations and I would thank both the Winston Churchill Memorial Trust and Brunelcare for the opportunity.

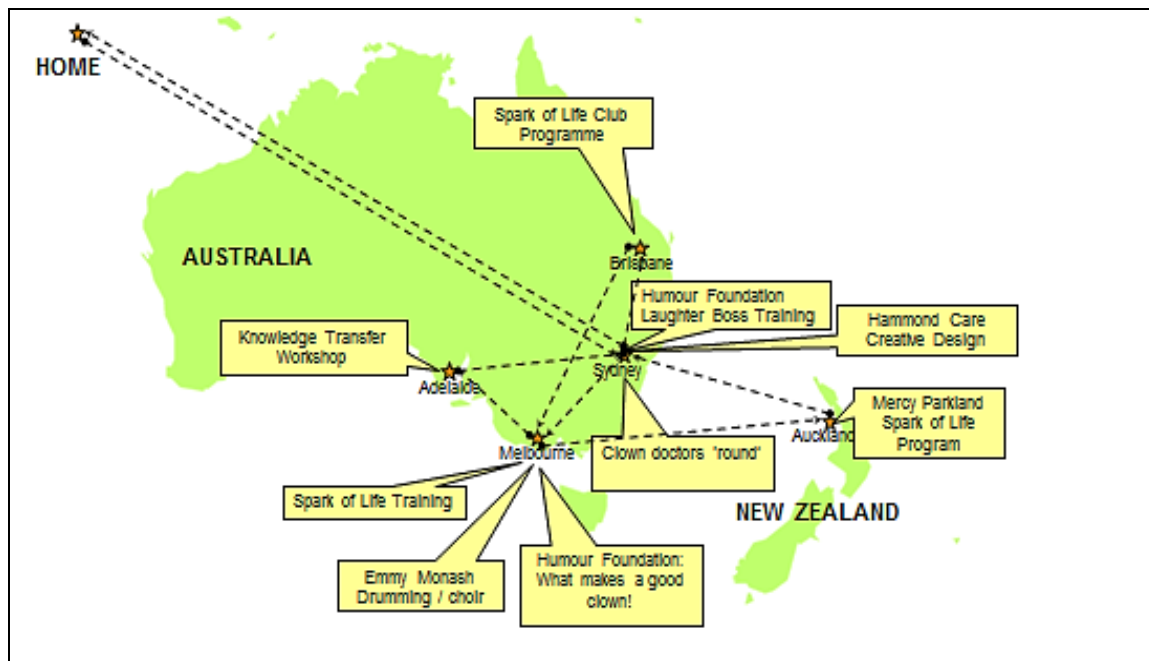


Sydney Opera House



Sydney Harbour Bridge

(iii) *Details of my travels.*



(iv) *What did I do?*

Some key Statistics:

- Travelled 27,000 miles
- Visited two countries – Australia and New Zealand
- 5 cities
- 5 different organisations
- 1 conference
- 2 Learning and development events

(vi) *What were the areas of investigation?*

- Creative Design at Hammond Care
- Laughter Boss at Humour Foundation
- One Voice : at Emmy Monash
- Re-mentia : the concept of the 'Spark of Life'



5. AREAS OF INVESTIGATION

(i) Creative Design: Design for Living

The visit to three separate Care facilities within Hammond Care was a great experience. The facilities were designed to encourage all of the activities of daily living. There was a clear link between the environment, activity and care. The staffing ratios were very low in comparison to UK levels, much of the activity was done with the residents – they would help with the meal preparation, the laundry, the washing up, the cleaning and the gardening. This gave the residents living with dementia purpose and meaningful occupation within the safe and secure environment of the 'Cottage'.

This was a huge area of study, and I later while at a conference in Adelaide had the privilege of meeting the original designer of the Hammond Care 'Cottages'.

Professor Fleming. He has devised an environmental Audit Tool (available from rfleming@uow.edu.au) Where he details that an environment that is to be used to provide care aimed at maintaining the abilities of people with dementia should:



1. Be safe and secure,
2. Be small,
3. Be simple and have good visual access,
4. Reduce unwanted stimulation,
5. Highlight important stimuli,
6. Provide for planned walking,
7. Be familiar,
8. Provide opportunities for privacy and community,
9. Provide links to the community,
10. Be domestic.

From my visit, discussions, observations and 'getting a feel for the place' it was very clear that the physical design did have a fundamental effect on the wellbeing and general levels of engagement that people living in the facilities experienced.

