Quality Dementia Care
Nurturing the Heart: creativity, art therapy and dementia

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Dr Patricia Baines the author of this paper trained as an Anthropologist, Psychologist and Art Therapist, and now works with Alzheimer’s Australia Tasmania. She holds Masters Degrees in Art Therapy from Edith Cowan University, Perth, Western Australia, and in Psychology from the University of Canterbury, Christchurch, New Zealand. Patricia also holds a Postgraduate Diploma in Applied Psychology from the Institute for Applied Psychology, (affiliated to the University of Zurich, Switzerland), and a Doctorate in Anthropology from the University of Western Australia.

Dr Baines has been working for several years as an art therapist at Alzheimer’s Australia in Tasmania with clients from support groups, the Living with Memory Loss program, and the day clubs. This was in large part due to the knowledge and vision of Debbie Slater, the CEO of AAT, who supported by the Board of the Tasmanian Association, knew that enabling creativity could positively improve the quality of life experienced by people with dementia. In 2004, AAT obtained financial support from the Hazel Hawke Alzheimer’s Research Foundation to run art therapy sessions in the dementia units and the day club at Meercroft Residential Home in Devonport. Since then, as a result of a benefactor to the organization, art therapy has been run in residential aged care facilities in both rural Tasmania and in Hobart. Two of these facilities now fund ongoing art therapy programs. Dr Baines has run art therapy workshops in Tasmania and in Canberra, to enable those working with clients living with dementia to understand the value of creativity and to provide some basic skills in freeing the imagination.

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Introduction

Honouring the capacity to create in people with dementia is the underlying intention of this paper. All human beings are creative, but, when one is living with dementia, that creativity may need to be supported and encouraged by others trained to foster creative expression. The paper is entitled “Nurturing the heart” to indicate that, as human beings, people with dementia, perhaps even more than before, need to feel part of a caring community, which values and respects them. They need to be valued, not just for what they have contributed in the past, but, as they are right now. Watching a person with dementia painting or writing is to be filled with awe, for, regardless of memory loss, the person is expressing and revealing a unique identity.

Practically, the paper is intended for all those people, who live with and interact with those courageous individuals, who have dementia. The paper may also be of interest to some of those living with memory loss, as it describes ways to free the creative flow so that creative activity is possible. For Art Therapists the paper offers a validation of their professional therapeutic work and provides some guidelines as to the special ways of working with people with dementia. Diversional Therapists, especially those working in residential aged care facilities, and family members willing to engage in creative activities with loved ones, may gain some useful hints about how to encourage a person with dementia to start on a creative project and glean some ideas about what kinds of creative activities may be satisfying to the person with dementia.

Art therapy is becoming increasingly recognized as having a contribution to make in the area of quality dementia care. Art therapy, which grew out of psychotherapy, engages with a person’s creativity to initiate a process – whether through painting or drawing, sculpting or writing – that is healing and whole-making1. The very process of being a creator empowers by allowing for a flow of energy and life. It makes well, because it is an essential part of being human. It strengthens because in using creative energy to make something external to the person, the work remains even after she or he has forgotten creating the image.

1 The use of music and song is the area of music therapists to individuals living with dementia and is not included in this article. Musical expression is also proving of therapeutic value to people with dementia.
Executive Summary

Some of the latest research now supports the idea that all human beings are creative. Further, research is also showing the value of remaining creative for maintaining our well-being and quality of life. The capacity of older people to be creative, despite health problems such as dementia, is part of the new understanding that individuals are able to remain creative throughout their lives, providing they have opportunities to use their creativity. Dr. Gene Cohen has provided the catchy slogan “Potential beyond problems” to enhance the concept of “positive ageing”.

Art therapy is no longer an adjunct to psychotherapy but is becoming important in enabling those living with various kinds of dementia to remain creative. Whereas spoken words “slip away”, paintings and poems remain as tangible objects to be found again and again. The emphasis of art therapy is on the process of creation, that making an image (whether in pictures or words) expresses something of the person. Self-expression raises self-esteem and enables individuals with various kinds of memory loss to express their feelings. Although empirical research is still limited, what is available, points to the therapeutic value of art therapy. Research in the UK (Rusted, Shepperd and Waller, 2006) has shown that 40 sessions of art therapy may be enough to produce significant positive changes in mood and cognition for individuals with dementia. Beyond the working through of grief, anger, and frustration that one's brain is “fuzzy” or “not right”, the creation of images may become a valuable and satisfying way of communicating with others, feeling of value, and experiencing intense pleasure.

Enabling individuals with various kinds of dementia to remain creative may require that the therapist assists by making the first mark on the page or writing down the initial words spoken. Miniature objects – so tangible items, which can be picked up and moved around – may in the later stages of dementia provide a way to create installations, which express feelings and thoughts. The paper offers some practical ideas for carers as to how to communicate creatively through the use of images.

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Everyone is creative

Everyone is creative. Finding ways to express our creativity in dozens of different ways is part of being human. Some people enjoy cooking, others planting gardens, choosing clothes, arranging rooms, or inventing things. Some sing or play music. Others express their creativity with paints or pastels, in poetry or prose. This paper is about creative enterprises which make images with art materials or words. The value of all forms of creativity is, however, acknowledged. Creative expression is a basic human need and maintains our sense of well-being.

For many individuals in the western world, art conjures up the idea of professionally trained “artists” with an exclusive right to produce art works. Whilst the cultural and inspirational contribution of galleries and exhibitions is recognized, the genuine value of all creative enterprises for health and healing is the underlying conviction of the writer of this paper. Dahlia Gottlieb-Tanaka, a trained architect, who lives and works in Vancouver, Canada, and, who founded the Society for the Arts in Dementia Care, said in a similar vein, “The arts are good for our soul and our well-being. This is true for everyone, but even more so for those who are ill.” (www.dahliagottlieb-tanaka.com).

