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Introduction

Hilary Lee and Trevor Adams

Dr Richard Taylor, who has Alzheimer's disease, in addressing the conference of Alzheimer's Disease International in Singapore, 2009, called on the dementia care leaders in the audience to put psychosocial interventions onto the priority list so that people living with dementia might have their emotional needs understood and met, 'We are millions living with dementia right now and we need your help to lead meaningful and fulfilling lives, while we are waiting for a cure' (Power et al., 2009).

The topic of this book responds to this heartfelt plea so powerfully expressed by Richard Taylor. The topic also fits within the new paradigm of placing the person first that is currently evolving in the health and care of people with dementia. This underlying approach of person-centred care combined with new insights from the frontiers of creative arts and science to enhance the health of mind, body and spirit combined. Recent research shows us that as the brain remains plastic, new or compensatory learning can still occur in dementia, so when we use creativity we can not only support improvement in abilities but also create a life worth living for people with dementia (Power, 2010).

Person-centred dementia care

The development of person-centred care in the 1990s began a change from a medically orientated focus on the disease to a supportive and individualized approach focusing on the whole person. This approach provides a strong theoretical foundation

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for the use of creative arts in dementia care. Person-centred care was initially developed by Professor Tom Kitwood, Founder of the Bradford Dementia Group, University of Bradford, United Kingdom. Kitwood was a visionary advocate for people with dementia and those involved in their care, and his work has underpinned progressive thinking on dementia care for the past 20 years. He challenged the idea that the biomedical model of illness was the only way of viewing people with dementia (Kitwood, 1997). Kitwood believed that seeing people with dementia in medical terms led them to be seen as objects with neither identity nor personhood. He pointed out that people's experience of dementia arises not only from their degree of neurological impairment and their physical health but also from social and psychological factors including their personal biography and day-to-day interaction with other people.

Person-centred care addresses the impact of social environment and quality of our interaction with the person who has dementia rather than the disease process itself. Person-centred creative approaches highlight the need for individualized support for the person with dementia. In addition, as this book demonstrates, it is the quality of our interaction, and our way of thinking and being while we facilitate creative expression that forms the key to unlocking the potential of people with dementia.

Kitwood (1997) described the task of good dementia care as

- sustaining personhood of each individual in the face of advancing cognitive impairment;
- understanding that people with dementia rely on everyone in their surroundings to guarantee, replenish and uphold their personhood.

Personhood is different from personality and Kitwood described it as a person

- having valid experience;
- living in relationships and
- being an originating source of activity. (Kitwood, 1998)

He defined it further as ‘a standing or a status that is bestowed on one human being, by another in the context of relationship and social being’ (Kitwood, 1997, p. 8). Kitwood also took a moral position, seeing personhood as sacred and unique. He shifted the focus from viewing people with dementia purely in terms of the disease to seeing them as sentient beings with an ethical and valued status thus emphasizing our obligation ‘to treat each other with deep respect’ (ibid.). Within person-centred care it is acknowledged that the personal and social identity of a person with dementia arises in and is supported by their social environment (including the arts).

For Kitwood, personhood becomes apparent when communication takes place, and he outlined 17 different interactive processes that may occur in dementia care settings which undermine personhood. He called these the malignant social psychology. His choice of the word ‘malignant’ emphasizes the harmful impact of these behaviours on the person with dementia. One type of malignant social psychology is ‘outpacing’ which occurs when information is provided at a rate that is too fast for a person to process or understand. Another is ‘disruption’ or breaking a person’s frame of reference. This occurs when there is a sudden intrusion or disruption to a person’s action. For example, a person may be engaged in a creative process, such as painting, when a staff member suddenly interrupts to carry out a routine task, taking them out of the room and thereby stopping their creative flow and thoughts.

