

BOOK REVIEW

Karrie Marshall, (2013). *Puppetry in Dementia Care: Connecting Through Creativity and Joy*. London: Jessica Kingsley Publishers. ISBN 978-1-84905-392-1

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Aims of the book

This excellent book is aimed at carers of people with dementia at home and in residential care with a wide focus identifying practice from different countries. Regular communication can be charged with all sorts of tensions that overwhelm a person living with dementia. The world of puppetry can be an enjoyable meeting space between people who, for whatever reason, have difficulty engaging in the ways we are used to. The author describes different scenarios in which puppetry can help facilitate connections when words fail and in times of distress and conflict. There is something about creativity that releases people from the confines of a label. It does not mean that people are cured of disease, or miraculously change personalities.

Organisation of the book

Each chapter begins with a story about puppetry with people who had experienced isolation. There are practical activities, hints and tips throughout the book. Chapter 1 briefly describes the different forms of puppetry we use with adults with dementia and refers to the puppet-making guides in the appendices. The puppet stories in Chapter 2 convey the importance of understanding individual needs and life preferences. In the story of Helen and the kitten, her preference was strong and clear. Other people may prefer a variety of activities. It is quite possible that someone might choose not to engage with puppetry at all. Each person's decision must be respected. There are still other ways to connect, other ways to care. Creativity has no boundaries.

Chapter 3 focusses on responding to changes in relationship. The puppet stories show opposite ends of the spectrum that relatives and carers find themselves in. One story involves a carer who wants everything to be back to the way it was, with everyone in their roles and all memory function restored. Another story is of a carer who found new and rewarding ways to be with her relative. This

shifting of roles in relationship is undoubtedly one of the areas carers find most difficult to achieve. But when they do, the way opens for connecting more deeply in other ways. These carer stories contain complex issues about our human desire to 'fix' things, to make things better. Our cultural and personal values may feel challenged when someone behaves differently. Many people living with the late stages of dementia experience these challenges in their relationships. Through creativity we can discover new aspects of each other and ourselves.

Knowing how to communicate beyond words and memory is the subject of Chapter 4. Chapter 5 is about connecting in times of conflict or confusion. People respond to their changing situations in different ways. A meaningful life is the subject of Chapter 6. Chapter 9 brings us to the world of bed theatre and Chapter 10 explores how to use puppetry to highlight feelings of self, regardless of memories. Chapter 11 looks at enjoyable and relaxing memory experiences, including old puppets. Chapters 12-15 provide explanations of enhancing people's lives through simple acts of creativity and stimulation. Besides the five appendices explaining how to make puppets there are stimulating photographs of puppets.

The thesis is creativity

We all benefit in some way from creativity. As passive recipients we appreciate the music that soothes us, the comedian who makes us laugh, the drama that moves us, the aesthetic power of art that lifts our mood. Research provides a wealth of evidence about the positive impact of arts for reducing medication, reducing stress levels and increasing cognitive function. For example, people with dementia are reported to have better memory function and word recall following music, singing or other creative arts session.

Puppetry, as the volume describes, is the term used for bringing an object to life. To animate something is to

breathe life into it. This takes a little practice, but creates magic and an emotional response in ways that do not always work between humans. The term *applied puppetry* is used occasionally, as a reminder that the puppets are not being used to 'entertain' (although entertainment happens). Their primary purpose is as an application to a creative process for wellbeing.

Over the years of working in care and community settings, the author has noticed that applied puppetry and creativity positively affect people's emotional states. The advantages of creative activity repeatedly show increased self-esteem and improved quality of life. There are many other anecdotal benefits, such as pride in personal achievements, reduction in stress, increase in self-expression and communication, enhanced spirituality, openness, enjoyment and skill development. Puppets engage people in imaginary worlds open to anyone. Creativity and imagination have no boundaries, no exclusion zones. Puppets have a universal appeal. They connect with us on an emotional level. We are somehow wired to connect to the magical life breathed into inanimate objects, which is why puppetry is used in so many adverts on television. In care work, puppetry creates a space, a meeting place, where verbal language, memory and questions do not have to be invited. Puppets have a visual and physical presence that attracts curiosity. In that interesting, imaginative area, we can share, as the volume describes, a positive and meaningful connection.