(ii) Humour Therapy: Having a Laughter Boss

Meeting Dr Peter Spitzer was an honour and a great privilege, although I was a bit anxious that I would not be 'funny' enough. As a 'dour Scot' humour is not in our national culture. However, I need not have worried, he was inspirational, charming and very down to earth. His



vision was that every person living with dementia should have fun – fun was part of living and even when cognitive abilities were reduced, he had found that the ability to laugh remained well after other functions had gone.

We discussed the various models of how this is able to work; the underlying principle is that

laughter is good for you. People living with dementia still can have fun, and that fun is part of living.

Humour worked on the principle of 'ambushing the intellect'. The introduction of the 'Court Jester' a silly person placed in a serious situation. Humour has been shown to:

- Reduce anxiety
- Improve mood
- Increases the ability to cope with loss
- Enhances communication

Laughter in any situation has a ripple effect, how many of us love to tell of something funny that has happened to us. We share the laughter.



Within a dementia setting this is essential. It's a serious situation, the intellect may well be impaired so to bypass it is not an issue and all people living with dementia have suffered loss.

So how do we introduce humour into the dementia setting?

Model's that are available:

1. *Use trained performers* – good as is shown with the work that is being done with Clown doctors, however used in isolation the bridges, the cues to make a connection with the person are difficult to establish.
2. *Train Care staff to have fun* – this way they will know the connections and the triggers for the individual, however not all Care staff have the qualities needed to be a good fun creator.
3. *Combine Professional Performers and Care staff* – this gives the 'best of both worlds' and was what I investigated with the Humour Foundation while in Australia. This brought play into every day situations. Using the life information that the Care staff already had to inform the performer, while involving the staff in the fun as well. It is good to that we all have fun.



There had been a huge research program into the actual benefits of having regular humour as part of daily living for the person living with dementia. Staff were trained in the techniques to actively support the professional performers. The research showed that a weekly humour session as the same effect on reducing challenging behaviour as daily doses of Ritalin (an anti-psychotic drug that has serious and significant side effects for the person living with dementia).

(iii) One Voice: Art, Drumming and Music

This was a very well developed and supported program of music that was in place in the Care facility. The Care facility was specifically for Jewish elders many of whom were Holocaust survivors. The program was designed on several layers, there was a choir for all residents,



drumming sessions for the people living with dementia and art appreciation sessions for small groups of residents.

The choir involved a local school who came to the facility to join with



residents. The choir was used to engage the residents but also to inform the school children of the Jewish traditions and aimed to work towards the removal of cultural barriers and stereotypes.

It was an excellent program which engaged the residents and did as far as could be observed achieve its aims in engaging and improving the lives of the residents while removing cultural barriers.

There was a lot of activity staff at the facility – more evident than the Care staff. The emphasis was on activity. The art appreciation session was particularly interesting. The Activity staff took a group of 8 residents, all who had dementia, and got them to discuss a painting.

- What was the person thinking,
- what type of person were they,
- were they happy,
- were they rich,
- what do you think they were doing at the time,
- what do you think was about to happen.

It was amazing the 'story' that unfolded. All had an opinion, and all the opinions were accepted as correct, between the residents, some of whom had significant communication issues they constructed an elaborate, creative and imaginative story to accompany the painting. It was creativity in action. All had a great time and then settled very easily into afternoon coffee and cake.

The drumming session with the local children was also very positive. One resident (with dementia) was very enthusiastic and did a solo. The children interacted very well with the residents and the residents were very happy that they children were there. The session was very positive and really did engage with the residents.



(iv) *Spark of Life: the model for Re-mentia*

This program makes the bold statement that there is a concept known as 'Re-mentia' It uses a framework of specific techniques to 'Reignite the *Spark of Life*' in each person who is living with dementia. It states that 'There are two disabilities of dementia – this a result of damage to brain cells, which at present remains irreversible. But there is another hidden disability; the excess disability caused by the care approach that positions, disempowers, isolates and over medicates that person.

"Creative engagement enables us to remove this excess disability, and people come to life with new abilities thought to be long lost to their illness." Creative Approaches to Dementia Care; edited by Hilary Lee and Trevor Adams.

The Care approach that constantly reminds the person living with dementia as to what they have lost, what they can't do which usually results in a loss of self-esteem, depression and person closing down or turning off their 'Sparkle' or in some cases becoming frustrated, anxious and aggressive.