Kitwood (1997) observed ten different types of good communication that promote personhood, which he calls ‘positive person work’. One form of positive person work is ‘stimulation’ which occurs when the person with dementia encounters sensory experiences such as those that are offered by the creative arts. Another form of positive person work is ‘play’. Play is central to all creativity, in fact without play there is no creativity (Estes, 1992). According to Kitwood (1993), two more positive person work concepts, ‘holding’ and ‘facilitation’ enable a higher level of communication between carer and the person with dementia, enabling cooperation and a reciprocal engagement. He explained that with successful communication the person with dementia feels recognized as a person, self-esteem

is enhanced, social confidence increases and hope is sustained. Rather than making extra demands on the caregiver, this approach can transform care-causing exhaustion to providing stimulation and refreshment.

Five core psychological needs of people with dementia were identified by Kitwood (1997). He depicted these as five petals of a flower with love as the centre. The petals represent inclusion, attachment, comfort, identity and occupation. It is essential that all these psychological needs are sustained by everyone who is supporting a person with dementia. Creative arts' facilitators play a vital role in meeting these core psychological needs. When warmth and love is part of their attitude, they will profoundly support the emotional well-being of their clients with dementia. The chapters of this book provide many examples of how the core psychological needs can be met in different ways when the person with dementia takes part in creative arts programs and projects. For example, singing in a choir may provide a person with all of the core psychological needs. Inclusion (and therefore belonging) comes from being part of a close group that meets for a common purpose. Attachment develops as the choir members form friendships and become close as a result of their regular meetings and common interest. Comfort is facilitated in a safe psychological environment through the loving, empowering and caring approach of the choir leader. The identity of choir members develops through their relationships with both the other members and the community where they sing because of the recognition that they gain. In addition, identity is supported by the common purpose, with the knowledge that each person makes a valid and valuable contribution towards the success of the whole choir. Finally, group singing provides meaningful occupation where members can creatively express deep feelings.

The intention of this book is to give health care practitioners and students and anyone who cares for people with dementia a unique reference to a range of creative approaches that will open up new opportunities for dementia care. The focus is not on the diagnosis or types of dementia, instead the book explores practical, and innovative creative psychosocial approaches. Although the book does not claim to enable readers to practise these approaches, as each one represents an area

of speciality that may take years to learn, there may be elements or ideas that practitioners can be inspired to use in their everyday care of people with dementia. International experts and pioneers in their own fields, provide an overview of their work, highlighting its value, and evidence-based theoretical frameworks, with some practical suggestions as to how they can be accessed and implemented.

This book provides a unique collection of a wide and diverse variety of creative approaches and the arts which go outside the boundaries of conventional thinking about dementia care. These include the *Spark of Life* Concept, the LaughterBoss (therapeutic use of humour), art, dramatherapy, storytelling, dance movement psychotherapy, photography, creative reminiscence work, videography, complementary therapies, spirituality and creative communication in the late stage of dementia.

Creativity

Dr Dalia Gottlieb-Tanaka has explored the nature of creativity for people with dementia in her doctoral research. She defines creativity as follows:

Creativity in the context of dementia adds something new and different to the world whether through intrinsic self-exploration as an individual, or sharing creative expression through interaction with others. The creative process is demonstrated through creative thinking and imagination in everyday living and may or may not result in a product. Through creativity, people with dementia could (can) enjoy meaningful, satisfying and (at times) unpredictable experiences that may last for only a very short while or as long as memory allows it. (Gottlieb-Tanaka, 2006, p. 43)

Creativity and personhood

Creativity has a strong value within person-centred care because it enables the strengthening and expression of personhood while also providing opportunities for enriched relationships. According to Kasayka (2002, p. 9), the core functions of the expressive arts are ‘the reclamation, the regeneration and

the celebration of the human spirit', the same primary goals of person-centred care. This quote comes from *Healing Arts Therapies in Person-Centred Care* which pioneered new insights into how the arts (music, dance and art, in this book) could form part of Kitwood's positive person work. Celebration of the human spirit is a theme that is brought to life in many of the chapters of this book, as the authors demonstrate the power of creative approaches to bring out each person's unique spirituality and the expression of their spirit or essence.

