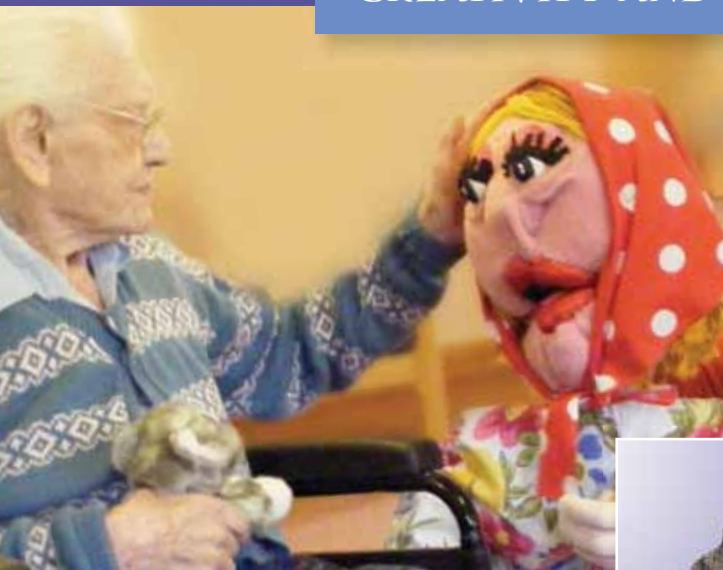


Puppetry in DEMENTIA CARE

CONNECTING THROUGH
CREATIVITY AND JOY



KARRIE MARSHALL

‘The puppet is a tool – a weapon to transform the subconscious, to stir the emotions and to re-connect our memory. I understand this concept, and as Karrie discusses, it really works. I have worked all my life in using the puppet to break down barriers and get messages across to the public throughout the world. Be it with AIDS education, democracy and corruption education or creativity and communication in schools, universities or the corporate world, the results are always the same. The puppet or inanimate object has an innate power to communicate on a “soul level”. A simple movement by an inanimate object fascinates us and can move us to tears without necessarily saying a word. Karrie puts it very aptly: we connect in the moment of “now”.’

– Gary Friedman, *Gary Friedman Productions, CEO Corporate Creatures, and editor of www.puppetrynews.com*

‘Triumph over adversity is something that is often praised, but this book shows us how to get so much more. Creating joy where there was despair is something so powerful as to seem miraculous. Karrie Marshall shows us the great value of using puppetry in care settings to achieve just that and then gives us the tools to do it for ourselves. Powerful, inspiring and empowering.’

– Keith Walker, *Policy Officer – Health Improvement, Highland Council, Choose Life Highland Coordinator*

‘Calmly and lucidly, Karrie Marshall tells extraordinary stories of the positive impact which just one art form – puppetry – can have in one crucial and highly emotive field of healthcare: dementia. In doing so she also reminds us that we’ve not yet grasped the full power of the arts to change lives.’

– Robert Livingstone, *Director of HI~Arts, promoting the arts in the Highlands and Islands of Scotland*

‘This book provides an excellent justification for the use of art, and more specifically puppetry, as a way of connecting with people with dementia who might otherwise have difficulties maintaining social interaction. Karrie Marshall has obviously researched her subject thoroughly and this book will be of use to anyone who has contact with people with dementia whether they be activity coordinators in

care homes, formal carers or relatives. It seeks to introduce novel ways of enhancing the quality of life for people with dementia, at whatever stage they are in the condition.'

– Dr Samantha Murphy, lecturer and Chair of the Open University module on Death and Dying, and module author on forthcoming Open University module on Dementia Care

'With her innovative, creative approach, founded on years of experience, mixed with compassion, humour and boundless enthusiasm, Karrie builds beautiful bridges of hope, empowerment and inspiration for clients, relatives and staff alike.'

– Jo Munroe, Project Worker (social care)

Puppetry in Dementia Care

Connecting through Creativity and Joy

Karrie Marshall



Jessica Kingsley *Publishers*
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*And the children in the apple-tree
Not known, because not looked for
But heard, half-heard, in the stillness
Between two waves of the sea.*
(‘Little Gidding V’, by T.S. Eliot 1942)

*We’re made of stars in the night
Shine on invincible.*
(Song lyrics ‘My Memory is Like a Dolphin’,
K. Marshall 2012)

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Introduction

The Man with a Kitten in His Pocket

David found it difficult to spend much time with his mum. She did not recognise him, and David did not understand her broken sentences. They sat in awkwardness. Helen's anxious glances at her son, who was now a stranger, bore more heavily on him with each visit. He checked his watch, waiting for a reasonable amount of time to pass before leaving.