"The Spark of Life approach is a philosophy/framework that offers a systematic, practical approach to igniting the human spirit, awaking dormant abilities and healing relationships." Jane Verity.

It is a 'Key' that in the hands of skilled, trained practitioners unlocks the dormant abilities deep within the person living with dementia. This key can be used in any creative situation, adding value and structure to the activity making the experience more wonderful for the person living with dementia.

This 'Key' properly applied, automatically helps to shift the perspective of anyone who is interacting with the person living with dementia. This shift of perspective enables the practitioners to transform the activity: music, drama, washing the dishes, any activity into an intervention that lifts the spirit and creates happiness

This shift of perspective helps and enables the person to see the situation from not their own perspective but from the perspective of



the person who is living with dementia. An example would be from a caregiver to a supportive partner; from disease to disability; from problem to unmet need. This shift will automatically change the approach and the behaviour of the person who is interacting with the person who is living with dementia.

It is not a natural technique that everyone is 'born' with, but it can be learnt. There are of course some people who do naturally have an empathy and ability to connect with others. However, the vision given by the *Spark of Life* training is that for most people the techniques can be learnt. The use of the techniques and principles will enable most people to make that vital heart to heart connection with the person living with dementia.

All that the person needs to bring is a positive energy, gentle encouragement and a belief of success that people living with dementia are naturally drawn towards. They have to have deep within them a sincere, authentic and genuine desire for the person living with dementia to have a Wonderful Day.



Spark of Life: Five Universal Emotional Needs:

- To be needed and useful
- To have an opportunity to care
- To love and be loved
- To have self-esteem boosted
- To have the power to choose.

Where an activity (or any engagement) meets all of these universal emotional needs in a manner that upholds the previous principles then it is very possible that the person living with dementia will be 'unlocked'

and once they have been set free then they are able to regain some of their previous lost abilities to communicate, engage in relationships, make choices and live.



This is a group of Residents that meet every afternoon for tea and cake. They work together to sort buttons which are then sold at the local markets to raise funds for the facility and also orphans overseas.

Spark of Life, properly used by trained practitioners, appeared to have all that it takes to deliver a ... Wonderful Day.

The *Spark of Life* uses these techniques in its whole systems approach to transforming the care environment; in its Torchbearer Program to sustain and grow the *Spark of Life* culture within an organisation and its Club Program to create an environment for people with dementia that meets all their emotional needs.

Visit the *Spark of Life* website to view the principles in action.

<http://www.youtube.com/watch?v=vZCPpMy7Jd4>

In my travels I both saw the Cultural Change Program (New Zealand) and the Club Program (Brisbane, Australia) and the experience was very positive. I was able to see and more importantly feel the difference that this framework was able to deliver. It was not perfect, and the people involved would never advocate that it was perfect but it was very, very good.

It came close to delivering that illusive.... Wonderful Day!

6. AREAS FOR CONSIDERATION

During my travels and my subsequent research I have come to consider some fundamental issues relating directly to dementia. These include:

(i) Medical vs Social Model of Dementia

Similar to the view that society previously held on Disability, where it was the person who was disabled rather than they were being disempowered by their environment, we need to change our perspective on Dementia.

From the Alzheimer's Society website, the definition of dementia:

Dementia is a disease....possible to have more than one of these diseases....symptoms can include memory loss, confusion and mood changes.

From Creative Approaches to Dementia:

Dementia is a different way of seeing the world.