Indeed the importance of creativity in our lives is now widely recognized. Rather than seeing creativity as belonging to the rare few “gifted” or “talented” individuals, creativity is recognized as needed in all areas of endeavour. There are Centres of Creativity and Innovation in universities, creativity training is often included as part of leadership training, and the World Wide Web has many sites devoted to the topic. The findings of the longitudinal study of human development carried out at Harvard University over six decades, led Dr. George Valiant, a medical doctor and current coordinator of the project, to the conclusion that “In retirement … creativity, like play, should be a primary goal” (2002:224).

Those trained in the psychoanalytical tradition, as the author of this paper is, would say that creative acts connect us to our unconscious and allow us to draw on resources and strengths, which a person may not believe that she or he has at her or his disposal. Some individuals may wish to say that creative inspiration comes from the universe. Obviously there are different cultural views regarding the way we are moved to create. However, whether one regards the power to express oneself creatively as coming from deep within or from without, does not really matter. That is a matter of cultural belief or theoretical orientation. What is known is that being creative, whatever happens to us, is good for us. It assists in keeping our brains functioning well.

This paper uses, not merely as illustration, but as evidence of creativity, the creative works of individuals with dementia. To display these works the permission of the individual creators has been sought, for he or she holds the copyright to his or her image or poem. The consent of the families of those with dementia has also been obtained. Thanks and appreciation goes to each one of them.

All names used in the text are pseudonyms unless expressly indicated that it is a person’s real name and used at that person’s request. For some individuals it is very important to acknowledge publicly that he or she has dementia. Otherwise I have tried to choose names, which are not names of anyone I currently work with or have worked with in the past. The real stories I recount will seem familiar as they are quite typical of what may happen for someone living with dementia.

The power of image making is that it allows an individual living with dementia to express herself or himself in ways that are satisfying and communicate with others. The made image does not disappear and can be rediscovered. Whilst such self-expression may have diagnostic significance, it is the ways in which creativity allows a person with memory loss to transcend the isolation she or he may be feeling, work through issues still troubling her or him, and enjoy the pleasure and satisfaction of the process of creating, which is the focus of this paper.
“More important than eating or sleeping”: the power of creativity from the perspective of persons living with dementia

Grace – a contented and wonderfully creative person in her late eighties, who has been diagnosed with dementia (initially thought to be Alzheimer’s Disease) – had just finished an image in water colour and pencil when she burst out, “This is more important than eating or sleeping!”

Grace had worked with intense concentration for an hour or more on her image, which transformed under her hand until she had created a woman wearing a large hat. A cup of tea and a sandwich sat untouched beside her. After her declaration, Grace burst into gentle laughter.

Above: The Church by Grace
Left: Green Hat by Grace
Grace had begun as usual, looking at the things placed around her – flowers, shells, tiny figurines of animals and birds, open picture books, anything indeed that might form the bridge to her own creativity. Sometimes it is a few words written on the paper in front of her that attracts her attention. At other times she chooses an object and begins to work. Despite her concentration, Grace often adds insights into the conversation going on around her at the long table at which another six individuals with various kinds of dementia are also working. When invited to share her written words, Grace may ask for them to be read for her or may read them out herself. Using the dashes she has made to indicate a pause, her words read as poetry.

Grace is one of many individuals, who, having lived some years with the effects of dementia, is able to use her creativity to find satisfying expressive forms. Indeed, as Grace draws or writes, her power of more usual verbal expression slowly returns to her, and she speaks with more and more clarity and confidence. It is as if the brain’s capacity to communicate has needed a “tune up” and, now, in the group setting where we gather around objects and art materials, she is finding herself again.

The declaration that doing something creative – whether painting or writing – was more important than other forms of sustenance, is the starting point for thinking about dementia and creativity. For when individuals with dementia are creating, they have transcended memory loss and can see something happening before them.

It is extraordinarily moving to stir the imaginations of those with dementia and watch as they slowly and with commitment, produce works of art. The point is not to produce works for the galleries or for publication (although this may sometimes actually happen), but to enable each individual to engage with her or his own creativity to make expressive marks in some form.

Sometimes it is a few hesitant lines – the first made in some months that evoke pleasure in the person living with dementia and the therapist. At other times it is that a person, who has been watching others create for some months, suddenly picks up an oil pastel and draws without hesitation. The therapist can only watch in wonder and delight.

Jock, who loves to make hatching marks in a range of colours of his own choice, said, after one art therapy session, holding my hand tightly, “This is very important for us. You should come again.” During the hour and a half he had changed from looking tense and sad, to working with intense effort and smiling. Creating images gives pleasure, and, as Grace so eloquently explained, it satisfies a fundamental human need.

The Tree of Life by Lol

Lol, who lives with dementia, enjoys making drawings of the English countryside of his childhood. He makes wonderful images of tractors and hay making, and of the hills where he walked as a boy.
Sometimes the most moving work is a duet. A man in his late fifties with severe language loss and considerable mobility problems living with dementia wrote his name over and over again as I sat with him. Whilst I recognized the importance of his affirming his own identity with his name, I wondered what my presence beside him did for the creative process. I wondered whether he felt less isolated, and, whether he was conscious of my being with him witnessing his creative work. One day, after many sessions in which he has written his signature, I asked him whether he could possibly put leaves on a tree I had just drawn, as he was writing. I held my breath as he thought about my request. Then slowly and carefully, he made the leaves. He turned and gave me a blinding smile. I still get a shiver down my spine as I remember the sense of connection.