A decade ago the culture of care and the medical world paid little attention to how people with dementia viewed their condition (Kotai-Ewers, 2007), but more recently through the development of person-centred care and an expansion of interest in the creative arts, health professionals now have begun to truly hear and appreciate the point of view of people with dementia. The creative process enables people with dementia to affirm their identity and validate their thoughts and feelings by expressing what is deeply meaningful to them. Through creativity they can share with others wisdom and stories they have gained throughout their lives. These expressions often take health professionals, family members and carers by surprise and provide deep insights into what the person with dementia is really experiencing. Creative communication with love and empathy can be extremely powerful and awaken dormant abilities that have been suppressed through traditional biomedical approaches towards dementia (Power et al., 2009).

Creativity connects people

Natalie Rogers (1993) points out how something magical happens when people work side by side, and how through companionship ideas and creativity are stimulated.

By offering new ways of expression to people with dementia, the creative arts give life and provide a powerful link between their inner and outer world. Rogers describes creativity as a bridge to the inner self, connecting us to our bodies, our senses and facilitating a journey in self-discovery and personal growth. She describes how by channelling emotions into expressive arts, people can gain a deeper appreciation of their

worth and release negative emotions. Creativity can also bring generations together, helping them gain deep insights about each other and forge new connections with people that make life both meaningful and joyful (Lee, 2005, 2006). Creating human connection through the creative arts also has a positive value in preventing or reducing depression in dementia care. This can be achieved through the positive relationships and friendships developed during the sharing of a project with others or through the opportunities to express personal thoughts, feelings and stories in a safe psychological environment (Lee, 2007; Lee & Blades, 2007). Creativity gives hope to those diagnosed with dementia because it not only offers opportunities to provide meaningful communication but also enables health care professionals to focus on a person's strengths rather than their limitations (Abraham, 2005).

Creativity enables improvement

According to Gottlieb-Tanaka (2006) person-centred care enables us to look at creativity as providing opportunities instead of focusing on the disabilities of people with dementia. She shows that creativity can enhance cognition, physical abilities, behaviour and enable new social responses to an enriched creative environment. Oliver Sachs in his book *Musicophilia* explains that music has healing benefits for cognition, and identity, even for those with advanced dementia because 'musical perception, musical sensitivity, musical emotion and musical memory can survive long after other forms of memory have disappeared' (Sachs, 2007, p. 337).

Swiss art therapist Beat Ted Hannermann (2006) argues that people with dementia are capable of improving their creative skills, sharpening their senses and strengthening their propensity to act themselves. Older people are often able to develop their ability of improvisation and imagination to a higher degree than younger people because of their more extensive experiences in life (Hannermann, 2006). Neurogenesis is still possible in old age according to psychiatrist and researcher Norman Doidge (2007). Doidge explains that even when the brain of an older person is going through a significant deterioration, it can still undergo a vast plastic

reorganization which could help compensate for the brain's losses. Creativity reinforces essential connections between brain cells, including those that activate memory (Cohen, 2000). Through creativity people with dementia can regain dormant abilities thought lost, such as communication skills, the ability to remember stories and other events, desire for social contact and interest in life (Lee, 2007). The therapeutic effects of laughter (for example, the work of the LaughterBoss as described in Chapter 3) have been shown to have lasting mental and physical benefits as demonstrated in psychoneuroimmunology studies (Spitzer, 2008).

Conditions that foster creativity

Natalie Rogers, the daughter of Carl Rogers (the humanist who formulated the foundations of person-centred care), described the external conditions that foster and nurture the internal conditions for creativity. The first two are from Carl Rogers and the third is from Natalie:

1. Psychological safety
 - a) Accepting the individual as of unconditional worth;
 - b) Providing a climate in which external evaluation is absent;
 - c) Understanding empathetically.
2. Psychological freedom
3. Offering stimulating and challenging experiences (Rogers, 1993, p. 14).