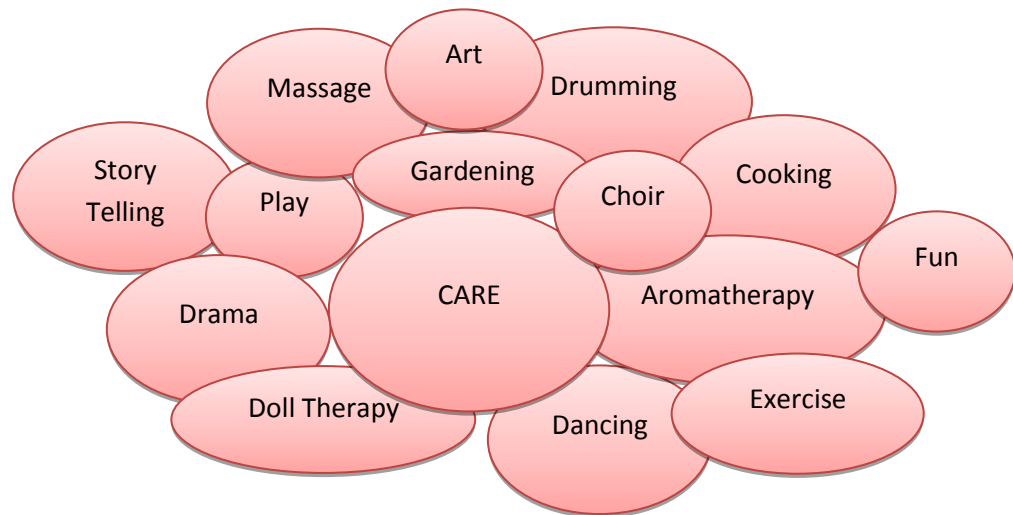
Our perspective informs our actions – to see Dementia only as a disease prompts us to offer care, medical interventions, drugs and palliative care to give the person suffering from this disease as much care and comfort as can be afforded,

However, to see Dementia as simply another way of viewing the world, we then invest our time and efforts in trying to see and understand the world from the other person point of view.

(ii) Creativity and what it offers to people living with dementia.

There is huge range of creative interventions that can be used with or offered to people living with dementia, but how does this fit with the necessary delivery of 'care'. We would all be appalled if people living with dementia although having 'fun' were malnourished, dirty and unkempt.

Currently in the Care Sector the range and amount of creative activity that can/have to be done are huge... here are just a few.



The challenge is have balance and perspective. Currently, in most (not all) the care environment will concentrate on the provision of care (washing, dressing, feeding and similar) some will offer 'person centred care' in that they will tailor the provision of the care to the needs of the individual, ensuring as far as possible that all of the needs (physical and emotional) of the person is met.

However, that can be increasingly difficult with the lack of staff resource, the 'culture of care'. Many care staff are good/excellent care givers but less able to see creative things to do. It is easier to wash and dress someone than to look creatively at a situation and turn such a routine even into fun, laughter and enjoyment.

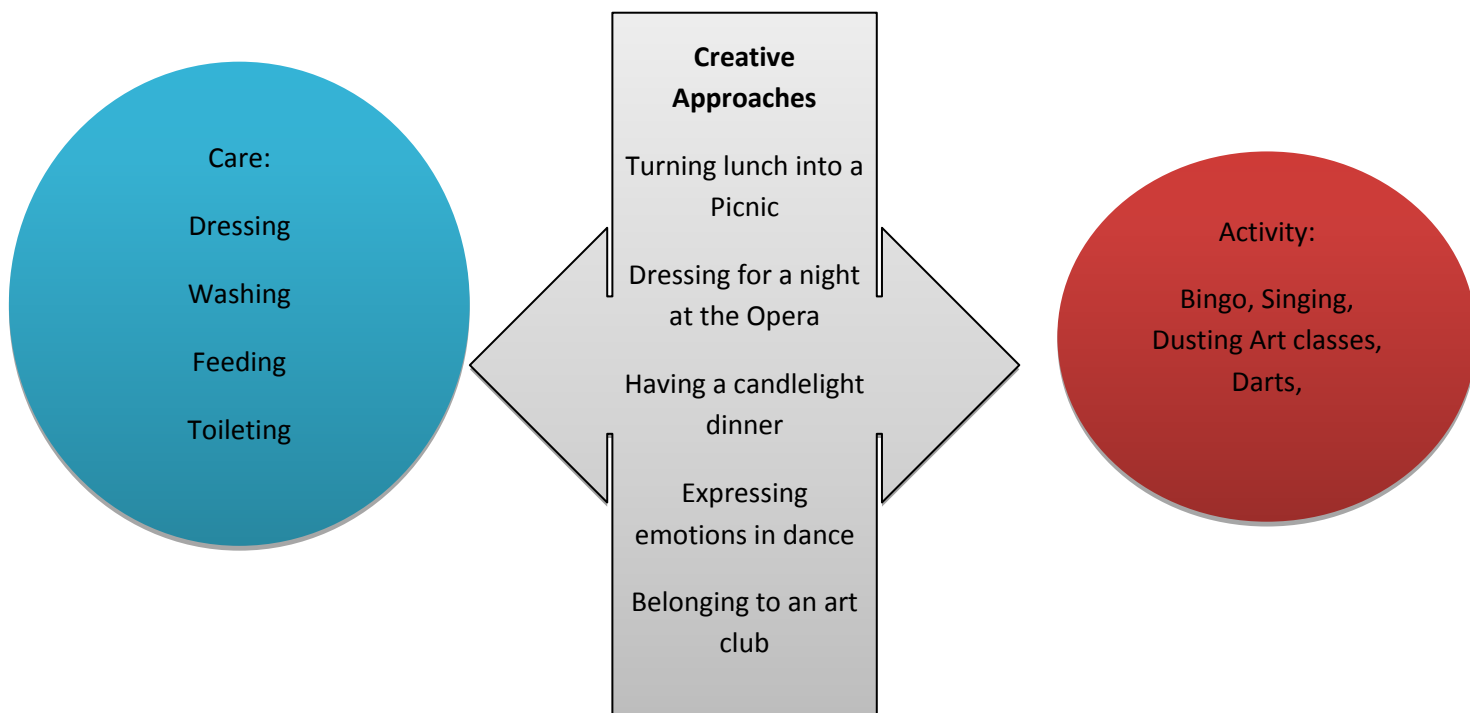
Thus they meet the physical needs of the person, but don't know or have the skills to understand and meet the emotional needs of the person. Care givers are wrapped up in the very important task of giving care and don't see the need to reach out to the emotional needs of the person. Unfortunately this can lead to the person who is living with dementia to become either frustrated – resulting in challenging behaviours or to withdraw from the environment that is not meeting their needs.