The possibility that a person living with dementia may wish to express herself or himself in words or images may seem surprising to those who have not seen those individuals deep in creative concentration. The assumption seems to be made by some people that a diagnosis of dementia constitutes the cessation of creativity. For some individuals, especially those who have been trained artists or art teachers, the pain at the loss of control over image-making may be overwhelming. One gifted water colourist, who had nursed her mother through some years of living with dementia, went on to make images of how she thought of her own brain as she herself began to live with dementia. When I met her, she rarely spoke and could no longer walk. She spent her days in a reclining chair-bed. When she saw the art materials she uttered two slow words to me, “Too sorry.”

I understood from her eyes and her words that attempts to draw now filled her with a profound grief. For others, however, with a range of different kinds of dementia, the diagnosis of memory loss may be a door to discovering new forms of creative expression. What may begin as a means to express depression, anxiety or anger may become a way to keep going and of experiencing satisfaction and pleasure. There are poets and artists with diagnoses, not only of frontotemporal dementia, but also of vascular dementia and Alzheimer’s disease, whose poetry and paintings are becoming more and more lucid and expressive.

Whilst short term memory may continue to be less than effective, the capacity to create seems to transcend the damage to the brain caused by disease. This of course points to the value of creativity in whatever form it may be expressed, in keeping a person positively engaged with the world. In allowing creative energy to flow through one to become embodied in images, one is open to creation.
“Potential beyond problems”: the research into the benefit of art therapy and creativity

At a brainstorming forum “Creative expression and dementia care” held at the University of Wisconsin, Milwaukee, in November, 2006, some of the leading American researchers in the field of creativity and dementia acknowledged that the benefit of creative enterprises – whether dance or music, writing or art – to people with various kinds of dementia was seriously under-researched. Yet the practitioners of the diverse creative activities present insisted on the benefits of being creative to individuals in all stages of dementia. They created a fascinating list of some of the potential outcomes:

- Positive emotional responses
- Reduction in agitation
- Greater social engagement/interaction
- Change in cognitive processes
- Increased verbal fluency
- Functional improvements
- Increased food intake
- Weight gain
- Increased mobility
- Greater physical strength and balance
- Improved mood and attention span
- Less stress (caregivers and receivers alike)
- Elevated quality of life
- Greater understanding of the human condition

In what follows I shall begin by looking at the available, if limited, research, which supports the value of creative expression as a means of improving well-being for individuals with dementia. Research carried out in the 1990’s by University of Sussex researchers Dr. Jennifer Rusted and Linda Sheppard in collaboration with Professor Diane Waller (University of London), was the first study to investigate the value of art therapy to clients with Alzheimer’s disease, which had a control group (www.sussex.ac.uk/press.office). Prior to that there had been the occasional article published in journals of art therapy but these, whilst valuable, were rather case studies of the use of art therapy with someone or some individuals living with dementia. Rusted, Sheppard and Waller were able to show that a ten week art therapy course for those living with Alzheimer’s disease and experiencing depression was more helpful than being a member of a group which talked and socialized. The research indicated that it was not simply being in a social situation, which alleviated the feelings of depression, but that the creative process itself played a part in recovery.

These researchers published a further study in 2006, which sought to extend the scientific rigour of their previous work. They were able to show by running social groups parallel to art therapy sessions, and holding all groups in a range of different residential facilities, that, whilst participation in either was beneficial for a person living with dementia, the art therapy sessions again improved a person’s mood and cognition more than just social activities. Although this study was again with small numbers (40 participants), Rusted, Shephard and Waller have carried out a further, larger research project, which they are currently writing up.

In Cincinnati, America, Jennifer Kinney and Clarissa Rentz have been seeking to refine objective measures to assess the value of the “Memories in the making” (copyrighted name) art program as against participation in an adult day club. Although they used a professional artist rather than an art therapist, and so some of their objectives were

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3 Professor Waller is in charge of the postgraduate art therapy program at Goldsmith’s College, University of London.
somewhat different, they were able to demonstrate that participation in the creative process enhanced well-being. Using the Greater Cincinnati Well-being Observation Tool they got trained observers to record behavioural indicators such as concentration on artwork, smiling, positive verbalizations and so on, at ten minute intervals, to create a measure of what the art activity meant to the person living with dementia. Although the number of participants in the study was small, their results showed that the same individuals showed more interest, greater sustained attention, more pleasure and greater self-esteem when involved in the art program than in adult day centre activities (2005).

Although not directly evaluating the value of art therapy as compared with other activities for those living with dementia, there is a growing body of research, which supports the value of creativity for those growing older and the possibility that the ageing brain may become more creative than when younger. Dr Gene Cohen of George Washington University Center on Health, Ageing and Humanities has been carrying out a Creativity and Ageing Study. He insists, pointing to the way in which folk art in many cultures is made by those up in years, that “The inherent capacity for creative expression [exists] throughout the entire life cycle” (2006:14). His research has also led to the finding that brain plasticity is greater in older individuals (as a result of control hemisphere asymmetry reduction) and that this greater connectedness between the left and right hemispheres is thought to promote creativity.

Developed in a climate in which the idea of positive ageing is growing, the approach of Cohen transcends the idea that successful ageing is the absence of medical problems and the retention of physical fitness and mental prowess. “The optimal treatment of the patient [person] focuses not just on clinical problems but also on the individual potential of that person. It is only when problems and potential are considered together that health is best promoted and illness best cared for.” This has led to the catchy phrase: “potential beyond problems”. His conclusions are supported by the findings of the Harvard Study of Adult Development, already cited. Valiant in his book “Ageing well”, which is an account of the study, found that for successful ageing, whether with or without physical illness, creativity was essential. “Creativity allows us not just to wish upon a star, but to throw ourselves into life…creativity provides a means of containing wonder as well as a means of resolving conflict”(2002:236). Quoting the findings of the research of Simonton into “later life potential”, Valiant offers Simonton’s conclusion, “Usually creators in their sixties and even seventies are as least as productive as they are in their twenties… An octogenarian can still hope to make important contributions, albeit at a slower rate.” (2002:239).