In the past he had brought news and photographs of his family. Together they would delight in the children's achievements at school, or recall recent happy birthdays, holidays, and Christmas celebrations. They would crack open a bottle of lemonade and eat favourite biscuits. Visiting had a sense of purpose. David knew what to do and Helen enjoyed herself too.

The loss of memory gradually reached the faces in the photographs, and then David himself. They still shared the biscuits, but even this seemed a little clumsy...out of context. The care home provided reminiscence therapy while checks were made for other possible underlying causes of memory loss and confusion.

David noticed his mum was doing her best to keep up the appearance of remembering, but this was a strain for her. Anxiety-reducing medication was prescribed for the severe bouts of nervousness that sometimes accompanied the confusion. David did not know how to be with her any more.

He did not want to give up seeing her, and yet he was struggling to see what benefit there could be for his mum. Helen always seemed a little shocked when he sat in the chair next to her, so he had found himself sitting a little further away, hoping she might feel more relaxed. Helen politely nodded, and her son nodded back. There was little communication.

It was a kitten puppet that changed things. The puppeteers worked with Helen. She seemed to like all the puppets, and fleetingly joined in with their songs or banter. But it was the kitten in a handbag that really made the difference. As soon as Helen noticed the kitten glove puppet, she welcomed it with all the love and delight in the world. Her voice was clear and her words were about beauty and joy.

The kitten became her constant companion. She sang to it, held it, kissed it, stroked it, and protected it. During one session, the puppeteers brought another kitten puppet to meet hers. Helen was thrilled. The kittens played together. Over subsequent weeks Helen had conversations about things kittens do. (The list is endless!) She described the kitten climbing up the curtains, or coming home with muddy paws.

David learned that he could also connect with his mum through the puppet. He kept one in his pocket for visiting. Together, and for the next two years, Helen and her son shared kitten stories. The visits regained a sense of purpose. They connected in the world of puppetry, where there is no pressure to remember anyone.

This is a book about possibilities. It is dedicated to all the people who experienced isolation because we did not know any better – and now we do. Knowing better comes from believing that things can be different. A person in the late stages of dementia may seem lost to the world, but what if there is another perspective? What if we can connect beyond words and memory? What if we can even find genuine joyfulness? Have a great laugh? Share significant moments?

Then we would not be filled with fear and despair. We would have a sense of hope for all the carers and cared for. This book aims to inspire creative and meaningful ways of connecting with people, whose memory, words and relationships are affected by conditions, such as dementia. My work is with adults who have recently been diagnosed with dementia as well as people experiencing mid and late stage dementia symptoms.

Over the years I have found common issues experienced by staff in care homes and carers at home, which affect the quality of life of the people they care for. Some issues are to do with perspective or cultural views about dementia. In the media and at conferences we have heard alarming phrases about dementia: ‘terrible epidemic’; ‘devastating’; ‘world time bomb’; ‘veritable health plague’; ‘most feared disease’; ‘dreadful suffering’; ‘cruel and tragic disease’.¹

And people with dementia say, 'Love us for who we are.' It is difficult for everyone concerned when the mass response to dementia is fear. It is a sensitive and profoundly moving subject. None of us likes to consider losing our identity or finding ourselves in a world that is unfamiliar, with people we do not recognise. There is a rise in the number of people diagnosed with dementia, which is in correlation to the increasing population age, but we must be clear that dementia is not an inevitable part of ageing, and not everyone experiences the same symptoms. What we need therefore is hope and information, ideas and practical help, and even the slightest possibility of joyfulness.

More people are realising that there are ways in which they can create positive connections. Sometimes lack of confidence or uncertainty about what to do is all that stands in the way of powerful contact. I have met carers (at home and in care homes) who describe the distancing that occurs as communication becomes more awkward. Exclusion and isolation increase. It does not have to be this way.