(iii) Care and Activity seen as one

Currently in many care facilities and activity are seen as separate – indeed in many facilities there are separate activity staff who come into the facility to provide the fun and laughter. The challenge with that is that it is additional resource which is often sacrificed/reduced when resources are tight.



There does need to be something, a framework, a way of working that works towards joining up these two important facets of giving the person living with dementia a wonderful day. This may be the vital key that unlocks the person for being treated as an object of care to being a unique and wonderful person.



(iv) How do we enlarge the creative experience?

We are by nature creative beings, indications are that our creativity is one of the last cognitive functions that is lost as the symptoms of dementia progress. To harness this creativity there needs to be a shift of focus in the care environment from one that treats the symptoms

of a progressive disease to celebrating the different ways of seeing the world that the person living with dementia experiences.

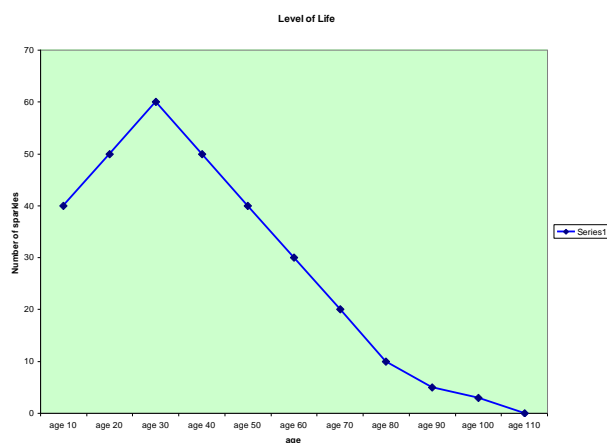
More importantly there does seem to be a real need to have a framework, a way of constructing activities that supports the emotional needs of the person who is living with dementia. Each unique person should have a wonderful day – Using the *Spark of Life* Universal emotional needs each day the person living with dementia should:

1. Feel that they are needed and useful
2. Have the opportunity to care
3. Love and be loved
4. Have their self-esteem boosted
5. Have the power to choose

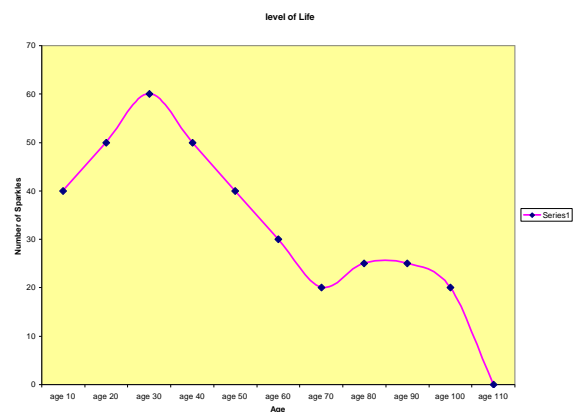
(v) Clinical Model vs Re-mentia Model

There is clear evidence from both research done at Mercy Parklands, New Zealand and the thesis done by Hilary Lee that using the *Spark of Life* core principles that the incidence of challenging behaviour significantly reduced. The *Spark of Life* does reignite the human essence (i.e. the spark of life) within the person who is living with dementia. It brought back loved ones – it does not claim to make a person live longer, just improve the quality of the life that they have. Eventually, as with us all, people with dementia will die. The hope of the *Spark of Life* is that they have more of life before that day comes.

