

# DOLL THERAPYIN DEMENTIA CARE EVIDENCE AND PRACTICE

'An honest and eye-opening exploration of the use of dolls in improving the lives of people with dementia. I found the key to opening my eyes was the statement that we shouldn't look at the dolls, but look at the person. Enough beneficial examples are given for me to feel comfortable about the judicious use of dolls while empirical investigations tease out who they are good for and under what circumstances.'

Professor Richard Fleming PhD, Director, NSW/ACT
Dementia Training Study Centre, Adjunct Professor,
Wicking Dementia Research and Education Centre,
University of Tasmania

'For some people the mere mention of doll therapy will induce fears of infantilisation and invalidation, and it will be quickly dismissed as inappropriate. I admire the fact that this author lays out his own initial thoughts of this nature at the start of the book. However, he then goes on to piece together a compelling and well-constructed book that will challenge any practitioner to dismiss this as a valid form of non-pharmacological intervention. The book wrangles with the ethical dilemmas of doll therapy, it uses well-researched evidence and highlights many personal stories. He gives detailed practice examples from some very well-respected services and he ends by offering some very useful practice guidelines. For such an evidence-based book it is an emotionally challenging read and I would encourage anyone in search of the best forms of human intervention for people with dementia and their families to read this. Enjoy the challenge, then make your mind up; I suspect you might change your view by the end.'

- Henry Simmons, Chief Executive, Alzheimer Scotland

'This is a book that is very overdue in the dementia care field... Gary writes in an engaging and accessible style, providing a comprehensive range of theoretical and practical illustrations of why every hospital, care home or day service, where people living with a dementia may find themselves, needs to ensure that dolls are an integral part of their repertoire of approaches. This is a book which has at its core the recognition that the real heart of all our human experiences is the need for love, and when we are facing the many losses and challenges of the journey of dementia, we need to be sure love is there for us even more.'

- Sally Knocker, Consultant Trainer with Dementia Care Matters

'I was asked to review Doll Therapy in Dementia Care by Gary Mitchell. To be honest I was reluctant to believe this could be used to alleviate distress or agitation. After reading the book two times as a person who has Alzheimer's and PCA, I thought it was written by a person who clearly had empathy and clearly illustrated how individuals at a later stage of dementia could satisfy their inner feelings of need, being loved and wanted. The most important aspect of care that a family want for their loved ones is ensuring they are content and happy within their environment. It can be very difficult for relatives watching their mum or family member cuddling an inanimate doll. Yet, perceptions can change once they see their "loved one smile with pleasure at holding something close to love again". The image of an older person cuddling and singing to a doll can seem strange and incongruous. Yet I realise I had the same need, and when my grandson was born, I was doing the same thing but instead of being a doll it was a real baby. I couldn't get enough. I had such a yearning to hold, love and want to have this baby as much as I could. The moral and ethical dilemmas should not supersede the reality of the beneficial impact – every person has a vivid desire to express affection, physical nurturing and emotional attachment that is clearly stored in the repository of their brains, irrespective of what type of dementia or stage they are at.'

> – Liz Cunningham, person living with dementia and Ambassador and Dementia Friendly Communities Champion for the Alzheimer's Society

'Gary Mitchell has refreshingly delved into controversy, effectively dispelling stereotypical, preconceived judgements surrounding the practice of using dolls in dementia care. Whether regenerating past relationships or regaining the space held in the world, he has provided an impetus to developing an increased open-mindedness in the provision of encounters that encourage positive ageing, this respecting meaningful experiences based on deferential reciprocity. Demonstrating another valuable way forward in the provision of person-centred dementia care and preservation of personhood. Delightful and insightful.'

- Leah Bisiani, Dementia Consultant, MHlthSc, 'Uplifting Dementia', shimmeringspirit.wix.com/uplifting-dementia

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# DOLL THERAPY IN DEMENTIA CARE EVIDENCE AND PRACTICE

GARY MITCHELL FOREWORD BY SALLY KNOCKER



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### Foreword

I write this foreword on a train journey returning from a care home in Wales where I have spent the afternoon observing the magic of dolls. A woman who had been experiencing some distress as she was asking for her own mother repeatedly was offered a doll to hold. Immediately her face lit up and she started to chat to the baby; 'Aren't you a smasher?' she says. 'You're my best boy!' (She seems refreshingly unperturbed the doll was dressed in pink!) She then proceeds to cuddle and sing to him for the next forty minutes, with no signs of her previous unhappiness. She had found someone to cherish and at once all is well with her world.