This leads us on to consider whether living with dementia works for or against engaging in creative activities. Dr. Bruce Miller of the University of California, has been a key person in publicizing the creative abilities in some individuals with frontotemporal dementia. He happened to recognize something interesting, when a son, who was caring for his father who was experiencing progressive memory loss, told him, that his father has begun painting and that the images were getting better and better. Dr. Miller said he now asks individuals experiencing various kinds of dementia whether there is anything they “are doing very well or better than before”. The acknowledgment that people with a form of dementia might, as well as experiencing losses and deficits, be experiencing new possibilities and novel creative urges, is behind Dr. Miller’s new focus.

Dr. Bruce Miller’s research has been pivotal in recognizing that degeneration in the left side of the brain, may reduce or “knock out” language, but may enhance and release musical or artistic abilities. (see transcript www.abc.net.au/allinthemind/stories/2005). In an ABC interview with Julie Browning, on 12th November, 2004, Dr Bruce Miller said, “As people lose the ability to name, to conceptualise what things are, they are forced into much more visual ways of thinking about the world.” However, what Dr. Miller attributes particularly to some individuals with frontotemporal dementia, seems from my own work to be true of those with a wide range of dementias. The point is that, whilst not all individuals with dementia may become extraordinarily creative, some do, and, in any case, even small adventures into creative activity may have positive effects on a person’s quality of life.
The capacity to be creative may be fostered or hindered by the environment in which we find ourselves. There has been important research across the globe looking at the creation of comfortable but stimulating accommodation for those living with dementia, who are no longer able to live in their own homes. The work of Dalia Gottlieb-Tanaka in developing the idea of a therapeutic environment is important here. Coming from a background in architecture, she has become committed to designing environments for those living with dementia, which promote creativity (2004).

Dr. Ken Rockwood, a Canadian medical researcher who is carrying out research into Alzheimer’s Disease, has also introduced an artist-in-residence scheme into his memory clinic in Canada. By having an artist in the hospital environment to interact with the individuals with dementia and their families and with the nursing and medical staff, and to create images of what she or he is experiencing as an artist, a new sensitivity and appreciation into living with dementia is being achieved. There is a excellent article in The Lancet Neurology describing the program (Rockwood, 2004).

Research findings in the neurological field have indicated that creative works may have diagnostic potential. The changes in colours chosen may reveal changes in the brain. It has been found that whilst the perception of the yellow-red spectrum remains in tact, individuals may loose the green-blue spectrum. As well as a change in the palette of colours, Maurer and Prvulovic (2005) found that in the paintings and drawings of a professional graphic designer, Carolus Horn, who continued drawing all his life despite Alzheimer’s Disease, other changes were noticeable. His work gradually lost perspective, faces became more schematic, and in the weeks close to his death he was no longer making recognizable images but was making abstract hatchings. The response of an art therapist is to say with reverence, “He was creating right to the end.”

4 I do encourage participants in the regular art therapy groups to continue to come to the group when I am aware that their human bodily existence may be drawing to a close. Other members of the group living with dementia seem equally aware of what is happening and seem able to encompass the impending departure. Being accompanied and supported as we approach our death seems part of being treated with respect and care.
Art therapy and dementia

Art therapy or art psychotherapy is first and foremost a therapy. It is a therapy that utilizes the creativity that is within each person to work towards that person’s well-being. Art therapists work in many different health arenas – with children who have experienced domestic violence, with suicidal adolescents, with refugees, who have been traumatized by war, with survivors of environmental disasters, with war veterans suffering post-traumatic stress disorder, with individuals experiencing psychiatric illnesses and, last, but certainly not least, with individuals living with dementia, to name but some. When working with an individual with dementia, the art therapist enables that person with memory loss to consider and often resolve psychological and spiritual issues related to their condition and to restore in some part their sense of self-worth and identity.

The practice of art therapy is the creation of a safe and nurturing space within which individuals who have challenges in their lives, may, through the making of images, produce positive effects within themselves. The emphasis of the time set and place set aside for creative activities is on the process rather than the end result. Indeed participants are reassured that whatever they choose to create will be accepted and will be “right”, that is, there is no judgment regarding the aesthetic quality of what is produced or whether it is well executed or faltering. What matters is that a person feels safe and comfortable enough to make marks, that is, is able to express herself or himself. The participation in an art therapy group is voluntary and how long individuals stay is up to them (some individuals with memory loss, once comfortable in the group, may be reluctant to leave and may need assistance moving to the next space). An hour and a half is quite a usual length of time for a group. There is no pressure to begin, although each individual has a place prepared for him or her with papers of various colours and types, oil pastels, pens, pencils. Small objects are arranged down the middle of the table but within easy reach, should someone wish to pick one up.

Art therapists may work with individuals or groups. Individual art therapy is particularly helpful when a person is so overwhelmed by something happening to her or him that the group would be flooded by her or his need to talk about personal concerns. Those personal concerns may also be of such an intimate nature that the individual needs the confidentiality of the one-to-one situation with a therapist, who can both hold what is being expressed, and, allow the individual to share with another person. The value of the group setting with individuals creating side by side with each other is that the individual is able to feel encompassed again by a community – thus breaking the sense of isolation. There is time towards the end of a group session for individuals to speak about their art work or read out their story or poem, should he or she wish to. The other group members respond respectfully to what is shared (the therapist sets up the group with guidelines which will respect and acknowledge each individual). There is, in my experience, genuine interest in the thoughts shared by others living with dementia and the session may engage in conversation as images and words stir memories and ideas.