Object puppetry requires a belief in the objects' ability to be alive. People use scarves, cutlery, lampshades, clothing, or anything that may resonate with the person. The object is moved in such a way as to express an emotion or become something else. Object puppetry allows imagination and innovation to flourish. Glove puppets (hand puppets) are so alive. People enjoy creating versions of themselves as they are today, but the author has also worked with people creating representations of themselves in a previous role or occupation. The basic glove puppet can be prepared for the person to dress and decorate. When activities are new to a person, having a task that can be attained within a few minutes helps to boost confidence. Sock puppets can be also used for participative and humorous singing sessions.

The person with dementia

Sometimes, the beginning of a journey into dementia is not clearly defined. Before a diagnosis is made, it is common for people to consider all sorts of possible reasons for changes in behaviour or memory loss. Indeed many changes can be due to factors such as stress, grief, physical pain, loss of role, infection, a series of disappointments, negative thought patterns and traumatic events. In such cases, when a person feels more settled and optimistic about life, his or her cognitive functions return. Explaining away odd remarks and quirky behaviour may continue for years. The good and the bad of family life now mixes with the mysterious realms of dementia. Although caregivers may have realised something was wrong, there is often a

long period before this is clarified. In the early stages, as happened for George and his daughter, one example given within the volume, the caregiver might believe the antagonistic and hurtful behaviour is personally against them, rather than the fight against losing independence.

Changes in relationship

When the person being cared for no longer recognises the carer, something dies. It can be hard to believe that memory has disappeared, disconnected or been covered over. Sorrowful thoughts are common, such as 'Do I no longer exist in the person's mind? Am I so insignificant that he or she cannot recall me? Did I not count for anything? Was it all a pretence?' We cannot underestimate the depth of loneliness that carers may experience in alienation. The next part of the journey for carers is to become more flowing, more resilient, open and confident. The support is always there, bridging the gap, but not everyone sees it. Some relatives become stuck in the whirlpools of unfinished business of the relationship. In care homes, staff do not always know how to communicate with someone who has lost words and memory. Focusing on the pain of what is not there is a difficult place to be.

Carers, as the volume expashes, may feel guilty for not having done more, been more, said more; for restricting someone's freedom, or being disloyal; for wishing the person they care for would just go away, or shut up, or stop breathing. Carers sometimes feel guilty if their relative moves into a care home. Guilt is one of those emotions that feels unpleasant for everyone. It offers little towards resolution and cannot produce positive interactions. The carer needs to find ways to soothe and comfort themselves. At times this might be as simple as sitting and staring into space, through to talking with friends or other carers, listening to music, walking, or learning something new.

One man left bath water running and accused people of hiding his glasses. He argued in the post office when they refused to give him cash in exchange for the bus pass he presented, instead of his pension book. This early part of the expedition can be hazardous. People who are experiencing memory losses do all they can to retain autonomy. They know very well there is something wrong. They barely speak about it because they are in a fierce battle to remain independent.

There is a tension between the desire to remain an independent agent, in charge of your own life, while other things undermine a sense of competence, so the person simultaneously acknowledges they have a problem, while fiercely resisting anything that might seem disempowering. Some people felt that their carers were bullying them into seeing a doctor, or they perceived offers of help as threats against their independence: 'some acts of care, no matter how well-meaning were interpreted by the recipients of care as a diminishment of their personhood'. The caregiver and care-receiver may cover up problems. This is not explicitly agreed, but somehow they maintain an illusion that all is well with other people. The caregiver, who sees

the personal struggle for autonomy tries to protect their relative.

The ground looks safe and solid, but those experiencing difficulties know they are close to treacherous marshlands. A wife will sometimes think her husband is just being a mean-spirited old man, or that somehow she had failed him. People describe the shock they feel when a person they love suddenly stops trusting them, or hurts them. Relationships can be very tricky to negotiate and talk about. The volume discusses all such observations and factors with clarity.

Person-centered care

We might have a strong sense of how it feels to be unwell, or confined to bed. But we may not fully know what a person experiences when they are unable to make themselves understood. Our viewpoints may be limited. If we are aware of this, we can stay open to the fact that we may not be seeing all there is to see. Some carers discover these purported values are not easily delivered within the care systems. When staffing levels are short or regimented the staff do their best to keep delivering from the core values. But something happens to people, when the values that mean so much to them, are constantly hindered by the working environment or culture. As people require more care and support, there is a tendency for staff and carers to do things from their perspective. They take control of all aspects of a person's life choices, treatment and direction. In their efforts to be caring, people sometimes fall into the trap of making assumptions. Carers fit people into their own ideas about what constitutes good care. Being person-centered means finding out what matters to the individual. The author of the volume explores ways of discovering and honouring individual preferences through people whose voices have traditionally been unheard.