Having a safe, non-judgemental psychological space for creative expression is vital to free feelings and ideas. Accepting the individual as having unconditional worth is achieved when the facilitator conveys their belief 'that each individual is precious regardless of any present words or behaviour' (Rogers, 1993, p. 15). Providing an environment where external evaluation is absent contributes to providing a safe psychological space, freeing the person to be who they are and knowing there are no winners or losers, and each person's contribution is genuinely valued. Inspired by her father, Natalie Rogers highlights the importance of

providing psychological freedom for symbolic expression of feelings and ideas through the creative arts. Finally, Rogers shares her insight that creative experiences need to be carefully planned by the facilitator to offer stimulating and challenging experiences. This notion is supported by the work of Mihaly Csikszentmihalyi, the Hungarian psychologist who created the theory of flow. Flow is the process for achieving happiness through control over one's inner life and how life can still be enjoyed despite adversity. Csikszentmihalyi (1992) found that as humans we need a balance between healthy challenges that stretch us and enable us to grow and the skills we have to meet those challenges.

Overview of the chapters

The *Spark of Life* Concept outlined in Chapter 1 offers both a powerful approach and framework for creative expression that builds on person-centred foundations as well as occupational science and neurolinguistic programming. The Concept is both philosophical and practical, and it also facilitates the finding of meaning in life at a profoundly deep level with a focus on the well-being of the human spirit. The positive and meaningful experiences in the safe psychological environment promoted through the concept contribute to a feeling of belonging, closeness and friendship that has a healing effect for people with dementia. In addition, the concept can be applied using creative learning processes with the entire care team, working towards enriching the organizational culture and environment.

The approach of blending art and science with love and compassion to lift the spirits of people with dementia is further explored in Peter Spitzer's chapter (Chapter 2). He describes the LaughterBoss concept as a modern day court jester which facilitates therapeutic humour in aged care facilities. Spitzer gives us the evidence for humour being good for our health – for our mind, body and spirit – with some practical examples of good practice. The value of humour is scientifically supported with supporting research as well as true case studies and practical examples.

Dramatherapy and dementia care by Joanna Jaaniste (Chapter 3) provides some deep insights into the value of dramatherapy in dementia care, which is as yet an underutilized expressive art form. She gives practitioners some very practical ideas to achieve success using drama with people with dementia. Jaaniste has illuminated on how to use dramatherapy with puppets, play, storytelling and improvisation. This author also highlights the importance of psychological safety and trust, ensuring that participants have the opportunity for reflection at the end of the session to share any uncomfortable feelings or memories that may have been stirred.

Personhood can be embodied, and this concept is explored in great depth in Richard Coaten's dance movement therapy chapter (Chapter 4). He explores and develops the significance of embodied practices as being of value in developing relationships, improving mobility, affirming identity and supporting effective communication. Coaten also illustrates how movement and dance contribute embodied pathways that provide a powerful link between the person and their experience of the world.

Creativity provides a new language that is liberated from the need to find words. Kirstin Robertson-Gillam (Chapter 5) demonstrates how people with dementia can communicate through song even when they are unable to make sense in sentences. She shows through her own clinical experience that people with dementia can use their non-verbal communication in music to express their inner spirit, and how rewarding this experience is for the facilitator. Killick and Allan (Chapter 10) have discussed how using photography, video and visual material offer powerful ways of communicating to those who find that language has become difficult. These media are not dependent on cognitive pathways and thus offer a special means to stimulate feelings, memories and imagination.

Art therapist, Pat Baines (Chapter 6), provides us with new insights as to how we can support people with dementia to express deep thoughts and feelings and also resolve difficult times in their lives through visual art. Baines supports the premise that all humans are creative beings and that people living with dementia also will communicate intimately and openly in a trusting environment. This author also provides

practitioners with important research evidence supporting brain plasticity and brain reserve that can explain some of the unexpected and profound improvements seen in individuals with dementia who have opportunities to express themselves creatively.