There is a danger when we talk about 'therapy'; there is a sense there is something that needs to be fixed. People living with a dementia don't want or need us to 'fix' them; like all of us, they want us to be alongside where they are from moment to moment, to put our own prejudices or assumptions about what might be 'good' or 'not good' for another person aside and to learn and trust the language of emotions.

This is a book that is overdue in the dementia care field. At one level, it surprises me that we still have to justify and evidence an intervention which is so obviously beneficial. Professor Tom Kitwood, whose ground breaking work in dementia care in the 1990s is referred to in this book, described the psychological needs of people living with a dementia as like petals on a flower: the need for attachment, comfort, inclusion or belonging, recognition of identity and the need to be occupied. As the following chapters will describe in detail, a doll can be many things to a person with a dementia: a treasured baby to nurture and protect; a way of communicating a need to others or a projection of their own vulnerable self; a source of companionship, playfulness and comfort; and a way to alleviate loneliness or boredom. Those of us

who have walked in a park with a young baby or a dog will know that we are also much more likely to find that people will want to stop and chat with us because there is a focus on our connection, which helps break the ice.

It is no coincidence that at the centre of Tom Kitwood's flower of psychological needs, that around which all the other petals grow is 'love'. With all the current emphasis on smart hotel-style environments and professional standards in many care services, we can sometimes forget the simple truth that when we feel loved and are still able to give love, we are likely not just to survive but to flourish in a care environment.

Gary writes in an engaging and accessible style providing a comprehensive range of theoretical and practical illustrations of why every hospital, care home or day service, where people living with a dementia may find themselves, needs to ensure that dolls are an integral part of their repertoire of approaches. This is a book which has at its core the recognition that the real heart of all our human experiences is the need for love, and when we are facing the many losses and challenges of the journey of dementia, we need to be sure that love is there for us even more.

Sally Knocker Consultant Trainer with Dementia Care Matters

## Acknowledgements

As you will learn, my first experiences of doll therapy in dementia care were quite negative. As a fresh-faced nursing graduate from Queen's University Belfast, I took up my first post within a dementia care unit in early 2010. Over time my feelings on doll therapy began to become more positive, thanks in no small part to my mentor within the dementia care unit at Oakridge Care Home, Sister Elizabeth O'Neill. It was fair to say that Liz was an extremely empathetic practitioner, and without her clinical mentorship I would not have eventually championed doll therapy within dementia care. Throughout my professional career at Four Seasons Health Care, I have also been fortunate to be supported in my understanding of doll therapy and its application to practice, as well as many other aspects of dementia care, by the specialist knowledge of Joanne Agnelli, who was indeed responsible for my first clinical dementia education sessions at the company as well as my continued professional development.

Through my experiences in practice and academia, I have come to appreciate that many people share differing views on a great number of issues. As it pertains to doll therapy in dementia care, opinion is still divided, and this book is my attempt to chronicle the evidence that underpins doll therapy, how it can be applied to a number of advocated theories within the context of person-centred care, bioethics and palliative care, as well as recommending best practice guidelines for operationalising doll therapy in dementia care. In addition, I am honoured to be able to provide reflections on doll therapy from prominent members of the dementia care community.

I reserve special thanks to my co-authors who have taken considerable time to help me shape the contents of this book – thank you Professor Brendan McCormack, Professor Tanya McCance, Professor Jan Dewing, Professor Ian Andrew James, Ruth Lee and the Newcastle Challenging Behaviour Team, Caroline Baker and Marsha Tuffin. I was especially honoured to have contributions from my own close personal friends Dr Michelle Templeton, Dr Helen Kerr and Jessie McGreevy – again, a special thank you goes out to you. I believe this collective expertise has helped me to provide a balanced and comprehensive overview of doll therapy in dementia care.

I am grateful for the support of Jessica Kingsley Publishers, and in particular my commissioning editor Rachel Menzies. Rachel's enthusiasm and belief in the project greatly assisted in helping me to deliver what is my first attempt at writing a book! I also thank the people behind the scenes at Jessica Kingsley Publishers who have helped make this project a reality.

Finally, I must thank my beautiful (and wonderfully tolerant) wife Claire, our little boy Zachary, my mum Sylvia, dad Trevor and other members of my family and friends. Your combined belief, encouragement and motivation have helped me immensely in the completion of this book.

## Introduction

Gary Mitchell

In 2010 I took up my first post in a dementia care unit. My nurse training had already garnished me with a number of experiences in oncology, acute medical admissions, surgery and the emergency room. If I was being honest, my first post in dementia care was only intended to be a stepping-stone until I could take up a post in a hospital. Like many healthcare professionals, I had no specialist dementia care training except what I had learned at university and later within my clinical place of work.