We all do the best we can with what we know; and what we know is often affected by how we feel. The better we feel, the more open we are to other perspectives. This book offers stories of love and joy. It is full of examples of human strength and capacity. People may have been written off in the past, but here we see their wonderful gifts, or their humour and sensitivities.

The book explains the importance of creative connections. I use puppetry to express ideas and communicate experiences with adults in education; adults in care work; adults using mental health services and people using care services in general. I also work with adults with fronto-temporal lobe dementia (FTD), Alzheimer's disease, vascular dementia and dementia with Lewy bodies (DLB), and with people who experience memory loss and confusion, but who have not been diagnosed with dementia.

As we explore the fascinating medium of puppetry, you will see how the form yields fascinating results. Other art forms are included, as puppetry encompasses many genres. Underlying care principles increase the quality of the work and experiences for people living with dementia. Respect for individuality, compassion, listening, empathy, creativity, support and a sense of possibility are key elements.

Each chapter begins with a story about puppetry with people who had experienced isolation. The stories are occasionally an amalgamation of two people's experiences, or the genders and names have been

changed. This is to protect the identity of individuals with whom we work, unless otherwise desired by the person and their family or staff.

There are practical activities, hints and tips throughout the book. Some exercises can be undertaken quickly. Other activities are designed as programmes, which are done in stages. This is the way we usually work – building activities over a few sessions, alongside single-stage events. The creative process is extremely valuable, so we explore ways to mark genuine success, even if the main task is incomplete.

Creativity is all-inclusive. There is no right or wrong about it. Sometimes people are concerned that they cannot draw, so they feel they are not creative. Yet they may have planned a garden or concocted a meal. At some point many of us have created mountains out of molehills, made a card, painted a wall, told a spur of the moment joke, invented a name, made up lyrics, created a scrapbook or arranged objects in a particular formation on a shelf.

Creativity can be found in ordinary domestic life as well as in the extraordinary world of arts, crafts and performance. This book gives guidance on the making and using of puppets. But first I want to look briefly at the role of creativity in health care.

A case for creativity in care

It is exciting to see all the research showing links between creativity and mental well-being. Hannemann (2006) explains that creative activity has been shown to reduce depression and isolation. There is a clear change in people during the puppetry sessions. Sometimes individuals begin low in mood or very tired. But they become more alert and their eyes shine. A host of factors contribute to this, as we explore later.

Activity coordinators, occupational therapists and other professionals see the positive impact of their work, particularly with people who can actively participate. Engagement in activities can improve quality of life in social, emotional, intellectual and physical areas. It is something all carers can do, in a variety of ways, from the simple to the complex, depending on energy and time available. People experiencing late stages of brain disease can still connect if we create the right environments for them.

Cohen (2006a) ran creativity and ageing studies. His findings show that we are capable of creative expression throughout our entire life cycles. Our creativity and imagination do not seem to reduce at

the same rate as memory or language. This explains why connecting through creativity rather than through words alone is so important. Some relatives tell us they notice an increase in creativity as dementia progresses, but it may be that as other skills or functions ‘fall away’, the imagination and creativity are more noticeable.

There is not an agreed definitive location in the brain for creativity. Perhaps, like consciousness and intuition, it is not tied to a place. Speech, motor skills, vision and hearing all have their locations in the brain, but even these may have the potential to move. Following a stroke, patients may improve as a result of the brain’s plasticity, which is the ability of undamaged brain tissue to take over functions previously handled by a part that was damaged (Burkman 1998).

Miller conducted research into how the brain is affected by degenerative diseases such as Alzheimer’s. He notes that even though our brains age, it does not diminish our ability to create: ‘As people [with dementia] lose the ability to name, to conceptualise what things are, they are forced into much more visual ways of thinking about the world’ (Miller 2004).

As words become confused or the memory shifts take place, we all have an opportunity to engage with people through creative practice. Creativity is an essential part of being human. It is how we get our ideas and innovations; how we solve problems and imagine our futures. And it is how we make things and express ourselves. Patricia Baines (2007), an Australian art therapist, writes about the sense of awe when watching a person with dementia paint or write, because regardless of memory loss, the person is expressing and revealing a unique identity: ‘The very process of being a creator empowers, by allowing for a flow of energy and life. It makes well’ (Baines 2007, p.5).

