

Foreword by

DR G. ALLEN POWER



Visiting the

Memory Café

and other

Dementia Care Activities

*Evidence-based Interventions
for Care Homes*

EDITED BY CAROLINE BAKER *and*
JASON CORRIGAN-CHARLESWORTH

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and other Dementia Care Activities*

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This book is dedicated to all of our residents living with dementia, their relatives and the amazing staff who look after them so well.

Any proceeds from the sale of the book will be donated to Barchester's Charitable Foundation, which is a registered charity that helps older people and other adults with a disability living within the community across England, Scotland and Wales.

www.bhcfoundation.org.uk



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Foreword

Nearly 300,000 people are living with dementia in residential care homes across the UK, and millions more worldwide. While such communities strive to provide optimal care and support, many people living with the diagnosis experience various types of distress, some quite frequently; and many are medicated with potentially harmful psychoactive medications as a result.

In my work to help eliminate the use of such harmful medications, I have learned that the drugs themselves are not the real problem. They are only a symptom of a care system that does not understand how to support the well-being of those living in their communities. Part of this misunderstanding stems from a misguided view that the person's distress is primarily the result of brain disease (often termed 'behavioural and psychological symptoms of dementia'); part of the misunderstanding also results from viewing our role narrowly as providing housing, medical support, and personal care, while failing to recognise other life-giving needs that make every person want to get out of bed in the morning.

The well-being model referenced in this book is my adaptation of a framework developed in a 2005 white paper¹ that was supported by a grant from The Eden Alternative[®], an

1 Re-released as The Eden Alternative Domains of Well-Being™: Revolutionizing the experience of home by bringing well-being to life. Available at <http://www.edenalt.org/wordpress/wp-content/uploads/2014/02/EdenAltWellBeingWhitePaperV5.f>.

international non-profit organisation ‘dedicated to creating quality of life for elders and their care partners, wherever they may live’. In that paper, the authors identified seven ‘domains’ of well-being that they felt were applicable to people of all ages, cultures, and abilities. The paper contends that these essential aspects of a life worth living are too often underappreciated, even ignored in most aged care settings.

In an effort to find a better approach, I adapted and re-ordered those seven domains as follows: identity, connectedness, security, autonomy, meaning, growth, and joy, exploring how each domain is challenged (by the illness and by our care systems), and showing how a transformational model can greatly improve the lives of people living with a diagnosis of dementia.

What is revealed is that the erosion of various aspects of well-being is the root cause of most of the distress we are currently medicating; and a quick glance at the seven domains listed above should make it abundantly clear why pills cannot solve the problem. What does work, however, is an appreciative approach that works proactively to enhance each of these seven domains for each individual, thus removing the root cause of most of the distress people experience, and creating more sustainable success, without harmful medications.

The team at Barchester Healthcare has taken this concept to heart, using the well-being framework to design, implement, and evaluate the various programmes they offer for those living with dementia, and gradually introducing them in over 160 aged care communities across the UK. Each chapter of this book describes the successes and challenges of the various approaches, and shows how they fulfill each well-being domain.

Throughout the book, the team presents a wealth of qualitative and narrative information; in doing so, they also provide a roadmap for other organisations who might wish to try similar approaches, but who may lack the resources

and expertise to conduct formal research on their efforts. The chapters are practical, compelling, and highly readable.

Most important, however, is that the Barchester team has broken free of the traditional paradigms of ‘managing challenging behaviours’ or offering generic, one-size-fits-all programming solutions that fail to meet individual needs and desires. So this book is also a roadmap for organisations to transform the underpinnings of their initiatives—from a narrow institutional view of ‘care’ to a mindset with the flexibility to identify and respond to each person’s needs and preferences, and to create the soil in which people living with dementia can flourish to the fullest extent possible.

Just as each initiative is measured against the well-being model, the seven domains provide a useful guide to help understand what is necessary for a truly individualised, relational approach. First, the domain of identity reminds us of the uniqueness of every individual, regardless of her diagnosis—a uniqueness that, if anything, becomes more striking as a person lives with dementia, because each individual will respond to the cognitive changes in a manner dictated by her unique history and personal attributes. Connectedness tells us that the only way to nourish an optimal sense of well-being is through close, continuous relationships that topple the walls of professional distance to enable deep caring and empathy.

Moving to the next two domains of security and autonomy, we see the need to develop a sense of trust, dignity, and respect between ourselves and those we support, and to use our deep knowing to negotiate risk and enable choice in as safe a manner as possible. We learn that in order for life to have meaning, people must continue to have purposeful roles, even when living in residential care, and that we must strive to find ways for people to visibly contribute to the life of the community as far as they are able. It is only through authentic relationships and truly meaningful living that

personal growth can occur; and with proper support, such growth is possible throughout people's lives with dementia.