When I began my first post I was fortunate enough to receive extensive person-centred care training, both on the job (through various training courses/mentorship sessions) and off the job (with the use of three books). The books were by Tom Kitwood, Christine Bryden and Dawn Brooker. They all celebrated the meaning of 'living well with dementia'. This shocked me at the time because it seemed quite impossible to me. The ethos of the messages from Kitwood, Bryden and Brooker was person-centred care – treating people living with dementia as unique. Absolutely nothing else would suffice. This was a message I could easily get behind.

Braced with an array of person-centred knowledge, coupled with newly qualified enthusiasm, I began my time in the dementia care unit. As I received a walk-through the unit on my first day, I met Clara and 'Tom'. Clara was an older lady living with dementia. She held tightly to Tom as she walked towards me. The nursing sister of the unit, who was taking me on the walk-through, introduced me to Clara and Tom. I was flabbergasted – Tom was a doll. What happened next made me feel as if I had followed Alice down the rabbit hole – the nursing sister, a dementia specialist

nurse with over 15 years' experience, took Tom as though he were a human baby, cradled him, kissed his forehead and diligently gave him back to Clara.

A number of thoughts flew through my head: Was this some sort of test? I could never believe that 'playing with dolls' would do much to expel the stigma of people treating those with dementia like children – the precise message of ALL of my dementia training. Had the nursing sister missed the whole point of personcentred care? Doll therapy was infantile, it was patronising. It was just embarrassing. I left the unit that evening with my head exploding...and I confess, when I returned home from the unit, I told my friends and family about the incident with the doll, and we all reached the same conclusion – that I should protect my nursing registration first and foremost, disassociate myself from the practice of 'doll therapy', and begin to look for another clinical position.

Surprisingly, six months passed by, and I still held the position of a dementia care nurse on the unit. The six months had been one hell of a steep learning curve. When I was left in charge of the dementia care unit, I initially removed Tom. But when the nursing sister worked on the opposite shift, Tom returned. This carried on back and forth, until a warm day in July 2010. I was accompanying Clara to the dining room to serve her dinner when suddenly she screamed. Tom was propped up against a window in a vacated resident's room. The door had been left ajar and this had allowed Clara to spot Tom. I remember that she was hysterically calling, 'Tom is going to fall.' Opting for reality orientation (assisting Clara to be aware of her current surroundings; see Chapter 1), I told Clara, as I did many, many times, that Tom was just a doll for children. Like the many, many times before, this served to distress Clara even more because this simply wasn't her reality. I resisted reuniting the pair for a time that day, which incidentally resulted in Clara refusing to eat her lunch, crying quite uncontrollably throughout the day, and generally being in a state of increased illbeing. I simply couldn't justify that I was providing good dementia care anymore. My principles of personcentredness were offset by the distress Clara was experiencing. I began, six months later, to sense that I was missing the point of person-centred dementia care.

Clara's reaction was so distressing that I was forced to reunite the pair later that day. When I did, everything changed in that moment; Clara's smile was instantly back, she enjoyed her evening meal, and engaged with many of the other residents in the unit. This enhanced wellbeing was so visible, so authentic and so real. As I left the shift that night Clara motioned as if to call me over... quite truthfully I thought I was going to be scolded for denying her interaction with Tom earlier in the day.

'How are you doing Clara?' I asked, and she responded in a soft voice, 'Shhhh...baby is sleeping.' I stared at Clara for a second or two. I was going to recite my usual message, 'That is not a real baby, that is a doll for children.' But on that day, for the first time since I began my post, I did not. While I was reflecting on doll therapy I stood in silence looking at Clara when she said to me, 'It is not me you should be looking at, it is him.'

As I was driving away from the unit that night I thought about Clara's words and concluded that she had it wrong – I had indeed been looking at Tom, the doll, all along. It was the doll that represented something that I could not warm to and that I resisted even trying to understand. Then, I was hit by a eureka moment. It was like a person-centred epiphany, if there is such a thing; all this time I had been looking at the doll when I should have been looking at the person...all that time I was looking at Tom, when I should have been looking at Clara.

Throughout my clinical practice I have always tried to do what is best for patients, residents, any person living with an illness, their family and care partners, and my experiences with doll therapy have been my hardest lesson in healthcare to date. For six months I denied Clara something that brought her great joy because I, a registered nurse, did not feel that it was morally right or appropriate. And I was not the only person who was against doll therapy; a number of my colleagues agreed, as well as numerous visitors to the unit. Clara's family were unable to visit the unit often, but they did not have much of a problem with doll therapy. They believed that if engaging with a doll brought Clara happiness, then it was okay with them...it is true that the person living with dementia and their family are almost always the experts.