Clinical model



Re-mentia model



7. CONCLUSION

- All of the creative experiences that I encountered in Australia were similar to what is actually happening somewhere in the UK, apart from the *Spark of Life* Program.
- *Spark of Life* appeared to be unique in that it appeared to give staff the tools/key to ensuring that every activity met the 5 key principles.
- What I saw and experienced in the Care facility in New Zealand that operated a '*Spark of Life* whole systems approach' was different – it did unlock the person and from the reports of staff, research and inspection reports it had reduced the incidents of challenging behaviour significantly.
- Experience in the Care sector would suggest that Person Centred Care although much talked about doesn't always give Care staff the tools to deliver a wonderful day to people living with dementia. It is very much dependant on the Carer being individually creative in what they do. There are a lot of very remarkable carers!!
- There is a gap in provision between the delivery of Care and Activity – they are seen as separate, there is no encouragement or framework to join up these two very necessary aspects of giving the person living with dementia a wonderful day
- There needs to be a change of focus away from a clinical model of dementia to a social/*Re-mentia* model if care practices are to change.
- It would appear that *Spark of Life* could be the framework to bring all of the creative approaches together, an application of clear principles that ensure that all of the emotional needs of the person are met.
- However this would need further research and possibly a care facility in the UK to pioneer/test the principles in the UK culture. The premise is that the delivery of a wonderful day would not be any more costly, in fact from the testimony of those using the principles it could reduce the incidents of challenging behaviour, accidents and improve the wellbeing of both staff and those who are living with dementia.
- It would be my proposal to bring the *Spark of Life* to the UK, as the principles that it uses do appear to be able to deliver a Wonderful Day to people living with dementia.

8. POST SCRIPT

The Churchill Foundation has agreed to fund my return to Australia, hopefully in May 2013. This would be to attend a three week Master Practitioner course in Perth, Australia. This would give me the skills to deliver the Club Programme, the Torchbearer programme and the Culture Change programme to facilities within the UK.

"To achieve great things you must first imagine that great things are possible."
Arsene Wenger

9. ACKNOWLEDGEMENTS

Winston Churchill Memorial Trust: for funding my traveling fellowship,

Brunelcare: for enabling me to take advantage of this once in a life time opportunity,

Humour Foundation: Peter Spitzer, Vicki Barclay, David Symons and Mel Farrell for their inspiration, kindness and fun,

Emmy Monash: Pamela Bruder, the Life Enrichment coordinator for her hospitality and insight into the work that is done with the older people at the facility, many of whom are holocaust survivors,

Spark of Life: Jane Verity and Hilary Lee, for their continued support and encouragement, their belief and positive energy in what the *Spark of Life* can deliver and their inspiration and hope for a better future for everyone, worldwide, who is living with dementia.

Helen Forrest (and Dean-na), Brisbane – who gave me a wonderful time, participating in a real Club Program was a great honour. I will never forget the singing duet of Laurie and Sylvia,

Helen Delmonte, Auckland, New Zealand – it was a real privilege and honour to be able to visit this facility. Possibly the best in the world!

Denise, Linda, Bronwyn, Peter, Jenny and Jacinta, it was great to share the *Spark of Life* Course with you all.

Antoinette; the lovely lady whom I met while in Melbourne while sitting in a garden. We chatted and I was both inspired and humbled by her

realistic acceptance of the realities of old age. May you always smile at the day and embrace strangers.

Professor Richard Fleming, a very informative conversation about the work he continued to do in designing place for people with dementia to live in. The evidence of what the physical environment can do to enhance life was clearly evident when I visit some of the facilities designed by him while he worked at Hammond Care.

Hammond Care: Colm Cunningham, Juliet Kelly and Rejane LeGrange, for being so welcoming and taking the time to talk to me about the work that you all do. The visit to the actual facilities was amazing, seeing the concept of the 'Cottages' enabled me to feel the difference that physical environment does to improve the lives of people living with dementia.

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