Person-centered care is a way of thinking about and responding to the person. The provision of care needs to be right, from the perspective of the person for whom the service is for. The person for whom the service is for who is the expert on what suits and does not suit him or her. Opportunities to gain person-centered care skills are essential. People can learn to fully appreciate the perspective of individuals whose language of life is changing. People are most effective when they tune in and focus on the person as they truly are, rather than on our assumptions about them. Being person-centered in the care home or in the family home means understanding and responding to personal values, personal needs and experiences. In theory, person-centered care is easier to deliver in the domestic home. The care can be more flexible and the pattern and pace of the day more individual. Carers at home say their relatives become more talkative after the puppet session. One man said he felt his brain was 'oiled' with the laughter and enjoyment. Having something interesting to consider or participate in helps raise pleasure levels, which increases self-esteem. When motivation strikes us, it seems as though our capabilities

expand. We gain confidence and feel more energised, which stimulates more parts of the brain.

The volume describes another person talking to the puppets. Some words are indiscernible, but it sounds light-hearted and caring. The daughter joins in by speaking to one of the puppets. The resident stops momentarily and beams at her daughter, as though they are best buddies sharing something wonderful. And the feeling of connection is real, albeit fleeting. We all sense it. Mother and daughter relax together. The mother's memory is still intact, but her family notice her behaviour towards others has changed. Sometimes she may even seem uncaring in her dismissal of people, but she enjoys sharing imaginative recreation. This reminds us that individuals have their own rules and their own ways of coping with life and dementia.

Care staff may experience battles as people living in the care homes resist loss of control over their lives. This is why person-centered care is an absolute necessity. Usually, care staff are able to support each other to deliver this. However, the family carer is dealing with changes with little support. Carers do their best and that best will fluctuate from day to day.

The author of the volume provides some very poignant glimpses of people whose carers had forgotten how to value the individuals. This can happen when the carer feels overwhelmed with the responsibility. Sometimes people need help to reflect on what is happening. Environments that offer regular supervision, or support, can help achieve person-centered ideas through mentoring and learning programmes. It is important to take notice of emotional, physical and mental exhaustion, burnout or carer fatigue which is caused by long periods of stress. This affects people in different ways, but creates a barrier to the provision of person-centered care. Some people may be present in body, but emotionally shut down and seem to lose the ability to connect on a humane level. Some people become hypersensitive to the suffering they see around them. They feel helpless and are in constant emotional pain. Either way requires intervention, support and change. Many people enter care work with good intentions. Family members care out of love and duty. The core care values resonate deeply with each of us. We all understand the human needs for dignity, respect, rights and choices, effective communication, self-worth, inclusion, privacy and protection from harm.

Eric, another example provided in the volume, sleeps in an armchair in the living room after lunch. When woken he is often upset and disorientated. Sometimes he seems rude or angry. The carers suggest it is better for his health and wellbeing if he is left to relax peacefully for the afternoon. They are very clear that Eric will not participate in the puppetry programme. There is a logic and kindness to these statements. Staff have experiences of caring for many people and they often know what helps and doesn't help a person feel well. The danger in many care settings, is that the assumption about a person becomes a fact told in a different way. In this case the sentence is 'Eric is to miss every afternoon opportunity for enjoyment, connection, participation and communication.' The carers draw these conclusions from their experiences of being shouted at and seeing the distress and upset on Eric's face when he is

woken. They are caring for Eric and they are doing their best for him, but they are also limiting his options.

Institutionalised thinking happens when we are not self-aware. It happens when we do not have time to reflect on the way we are working or thinking. Institutional ageism or dementia-ism is something to be alert to. This occurs in the way institutional racism was found to exist, when the discrimination against an individual is inherent in systems, policies and procedures. It is not necessarily the action of one individual against another, but a persistent way of thinking about individuals seen as belonging to a particular group or label.