Complementary therapies provide us with creative non-pharmacological alternatives in ways to physically and emotionally support people with dementia. Kirsten James covers a number of these approaches in her chapter (Chapter 7), with some practical ideas for safe implementation. She demonstrates how complementary therapies are person-led and represent creative ways of engaging individuals with dementia in a way that enables them to feel cared for and secure. James describes some of the science that supports the use of these therapies such as endorphin stimulation that can improve mood, promote relaxation, reduce pain and boost the immune system.

Telling each person's unique story is an art in itself, and Trisha Kotai-Ewers (Chapter 8) illustrates powerfully how a transformation in the person can occur through storytelling when facilitated both individually and in a group. She describes how this process can enable people to make sense of their present and past, because the stories represent the essence of our identity. Kotai-Ewers argues that giving people with dementia opportunities to tell their stories can not only help to prevent depression and anxiety, but also reduce the stigma of age and mental illness that are associated with older people with dementia. Storytelling provides opportunities to be listened to, to be understood and to express one's own truth; experiences that are too often lacking for those with dementia. This author's moving case studies show us that there is an important value in storytelling in exploring the meaning of changes that occur in the life of the person. Her practical strategies include approaches to understanding the creative language of people with dementia.

John Killick and Kate Allan (Chapter 10) explore new ground in their chapter on the use of photography and videography for whom language has become difficult. These media are not dependent on cognitive pathways and thus offer a special means to stimulate feelings, memories and imagination. These authors share their insights from projects and practical

experience in a field that is emerging to have an important value and potentially wider application by health care professionals with people with dementia. This chapter includes the voices of people with dementia, who share their perceptions about what visual arts mean to them, and how this insight can enable health professionals and carers to find creative new ways to communicate.

Taking the time to know each individual is confirmed as essential by Pam Schweitzer in her chapter (Chapter 9) on innovative approaches to reminiscence. People with dementia will feel special, unique and valued as individuals if those who care for them know who they have been or who they are now, their stories, values, interests, likes and dislikes. This author stresses that listening to the person is vital to drawing them out, supporting their self-expression and enabling them to connect with others. She describes how appropriate multi-sensory stimuli can be closely matched to the individual's known background and life experience to trigger meaningful and personal memories.

Elizabeth MacKinlay (Chapter 11) shares her extensive research into how we affirm personhood and enable people with dementia to experience meaning in their lives. She highlights that to effectively facilitate well-being, we must include the spiritual dimension. Her recommendations include the importance of rituals (either religious or secular) to connect to meaning. She states that the search for meaning reaches to the core of human existence, which is the spiritual dimension. Trusted relationships can provide support to the person with dementia during this journey. MacKinlay recommends spiritual reminiscence with such relationships either individually or in small groups to explore meaning and spirituality.

John Killick and Kate Allan provide innovative ways to successful communication with those people who may have been given up on in the past, assuming they could no longer communicate. These authors discuss how important it is to be fully present for the person with dementia, especially at the end of their lives. They advise us to be in the moment, feeling less driven by our thoughts, more connected with our surroundings and to be at greater ease with time. They show us the value of being open to the person with dementia, to share not only

what they are experiencing but what they are giving to us during the time we share with them. These authors take the view that all attempts at communication have meaning and have shared practical suggestions to connect with body language and take inspiration from the coma work of Mindell that uses close observation and mirroring of actions and sounds.

Conclusion

It is the editors' vision that this book will add a wider dimension to the traditional education of health professionals in order to give rise to a new understanding of the importance of person-centred creative approaches in dementia care. This book aims to encourage a shift to being open to new uncharted ground and the importance of bringing in professional creative artists and specialized practitioners to enhance a dementia care program.

Creativity is like electricity – it spreads with positive energy and ignites people. When combined with loving interactions the possibilities for creating improvement in people with dementia become real and exciting. A spectrum of limitless choices and options is available to all of us to select at will, and we can all learn to turn our imagination into reality. The readers will discover within this book that the arts and creative approaches have a far broader application than the traditional view of purely providing occupation.

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