Dolphin and flowers by Fred Newman

Fred Newman is a gifted musician who plays the banjo. He and his wife visit residential aged care facilities and entertain residents with their singing and making of music. Fred now lives with dementia. He used to do a lot of oil painting. He has begun to paint again.
Dementia, in its many forms, can affect individuals in various ways. A common effect is to make starting something creative difficult. There are technical terms for this condition (such as damage to the executive function in the brain) but, simply, it means that writing the first words or making the initial strokes of a pencil or paint brush may be a prohibitively difficult act. The lesson was brought home to me by a delightful octogenarian, who nodded and smiled at my invitation to draw, but sat with the hand holding the oil pastel suspended in space above the paper. I asked her permission to draw a circle for her (research has shown that people experiencing damage to their brains enjoy circular forms), and, it was, as if I had released her frozen gesture, for her hand descended to the paper and she began to draw with vigour and concentration. She was delighted at the outcome.

Another way to begin may be, with an individual’s permission, to assist by acting as scribe or by starting a picture as a combined project. The person living with dementia when handed the brush, pastel or pen, can, once ‘the switch’ in the brain has been ‘flipped’, continue on her or his own. I rarely draw for those in a therapeutic relationship with me (my leafless tree was a rare exception), preferring to make a few small strokes or a shape. I am simply assisting the part of the brain that needs to be reminded to begin by modeling a few strokes. When acting as scribe, I always write exactly what the person has said, in very large, careful, hand writing. I do not change grammar or correct (unlike the poetry that John Killick makes using the words of those with dementia but adding to them). I might encourage someone to add words by sharing the feeling her or his words are giving me. I have found that almost all individuals who have learned to read as children are able to read their own words (this was also found by Kathy Laurenhue in the United States – personal communication) Often they read them out aloud, so I know that they are able to read. If I am asked to read for the person, he or she may read alongside me, nodding at the text. This is clearly important for more than art therapists to know.

Sometimes lengthier modeling of writing or drawing may be needed. It is always good to offer the person living with dementia the opportunity to make the marks himself or herself, as the satisfaction of active creation is often stronger than having someone write for one.

When words are failing and the brain no longer allows the hand to create the strokes it wishes, the manipulation of miniatures – figurines of people and objects in the world – may permit a kind of sculpture or installation to be produced. This may be done in a tray of sand (the sand facilitates the positioning of figures as well as brings something from the natural world indoors). Stones and shells, seeds and flowers, leaves and bowls of water, all provide connections with nature. The joy and interest, which objects produce in those in the middle and later stages of dementia, would seem to indicate that this is not experienced as treating them like children. Rather the objects assist the recall of places and people.

I have also tried group installations as a way of assisting everyone’s creative flow.

Babies and superwoman (a figurine which was given out by a fast food chain) often feature in these diminutive installations. Madeleine lined up all the miniature chairs available and placing the tiny brass goblet and the diminutive brass chair in the centre, she slowly, in a series

5 John Killick is a Scottish poet who has for many years now worked with individuals living with dementia, using their words to form poems. Information about the way in which he uses poetry with individuals living with dementia can be found at: http://www.dementiapositive.co.uk. There is also a transcript of a radio interview with John at: http://www.bbc.co.uk/radio4/youandyours/transcript_2005.
of hesitant moves, sat a tiny naked baby on the central chair. Such enthronement of a child (Jungian analysts would say “the holy child” – the goblet/chalice would support such a labeling) by a woman, who with others in the group can no longer remember clearly how many children she had, is moving. What remains for some women as dementia progresses are essentially two understandings – the first that they have children, grandchildren, great grandchildren and secondly, that the world is full of their children (hundreds of them they often tell me). Very often their own childhood is near and eighty and ninety plus year olds glow with pleasure as they recall parents and teachers, people with whom they have boarded, those who nurtured them and encouraged them. Meg, who had great difficulty articulating words, was drawn to the figurines, with which she made groupings of babies and animals with “super woman” in the middle, apparently guarding them. Once she had made her arrangement, she actively sought to engage with me, seeking my attention to look at her arrangement of figurines, as they clearly were communicating something of importance to her. Through her arrangement of objects we were able to reach an intensity of understanding that we could not achieve in any other way.

Men and women respond with equal interest to objects (especially if objects more reminiscent of a man’s world are included – so cars and planes, tools, tiny fish etc). Individuals living with dementia, but retaining insight, may comment on what it is I am encouraging them to consider. It is important to remember that despite experiencing memory loss, those living with dementia respond with interest to new objects, which they have not seen before. I suppose the lesson is that it is possible that some part of the brain has registered something in the past and novelty creates new interest.

Figurines arranged in the sand.
Balancing the bad and the good: the therapist’s task

The therapeutic space may feel safe enough for a person living with dementia to wish to work through memories of tragic or frightening events. However, feeling that one’s brain has become “fuzzy” or “funny” or that it is “not right” (to quote some of the things said) may in and of itself be a frightening experience. The fear experienced may lead a person who is experiencing memory loss to create a story of an imaginary frightening event, which nonetheless gives expression to her or his emotion. Whether the anxiety and distress is caused by past or present fears, whether the images are of real or imagined events, the therapist must not just hold sad or terrible images but must bring personally meaningful, positive images to sit alongside the distressing one. This is not a denial of sadness and grief but to ensure that the person with dementia does not become fixed on the image of pain, fear, or loss.

An art therapist working with individuals living with dementia needs to put in some “safe places” as landmarks amidst the darker thoughts – the grief at the changes in one’s abilities, one’s growing awareness of mortality, one’s fear of separation. “Safe places” (so safe images) may be as simple as one’s own favourite armchair or bed, as detailed as a childhood place with every blade of grass recalled and every mountain named, or an imagined beach on a sunny day or a lake beside which one can sit with a friendly animal alongside. It matters less whether the place is imaginary or real than that one has some inner image to bring alongside the bleaker internal landscapes.