The volume provides a further example. The staff are aware that Mrs P.'s appearance is important to her. However, what she wears is in contrast to other people in the home. The staff have plain uniforms and comfortable shoes. Some carers have their hair tied back, but many do not appear to have had time to do much with their appearance. Our own clothes are just as casual. People living in the care home are in various states of dress: baggy trousers on the gentleman who is losing weight, fallen stockings bunching around the ankles of a lady, saliva stains on the shirt of another gentleman. There is discord between Mrs P.'s values and what is present in the home. From the world of dignified, beautiful clothes, there is nothing to relate to, not even a picture on the wall to reflect her preferences. When a person has nothing to relate to, he or she becomes increasingly self-contained and sometimes fearful. In such a situation it is likely that all further invitations to participate are declined, because without a sense of connection, nothing can develop. It was not the puppet that Mrs P. responded to, for she was not initially interested in any of the other puppets. It was the acknowledgement of what is important to her. Beautiful clothes, dignity, the silk scarf. On its own the silk scarf did not generate the relationship, but there was a connection. The puppetry allowed this connection to build without words, in a way that Mrs P. could express herself and communicate the friendship. The words were the last part in this process.

We see from the volume that the first connection opens possibilities for more. We are more effective when we tune in and focus on the person as they truly are, rather than on our assumptions about them. Being person-centered in the care home or in the family home means understanding and responding to personal values, personal needs and experiences. In theory, person-centered care is easier to deliver in the domestic home. The care can be more flexible and the pattern and pace of the day more individual.

Communication - working with silence

Compassionate silence is where the silence is shared comfortably and a sense of compassion is present. This kind of silence, as the volume makes clear, can nurture a mutual sense of understanding and caring. Each person will have a range of coping mechanisms. The use of

silence is one way to gain inner calmness, while creating a space for the person with dementia to connect. People struggling to express their words or memory need reassurance. Even if the carer is unable to understand the person, they can help reduce stress. Carers can show respect and appreciation for the words. When communication is difficult, it is good to remember that words are not everything. We can communicate in so many other ways. Experiments can build confidence to work with silence, emotions, movement and puppetry.

Although one gentleman could speak, words were not the way into this relationship, silence was. Words may not be very effective with people who are confused, hard of hearing, or distressed. The words of a carer are often said from a cognitive position, while the person is functioning on a more emotional frequency. Tuning in to where the person is requires the carer to find some internal stillness. In contrast to the required busy atmosphere of nursing in earlier periods where the emphasis was on physical care, many care settings today value holistic care. Staff are aware of the importance of emotional wellbeing and social inclusion. The majority of staff remember these values and are compassionate and congruent. The author of the volume describes sitting at the bedside of a lovely lady in her late nineties, as she lay dying. She had been her nurse for a few months and had shared many hours of reading and chatting. The family needed a break from their constant vigil. As the author listened to the tiny breaths, she held the woman's hand and gazed out of the window. Earlier she had washed one of her long nightdresses and hung it from the hem on the washing line and she could see it gently flapping around. Suddenly, the nightdress was swept up with the wind. It caught in the birch tree, as though standing on the washing line. This lively tightrope walker mesmerised her. She told the lady what her nightdress was doing and the lady opened her eyes and smiled. Then she fell into a deep sleep and her family were gathered together to hold hands with her as she passed away. It was a very peaceful gentle death.

Conclusion - benefits of puppetry

Carers at home say their relatives become more talkative after the puppet session. One man said he felt his brain was 'oiled' with the laughter and enjoyment. Clearly, stimulation is important, as is emphasized throughout this book. Having something interesting to consider or participate in helps raise pleasure levels, which increases self-esteem. When motivation strikes us, it seems as though our capabilities expand. We gain confidence and feel more energised, which stimulates more parts of the brain. Sometimes, people need time to become aware of the offer to engage with us and even longer to begin to participate. At other times, the response is immediate. Either way, the connection builds. Creativity begets itself.

The majority of the author's work is focussed on connecting with people who desire to be connected. She facilitates communication to express experiences, feelings and desires through the medium of puppetry. Helping

people create their own puppet is deeply rewarding. The puppet can become an extension of the individual. It communicates or interacts with other puppets or people, often with great humour and insight. This is vividly demonstrated by the short case studies provided here. For example, two older ladies began communicating with each other through their puppets. They shared the same care home, but had not conversed before. Many people living in the home seemed self-contained. Not being disturbed by anyone has its merits for those of us who enjoy solitude. But through the puppets they discovered that people wanted to be in connection with other people.

Everyone in any way involved in caring for a person with dementia should use this book to stimulate the quiescent creativity in the person with dementia.

Conflicts of Interest

The author declares no conflicts of interest.