Coming from a family of carers and artists (and philosophers), it has always seemed natural for me to marry creativity and care work. Care may include the arts as part of a holistic treatment (arts in health), or art may be used as a therapy in itself (art therapy). While my interest spans both areas, I find myself drawn to arts as a part of holistic caring – arts as something in which we can all participate in numerous ways. Understanding of the value of creative practice has been known for generations.

Medical superintendents inspected asylums in the 1800s and recorded their observations and suggestions for improvements. Bible readings, storytelling, drawing, sewing, dancing and annual concerts

were encouraged. A promoter of activities for mental and physical well-being was the medical officer of Crichton Royal Institution, Scotland, W.A.F. Browne. In the 1830s, he advocated gardens, farms, occupation and a range of activities including art, drama, music, readings and games (Browne 1976).

The term 'art therapy' came in 1942, when Adrian Hill practised art while recovering from tuberculosis (cited by Hogan 2001). He was later employed as a therapist and developed art therapy through the British Red Cross society and the National Association for the Prevention of Tuberculosis. The National Health Service (NHS) took on artists informally. Now there are dedicated art psychotherapy university courses. State registration is required before practising as an art therapist. The job includes enabling individuals to work through their emotions about their illness or conditions.

Arts in health can have a social function. It was an important part of life in the long stay hospitals. Staff and relatives of people living there made costumes and attended the annual concerts and pantomimes. These participative arts were often considered the highlight of the year. As many people as possible would be included. It was an opportunity to shine; to be important and break out of the everyday routines. The therapeutic gains of being a part of this creative experience are still remembered by staff and former patients.

The benefits of creativity in care have regularly been identified through qualitative evaluations. This often takes the form of people expressing how arts and art activities have affected them. My own observations and experiences in care homes are often recorded on film. 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.

Arts as part of the physical and aesthetic environment is important too. Hospitals now incorporate professional art, design and architecture in their refurbishments to enhance the patient experience. Research in the 1970s by Roger Ulrich showed that people recovered more quickly from surgery when they had views of landscape and trees (cited by Miles 1994). How simple it is for us to hang a picture of beauty in clear sight to help someone feel better.

People who are used to creative practice are probably familiar with the accompanying deep sense of peace. This might not be expected with people in the mid to late stages of dementia, whose focus and concentration spans are so variable. But we found the creative peace was there just the same as for any other group of people. Years have shown us that creativity has its own magic. People who engage seem to experience the creative silence. It comes when they are the makers, the explorers, the poets or painters, the puppeteers or the observers.

Creativity is more than the making or the doing of something. Young (1985) explains that the word 'creativity' derives from the Latin 'creare' (to make) and the Greek 'Krainein' (to fulfil). He refers to the paradoxical nature of creativity as an integration of doing and being, and that the creator becomes something more through the act of creating. We have often witnessed the growth in people, in confidence and in presence, through creative process.

My passion for creative connections comes from my understanding of creativity as an energy that flows in all our lives. The more I work in this field, the more I regard creativity as the essence of life. It is thrilling that more people are recognising the positive and powerful effects of creativity on mental well-being and self-esteem. We seem to experience creativity as a *feeling*, as much as we see, hear or touch it. The doing and the being are integrated.

This too is our experience of puppetry. There is the act of creating the puppet, which might be from paper, fabric, wood or recycled objects. Then there is the animation of the puppet. Breathing life into something that was previously inanimate. The process of animation requires a particular way of being, which we can all learn. Sometimes, as can be seen in the book, the puppet appears to take on an 'aliveness', regardless of the skills of the puppeteer.

What you will find in this book

Following this introduction, Chapter 1 offers remarkable insights about the world of puppetry. We see why people with dementia respond so well. The work is not art therapy, but it does offer therapeutic value. Puppetry has a long association with restoration and well-being, from the African healing rituals and ceremonies, to puppets used by therapists with children traumatised by war or abuse. The chapter briefly describes the different forms of puppetry we use with adults living with dementia

and refers to the puppet-making guides in the appendices. 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 well-being.

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 (although rare in our experience) 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.

The Department of Health and the World Health Organization promote the need to understand how individuals want to be cared for from their perspective. Being person-centred means finding out what matters to the individual. There is greater movement for people to be involved in decisions affecting their life and care plans. The chapter explores ways of discovering and honouring individual preferences through creativity. BICEPS is a set of principles using creativity and person-centred principles to connect with people whose voices have traditionally been unheard.