The value of survival is often the most healing image for those now living with memory loss who are overwhelmed with fearful memories from childhood. Fears during wartime of being tortured or killed may surface. Moments of being abandoned as a child or getting lost may become a powerful, repetitive, image.

Vanessa needs to tell the art therapy group repeatedly that she was left all alone as a very small child and was only found when her crying brought neighbours to her. The group members acknowledged her right to share her sense of being neglected and abandoned and offered her with their warmth and understanding, acceptance and care. Alongside this Vanessa made images of angels, dogs, and teddy bears – that is, all images to comfort a frightened inner child. At the same time I reminded Vanessa that she is a wonderful mother and grandmother. We also speak of Vanessa’s home. Vanessa’s home is her safe place and it is full of beautiful dressed dolls and teddy bears that she once made.

Claude claims that he can remember very little at all. The memories that he does recall, despite his dementia, are painful ones. He remembers his father being angry with him when he was a small boy, and, shortly afterwards, his father died. He remembers his mother’s strapped financial situation and her having to budget carefully. Yet Claude had actually survived in a potentially life-threatening situation as a young man during the second world war and had gone on to have a distinguished professional career. These latter two facts Claude often cannot recall, although I always set them beside his images of a frightened child. In working with Claude’s “I’ve got no memory”, we imagine things he enjoys. He is able to give out wisdom about living in the present, such as having a sense of humour, and being courteous and behaving in a gentlemanly manner.

Grace, so often now contented and at ease, went through a period of some months when she kept describing the image of a woman stepping off a boat with all her children around her and dropping dead. She could not clearly identify the woman, suggesting it was her grandmother, her sister-in-law, or some other close relation. I asked Grace’s family about the repetitive image and they had no idea what she was describing, saying that nothing like that had happened in the known family history. They wondered if Grace had read it in a book or seen it on television.
It was agreed with Grace and her family that I would work with her for some weeks one-to-one. I wondered in fact whether Grace was sharing with us some of her fears about her own death, since she was in her mid-eighties. The issue of mortality, that we will all one day die, is something that is from time to time brought up by group participants, although group members may deal with it with humour and resilience. Nevertheless the death of members of the group, or, of past members of the group, who have become ill, are part of the consciousness of individuals living with dementia. Group members right to speak about their sense of loss and grief must be acknowledged. It could well be that the death of another person in the residential home had affected Grace.

Instead of working on the image of a woman dropping dead as she stepped on land, I asked Grace whether she had some special place where she felt safe and happy. Grace began to make image after image of the gate to her grandparents’ farm. As she made each image she talked about running from one property to another, meeting relatives, being welcomed and recognized. Gradually she no longer told the story of the woman who dropped dead and a couple of years later I have not heard it again.

I shall never forget working with Maimie who, through a series of tragic deaths of family members, found herself in her late seventies alone in a foreign country (i.e. Australia) with some memory loss and an overwhelming need to curl up in a foetal position. Her first image with me started as a water colour of a beautiful pink flower but gradually turned into what could only be described as a bleeding fissure. That Maimie was hurting badly and felt injured was clear. The second time I worked with Maimie I encouraged her to make images of some of the things that gave her life meaning and comfort. She made a careful drawing of a packet of cigarettes, then of two beer bottles, and finally she wrote, in what for her were large letters, SEX. She was in a residential aged care facility, where there was a non-smoking policy, and, alcohol was prohibited because of her medication. She burst out laughing when I suggested that these were images of “never gets”. I tell this story as it shows clearly the difference between making art as “art” and making an image as a therapeutic enterprise. Maimie went on to make drawings of the first home she and her deceased husband had owned, the beach the whole family went to every Sunday when it was warm (her “safe places”) and later wrote her husband a letter about the recent death of one of their children (although he was no longer alive she still held an inner conversation with him, so we simply externalized it, so that I, as therapist, could hold the pain with her/them). The creative activities allowed Maimie’s legitimate grief to be expressed and she became articulate about what she wanted, which was to return to her homeland. This was made possible.

Below: *Mount Wellington* by Mort Denwer.

Mort Denwer began painting and writing poetry after he was diagnosed with vascular dementia. To date he has produced more than sixty paintings and has explored water colours, oils, and pastels. Mort very generously has allowed us to reproduce some of his images on cards, which Alzheimer’s Australia Tasmania sell to raise money for the Association.
The value of exhibitions

Although art therapy is primarily concerned with the process of creation rather than the end product, for those living with dementia, what has been created may be of importance as the created work has a constant existence. As compared with talking therapies, after the session, there is something remaining to be viewed or read again and again. Although an individual living with dementia may forget having made a particular picture or poem, when she or he re-discovers it, she or he is often able to recognize it as her or his own.

This capacity to reconnect with one’s own creative works is fascinating. Having carefully displayed the created works of a group who took part in art therapy over some months at all different heights on display boards so that no one would feel favoured or neglected, I was intrigued as a lady, who had been diagnosed with Alzheimer’s disease some years before, went up and down picking out her own images. She would say “I like that one” then laugh softly, and add, “It’s mine.” When handed back a typed version of her or his words, an individual living with dementia may declare that she or he cannot remember ever having written down or dictated the words and yet she or he knows that the phrases and stories are their own. They re-own their own stories because they recall moments that are part of themselves.

Shadow Land and Judgement Day

The Eastern Shore at sunset as seen from Nelson Road on the Western Shore. Written Wednesday 6 December, 2006 and after many revisions.

Hollows and shadows in the Eastern Hills
Are only seen by me. They appear as if
By magic as the evening stills.
When the sun sinks low but brightly in the West
This is when the features are visible at their best.
Who lives or now dwells in their shade?
In the dark caves by man or nature made?
The answer to this riddle we may not learn
Until a traveler to Shadow Land does return.