Through my personal experiences using doll therapy in dementia care, I know that there is limited awareness and understanding about what doll therapy actually is and how it can be used effectively for people living with dementia. Today it is considered a 'controversial' therapy, and is often absent from the literature or practice guidelines when considering other effective therapies or non-pharmacological interventions that can be used within dementia care. It is often started or withheld based on the assumptions or education of the clinician in charge. In relation to non-healthcare settings, and based on my personal experience, there are not many non-clinicians who know that 'doll therapy' actually exists. Unfortunately there is limited reference to doll therapy in dementia care in the literature from charities, policies or practice guidelines worldwide.

To understand more about doll therapy in dementia care, you have to trawl the internet for published blogs, newspaper articles or journal accounts of how it can be effective. My personal and profound experiences in using doll therapy in dementia care have inspired me to write this, my first book with Jessica Kingsley Publishers. The aim of this book, the first of its kind, is to provide an overview of doll therapy in dementia care for all grades and specialities of healthcare workers, as well as for the families and care partners of those living with dementia.

In short, doll therapy is when a person living with dementia engages with a doll, and this engagement comes in a variety of forms. In Clara's case this was holding the doll, talking to the doll, cuddling or hugging the doll, feeding the doll and dressing the doll. The benefits Clara associated with doll therapy include increased levels of engagement with other people, reduction in episodes of distress, improved dietary intake and generally an increased level of wellbeing. And the therapeutic use of doll therapy has been growing globally, with accounts of its use in the UK, Australia, Japan and the USA.

Of course not everyone living with dementia will engage or even benefit from doll therapy, but there is no way to know if a person will derive benefit or not until it is facilitated. It appears, however, that people living in the advanced stages of dementia are the biggest users of doll therapy. The reason for this may be related to the need for attachment in a time of greater uncertainty. For those living with dementia, a doll can arguably act as an anchor in an ever-changing sea of uncertainty.

This book has been written so that each chapter can be read as a stand-alone piece. Naturally, however, reading the book in its entirety is recommended so that all the elements and themes of doll therapy in dementia care can fuse together.

The following is a synopsis of the chapters of this book:

- Chapter 1 provides a general introduction to dementia, the manifestations of the dementia diseases, and the move away from pharmacological interventions and how doll therapy itself is framed within the context of a non-pharmacological intervention that should be promoted and explored within dementia care.
- Chapter 2 provides a thematic overview of the research that is currently available in relation to doll therapy within dementia care. This evidence details how and where doll therapy can be practised, who can facilitate and participate in it, what the benefits and barriers of doll therapy usually are, and why it can work from a theoretical point of view.
- Chapter 3 presents Tom Kitwood's work, and considers how doll therapy, if practised correctly, can be a person-centred approach to dementia care. It also highlights how poor practice of doll therapy can actually perpetuate the stigma associated with the dementia diseases.
- Chapter 4 looks at the ongoing ethical debate that has always been associated with doll therapy. It considers the argument from those who are in favour of doll therapy and those who are not, before providing care partners and healthcare providers with practical assistance in negotiating the potential dilemmas.
- Chapter 5 provides a background on the importance of palliative care in dementia and explores, probably for the first time, how doll therapy can be considered a therapeutic tool within this ethos.

- Chapter 6 illustrates the important role of the Newcastle Doll Therapy Programme, which has greatly informed and shaped practice as it pertains to using doll therapy in dementia care. Indeed, the Newcastle team are considered the global experts in relation to the research they have published on doll therapy in dementia care.
- Chapter 7 is a thoughtful account of a family member's experience of their loved one using doll therapy within a dementia care facility. It highlights how personal feelings of doll therapy can evolve over time.
- Chapters 8 and 9 provide reflections from senior dementia care leaders within the care sector.
- Chapter 10 concludes this book, offering recommendations for healthcare providers, family members and care partners for implementing doll therapy within their practice.

I truly hope that you find this book both useful and enjoyable. Naturally, I dedicate it to all those who live with dementia, their family, friends and care partners. It is my sincere hope that it will help some of those people living with dementia to live better through engagement with doll therapy.



Joanne Agnelli, dementia specialist for Four Seasons Health Care, engages in doll therapy with a resident and a care assistant from Castle Lodge Care Home in Northern Ireland