Chapter 3 is about responding to changes in relationship. The puppet stories show opposite ends of the spectrum that relatives and carers find themselves on. 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. That need is palpable and poignant through all the creative activities we shared. The other 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. The chapter uses the metaphor of a map to understand the journey the caregiver and care-receiver navigates to experience 'wonderment'.

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. Many of us are used to speaking, talking, chatting, gossiping, conversing, discussing. It can feel bewildering to be confronted with confused words, broken sentences or no words at all. In our uncertainty we tend to withdraw from the contact. And yet there are myriad ways to connect beyond spoken language.

Working with silence is a beautiful art that also benefits the caregiver. Students of my counselling courses thought they would find this the most difficult aspect to learn. Yet it often became a favourite request when they understood and felt the power of silent connection. This chapter's puppet stories show ways to work beyond the words. Not speaking allows us to be more aware of body language. You may already know the majority of our communication about personal or emotional matters happens through non-verbal language anyway. Having more confidence in connecting without words opens up a range of enjoyable encounters. We also work in silence with people who have visual impairment.

Chapter 5 is about connecting in times of conflict or confusion. People respond to their changing situations in different ways. Not knowing where you are or who anyone is can be extremely frightening, unless the person has a strong sense of being safe. Usual responses to fear are to withdraw or attack. One story gives an example of how puppets can step in and lift the person from their war zone.

Dealing with difficult situations is an area many carers ask for guidance on. It is important for each of us to feel safe in life. Conflict can be due to memory loss, or confused visual perceptions, which the carer must learn to negotiate.

My background includes working with people who communicated through anger and aggression. This behaviour is usually due to emotional turmoil or intense fear. But there are many triggers to be aware of. Sometimes the carer becomes the target of a rage against loss of independence, or other deep anguish. This chapter explains effective de-escalation techniques. Puppetry can help a person express their feelings, which is seen later on in the book. The underlying principle of this chapter is maintaining a focus on individual qualities and positive connections.

One way of preventing situations from escalating is to look at how a person's day is filled. Boredom is in itself a stressor. A meaningful life is the subject of Chapter 6. In discussions with staff or carers who

work with people in the later stages of dementia, I ask: 'What makes a life worth living?' I am often struck by the immediate silence. It is as though we are all suspended in time and space, as we consider the meaning – I always find the answers inspiring.

In the past our society dismissed older people, and people with dementia. There was a collective sense that their lives were somehow less worthy. People justified these prejudices in terms of saying 'He's had a good life, it's someone else's turn now' or 'She's had enough. It will be a blessing when she pops her clogs.' The idea of therapeutic input for people with dementia was more or less rejected. Things have changed for the better.

Although concerns about ageist attitudes still exist, there is growing awareness of the need to value all people in our society. The chapter highlights the importance of increasing feelings of self-worth. The stories show two men helping to build puppets and a small theatre. Being involved in the creation of something for themselves and other people is stimulating and empowering. Having a sense of purpose, relevant to the individual, increases quality of life.

I often use a combination of applied puppetry with life story work or narrative work. Since 2003 we have made many memory boxes with people at home or in care settings, and you will find other ideas for enjoyable stimulation. In Chapter 7 I show how narrative work and puppetry can be done as a social group activity, with teamwork and conversation. Sometimes people are able to express how it feels to have dementia through their puppet. People may experience distress or fear about not being able to remember something. They may also find it very funny or awe-inspiring to be forced into the moment of 'Now' every day.

Themed days can also be wonderful experiences in care settings, as well as enjoyed in domestic homes. Some people enjoy having a restful, quiet life. Other people enjoy surprises and welcome opportunities to celebrate. There are many themes to be explored, some of which may involve a wider circle of people; other themes can be explored on a more personal basis.

Singing is widely known to have both physical and mental benefits for a wide range of people. It is so uplifting and of course we have singing puppets, which often add humour. Chapter 8 is dedicated to this energising activity. Research also shows how the singing helps people feel calm and connected. You may know that songs and music

are often more easily retrieved than other memories. We have met many people who had stopped talking due to frustration over their loss of words, but who sing all the words to songs they knew. Organisations such as the Alzheimer's Society offer 'Singing for the Brain' sessions.