The second big bang

by Roy Harden Jones

The expanding universe
Suddenly broke.
God in his heaven smiled.
It was his next big joke
On his children down below.
And now not one of them would ever know
From where the World had come from or to where it would shortly go.

Roy comments:
After breakfast.
Written as the words came out of the pen with some rhyme and rhythm and a little conscious thought.
My mind was empty and I wrote down the words as they came at about 09.30.

Roy Harden Jones, whose professional career was as a research scientist, and who wrote some major publications on fish migration, now lives with memory loss, diagnosed as Alzheimer’s disease. He has written many poems and some prose since living with memory loss.

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Shadow and Judgement Day
Shadows are stored on hangers in a Great Hall in Shadow Land under soft dim lights so they will endure for ever more.

Shadows of people, reality, and make belief of Kindness, Love Happiness and Sin: left by people of little or lasting renown from the Poorest Peasant to the Greatest Crown.

All power, all weakness and most deeds and ideas will cut a shadow,
Whether of joy or tears. All these are sown on our personal judgement day
Which is not more than forty days after the thought was made or the deed was done. Judgement will be in the twinkling of an eye or thought, and some of our dreams may come to naught.

Indeed a certain degree of healthy envy was evidenced, when those not part of the art therapy group asked that they too be allowed “to do art”.

In 2003 Dahlia Gottlieb-Tanaka held an exhibition of images made by individuals living with dementia in Vancouver and over four thousand people came to view the exhibition. Such public exposure and recognition allows individuals living with dementia to feel valued and acknowledged. In Vancouver in May, 2008, The Society for the Arts in Dementia Care and the Institute of Neurosciences, Mental Health, and Addiction are holding a conference entitled Creative expression, communication and dementia. As an extension to the conference, another exhibition of art works by individuals living with dementia is being organised.

In 2006 Alzheimer’s Australia Tasmania was visited by Kathy Laurenhue from the United States. Kathy is deeply committed to the use of creative endeavours with those living with dementia. She sent us La Doris “Sam” Heinly’s book, I’m still here. This is a publication of images made by people living with dementia and with each image is a short written piece about that person. Although ordered according to the three stages of Alzheimer’s disease, the book’s main message is of the feisty, life-affirming creativity of the artists, whose work appears in the book.

Typing the words of someone with dementia may make the words easier to read and to share. It also honours the words and the authors of the words often voice their approval of a typed manuscript, saying that they feel their words are important and valued. Dr. John Killick, a poet working through the Dementia Unit at the University of Stirling, Scotland, has for a long time now been taking the words of individuals with dementia and makes poems with them, which he then brings back to the individuals. In Tasmania, we have made in-house books of the wise words of those with dementia and of poems written by some of the support group members. Publication of an individual’s words, whether done modestly or on a grander scale, is a way of raising the damaged self-esteem and reaffirm the continuing worth of a person living with dementia.
Art therapy A poem by Mark Rimmer

I choose art for it comes from the heart,
Your spirit lifts free as you choose to be,
A creature of air, a creature of wonder,
We are creativity bound.

Let your mind soar, let your vision run free,
What you see is never all,
Find the still small voice within,
Follow it, too true.

Photographs can catch the form,
With art you need to look deeper,
Find the spirit that animates,
Express it with your heart.

In short let us love every brush stroke revealing,
That deep sense of care
For the subject we dare.
To reveal with each stroke of our hand.

I am excited, I must tell you why,
For I feel connected to everything now,
Your spirit runs free, your heart revealing,
Those deep seated visions of love.

Mark Rimmer has been and is a wonderful “ambassador” (his word) for Alzheimer’s Australia Tasmania. He insistently uses his real name. Mark was diagnosed with frontal lobe dementia. Since being diagnosed with dementia, Mark has devoted his talents to painting and writing poetry.
Words slide away”: but images may transcend memory loss

Working in residential aged care facilities one seeks to turn everyday spaces into therapeutically responsive places. With this in mind on a misty, grey, early spring morning, I arrived at a dementia unit with a bunch of bright yellow jonquils. Having put them in a vase, I placed them on a small table in the middle of the room and arranged other small tables in a ‘Maltese cross shape’ around them. Edwina clapped her hands with evident delight. Edwina was, at the time, living with quite advanced dementia. Two weeks later I returned with old photographs (so no clue to the previous session) and began the art therapy session. Edwina looked at me very pointedly and walked into the enclosed courtyard garden. I noted her gaze but did not know what she was communicating. She returned some minutes later carrying a vase of daffodils. She placed them on a small table in the middle of the room, then attempted to move the other small tables around the central one. She turned to me and smiled. Needless to say, I applauded.

Evidence that images may remain when words fade, or, as one person with dementia eloquently put it, “slide away”, was also demonstrated vividly by Emma. Emma, who has had Alzheimer’s disease for some years, found a pig amongst the miniature creatures I had brought with me. She began by drawing the pig and, when I spent some time with her, began to tell me about the piglet she had had as a pet when she was a child. She had lived on a farm and had been allowed to feed the piglet, carry it around and generally shower it with affection. We wrote the story down. Emma shared her pig story and image with the group, who responded with warmth and interest. I did not see Emma again for six weeks as it happened. She had visitors from out of town. She therefore returned to the art therapy group after a long break but as she walked in the door, she said aloud to me, “I’ve got more pig stories.” Her words had neither been prompted nor solicited.

These same individuals, who hold certain images, may have let others go. Sometimes a woman with middle stage or late stage dementia may admit with an embarrassed giggle that she cannot really remember what her deceased husband looked like. This may go along with the inability to recognize photographic images of her younger self.

I speak of these events as it points to things we do not fully understand yet. We know that creative activity keeps our brains functioning better than if we do nothing. Clearly there is room for research into how our emotional involvement in an image may affect its retention.