Chapter 9 brings us to the marvellous world of bed theatre. I have long been interested in how we ensure that our work is inclusive of people who, through illness, disease or disability, remain isolated in their beds. Sensitivity towards individual levels of engagement are always required. Bed-bound people often have long periods with little going on around them. It is important to build the activities a bit at a time, so as not to overwhelm anyone.

Sometimes, puppet work allows a connection to be made that would otherwise have been difficult to discover. One of the stories shows how the puppet work enabled staff to understand a situation differently and gain confidence in engaging with someone who was very frail. The activity can turn out to be the opposite of what we might expect. Puppets dare to do or say things that most of us wouldn't consider. They can bridge a gap – make the way for more human interaction and bring out individual personalities.

Having a sense of identity is important. There are many social and psychological theories about our individuality and identity. We might maintain self-identity through our values, our work, the groups we join, the things we do, or through the objects and people in our lives. When carers talk about dementia, this is an area that concerns them. Chapter 10 explores ways we use puppetry to highlight feelings of self, regardless of memories.

The stories are moving and yet uplifting as we see what is possible with people whose memories or words are being expressed differently. Validating individual experiences is an important part of the work.

For a long time reminiscence therapy was considered to be the answer to dealing with dementia. It certainly has an important role and is actively encouraged in many care settings. Many people enjoy discussing events of the past and recognising the richness of life. It is important these activities include non-verbal elements for people experiencing later stages of dementia. Chapter 11 looks at enjoyable and relaxing memory stimulation experiences, including old puppets. These activities suit people who struggle with the pressure of memory quizzes or are disadvantaged by the verbal exchanges often used in reminiscence work.

Many people have memories of pets. Animals can bring a special energy into the home. We've seen the great pleasure a big floppy-eared rabbit can bring to a hospice, or the love of cats who purr like outboard engines, and dogs who roll over for a belly rub. Pets can motivate people who are withdrawn, or calm people who are anxious. The mixture of stimulation and gentle appeal is probably why animal puppets are so well received. Chapter 12 shows examples of how glove puppet cats and dogs, and shop-bought soft-material animals can be used with dignity and respect for the person with dementia.

People's lives can be enhanced through small and simple acts of creativity and stimulation, just as much as through the bigger projects. Chapter 13 shows the value of even one tiny creative connection. It is important for staff and carers to get a sense of what they can easily achieve within a busy week, and to really know that this can make a positive difference. Staff and carers report feeling more motivated and inspired as a result. Caring can be draining, so it is important to find moments of joyfulness. This undoubtedly has a positive effect on the person being cared for.

Some carers may be in a position to support a few minutes of daily mental stimulation or learning therapy, as Kawashima (2012) calls it. His research with older people shows improved working memory and other thinking abilities. This is with people in all stages of dementia. There are more studies indicating the effectiveness of mental stimulation (or cognitive stimulation therapy – CST). We share a few ideas for incorporating creative mental stimulation and connection in daily life routines. These are things we can all be doing for ourselves starting now. It is in all our interests to be as physically fit and well as we can be.

The final two chapters look at puppetry as both passive and participative entertainment. Chapter 14 is about puppetry as entertainment for older people. There is a long tradition of puppet theatre, which can inspire exciting childhood memories. Some care homes are able to buy in professional entertainment. People enjoy watching the performers put everything together as much as they enjoy watching the show. However, this chapter is primarily for carers, activity coordinators or performers interested in entertaining in a domestic home or in a care home.

The chapter contains a sample script for puppet characters we have fun with. Often these performances work well without a set or scenery,

but I have included instructions on how to make a simple booth for those who would prefer a set.

There is much fun to be had from do-it-yourself shows, involving older people who use care services or people living with dementia. Chapter 15 pulls together the various techniques described throughout the book for people to create their own performance art. The puppets, the sets, the sounds and scripts contain many aspects that can be broken down into user-friendly steps. We describe the process and highlight the importance of ensuring tasks are accessible, achievable, meaningful and above all else – enjoyable.

Ideas are given for intergenerational work as well as the power of using puppetry to convey messages to a wider public. The chapter explores the strengthening of community links for dementia friendly communities, and the role of people with dementia, carers and families to use creativity in that process.

Note

1. Recorded phrases at the International Conference of Alzheimer's Disease held in London in March 2012.