Creative living: some practical ideas

Rainbow by John
for carers

The power of image making is that it allows those with dementia to express herself or himself in ways that are satisfying and can be rediscovered. Whilst such self-expression may have diagnostic significance, it is the ways in which creativity allows those with memory loss of various kinds to transcend the isolation they may be feeling, work through issues still troubling them, and enjoy the pleasure and satisfaction of the process of creating, which has been the focus of this paper. Certainly resolving psychological issues with art therapy requires professional training, but it is clear that some of the ideas documented here can be used by family members and professional carers to improve the quality of life of those with dementia.

Dementia is one of the challenges, with which some human beings – an increasing number – come to live. An individual living with dementia has need of creative expression by virtue of being human. Family members of those who live with dementia, have creative impulses, which, given form, help to maintain well-being. I acknowledge this latter point because I am aware that family care givers may sometimes come to resent the emphasis on the creativity of the person living with dementia, as it appears to overlook their own creativity, which may be thwarted by the demands of caring. Acts of the imagination, whether fully understood or not, slowly but constantly, allow the anxiety and grief associated with the diagnosis of a deteriorating condition to find perhaps fierce resistance, or, later, courageous acceptance. The capacity to accommodate ourselves to alterations in our abilities and to accept our mortality comes from deep within and is connected to our creativity. Creative acts also often give joy.

Individuals with dementia enjoy drawing with family members. I witnessed a wonderful interaction between a ninety three year old father living with Alzheimer’s disease, and his son. The son made an image of the boat in which they used to go out fishing. The father responded by drawing a fish. The son made an image of the fishing shack in which they stayed. The father made a picture of the chair he sat on. Backwards and forwards it went for twenty minutes. The images became both reminiscence and playful interaction. They spent a very happy time together.

Family members may also find it helpful to write down what their loved one with dementia says. Here one must be careful not to correct the memory, although this may be very tempting (much easier for an outsider, who has not been part of the story). Instead treat the words as fiction and see what the person’s mind has done with something that once happened. Be fascinated rather than annoyed.

Leaving art materials around may be useful but many individuals with dementia may not be able to start without the help of someone to make the first mark or write the first word. You may need to ask a carer to give that assistance, if you wish that a person in permanent residential care has creative moments when you are not there. It may be worth trying to leave a page with a few words already written (e.g. “A thing of beauty”, or “Once upon a time”, or “I remember walking along”). I did this for a lady who lived alone – she was living with vascular dementia – and she was able to write pages and pages from my prompts. You could try leaving a page with a piece of a pattern drawn or a circle.

What follows here are some ideas, which may assist in maintaining communication with a person living with dementia, when she or he can no longer actively create. To do this well, you need to engage with your own sense of wonder and joy at the world.

- Make up a small box of interesting objects that can be taken out and replaced. Ladies may enjoy bits of lace, fragments of silks or
shiny, colourful materials, shells, jewelry, tiny friendly animals and so on. Men may prefer to find walnuts, polished stones, fossils, and packets of seeds, drill keys (the one which unlocks four different sizes is a lovely shape), old pipes, toy cars. As a family member you may have access to familiar small objects, which have been part of that person’s life, which is even better.

If someone is mostly unable to speak, talk slowly (allow the words time to register) and tell the person about the beautiful world around you both – describe walking along the beach, watching a sunrise, children playing in the garden. (Individuals who do not hear conversation become less able to speak.)

Add slowly through art books or books of gardens.

Read poetry aloud – choose rhythmic versed, or, if not, familiar poems – Henry Lawson, for example. There is also some prose which reads well (e.g. Dylan Thomas’s Under Milk Wood).

Give the person things to hold and feel – small, beautiful things – shells, sparkly and soft materials, things with textures.

That an individual with dementia may have things to share with and impart to others, is not part of the everyday image of those with memory loss. My eight year old grandson, discussing the value of a drawing he had made, exclaimed “But it’s got my heart in!” He meant, of course, that the image that he had made was therefore of great value. This is equally true of the creative works produced by those living with dementia. Memory loss does not necessarily blunt the heart, it may in fact make it more sensitive and aware. Although research has indicated that dementia may reduce or release creativity, if one takes creativity in its broadest sense to be all acts of creative expression, then there are few individuals with memory loss, who do not have something to share, providing one can find a hook or connection or switch to start the creative process.

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John lives with Alzheimer’s Disease. He loves colours and patterns and paints with great concentration and enjoyment. John has also started writing poetry.
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www.memory.ucsf.edu provides information about Dr. Bruce Miller’s research.

www.abc.net.au/allinthemind/stories/200 provides the transcript of an interview with Dr. Bruce Miller and other neurologists. The transcript is called “Grandad is an artist. Dementia and the creative mind”.

www references


Gottlieb-Tanaka.com Further information about the current work of Professor Dahlia Gottlieb-Tanaka.

www.sussex.ac.uk/press.office Information about the original research carried out at the University of Sussex by Rusted, Sheppard and Waller.

Useful Websites for further information about art therapy

www.anzata.org The Australian and New Zealand Art Therapy Association

www.arttherapy.org American Art Therapy Association

www.baart.org British Association of Art Therapists

www.catainfo.ca Canadian Art therapy Association

There is a useful article available through the free encyclopaedia: en.wikipedia.org/wiki/Art_therapy

Alzheimer’s Australia Publications

Quality Dementia Care Series
1. Practice in Residential Care Facilities for all Staff

2. A Guide to Practice for Managers in Residential Care Facilities

3. Nurturing the Heart: creativity, art therapy and dementia

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National Dementia Manifesto. 2007-2010

These documents and others available on www.alzheimers.org.au
Looking at the Ocean by Mark Rimmer.
Mark Rimmer at work on his painting.
Above: *Man Looking at the Ocean* by Mark Rimmer. Above left: Mark Rimmer painting *Man Looking at the Ocean*.