Lastly, we understand that well-being is not simply the absence of all distress; in fact, our expectations for people living with dementia far exceed what we demand of ourselves with respect to our ability to experience times of anger, frustration, or sadness. The concept of joy is much more than simply being happy. It means creating a deep sense of personal and spiritual fulfillment that sustains people through good times and bad, with the support of the authentic relationships developed within the community.

In summary, Visiting the Memory Café is much more than a roster of programs and therapies; it is a guide to a new way of thinking about how to best serve the individuals in our communities, and it provides a framework for evaluating whether your approaches support the people in your care to the fullest extent. I hope that as you explore this book, you will be inspired to think of ways in which your own organisation can shift from simply mitigating decline to creating true well-being for all of the members of your community.

G. Allen Power, MD

Rochester, New York, USA

10 July 2017

Acknowledgements

The people that we need to thank first and foremost are our wonderful residents living in our Memory Lane Communities within the organisation. Thank you for letting us try out our new activities with you; we are really pleased that most of them have been (and continue to be) a big hit!

Second, we would like to thank our amazing relatives and friends for helping to provide us with life story information, favourite music, photographs and memorabilia, and for your support with our programme.

Third, we would like to give a special mention to the fantastic staff working within the care homes. Your dedication, enthusiasm and levels of person-centred care for people living with dementia are a joy to observe.

We would also like to thank our team – a collection of dementia care specialists (who all have chapters in this book) – for always ‘going the extra mile’ to ensure that our residents, relatives and staff within the homes are fully supported across the UK.

Furthermore, the new dementia care programme would not have been possible without the full support, encouragement and guidance of our board of directors and senior management team at Barchester Healthcare, who have helped us not only to build a great team, but also to roll this programme out across all 160 care homes, providing care for people living with dementia.

We would also like to extend a particular thank-you to Sara Jones, Namaste project worker with St Luke’s Cheshire Hospice/The End of Life Partnership, for working

alongside the team at Adlington Manor Care Home to help to improve the lives and well-being of residents living with advanced dementia.

Our colleagues in the marketing department have been such a help to us in getting the Getting to Know Me Board Game and Book professionally produced, and our colleagues across the company have all been so supportive of the programme and helped us to get it off the ground.

Last but not least, we are extremely grateful to the team at Jessica Kingsley Publishers who have helped us to put this collection of activities and interventions together as readable chapters!

The Contributors

Caroline Baker

Beginning as a care assistant on a dementia care ward, Caroline went on to qualify as a Registered Mental Nurse (RMN) in 1989 and is now the Director of Dementia Care at Barchester Healthcare, working with a team of seven specialists to support over 160 care homes that care for people living with dementia. Caroline won a Lifetime Achievement Award in Dementia Care in 2014 and is the author of *Developing Excellent Care for People Living with Dementia in Care Homes* (2014; Jessica Kingsley Publishers). Caroline has recently worked alongside the team to develop a new programme of dementia care delivery to enhance dementia care, called 10-60-06, which has achieved some incredible outcomes for people living with dementia.

Jason Corrigan-Charlesworth

Jason has worked in a caring role for people living with dementia for nearly 30 years, undertaking various roles within different organisations in this time. He initially commenced his career as a care assistant and worked his way up to be a home manager and then a regional manager. Jason then decided to put his skills and knowledge into training and development and for the past 15 years has specialised in dementia care, ensuring that those providing care delivery do so in a person-centred, holistic manner. Jason's current role as Deputy Director of Dementia Care reflects this passion and

dedication in improving the quality of life not only for people living with dementia, but also for those who care for them.

Ann Marie Harmer

Ann Marie qualified as a nurse in 1987 and has worked within Barchester Healthcare for over ten years as a dementia care specialist. Ann Marie is currently undertaking an MSc in Dementia Care and was a finalist in 2016 for the UK Dementia Congress (UKDC) awards for developing the Getting to Know Me Board Game. Ann Marie has a real commitment to ensuring that people living with dementia receive the very best of care, and currently works within the central region of Barchester Healthcare helping to support a number of care homes.

Phil Harper

Phil's career in nursing spans a period of 45 years. During the later years of his professional life Phil specialised in elderly care and is now dedicated to dementia care development both for people living with dementia and their carers. Following 40 years of working in the NHS, his present role as a dementia care specialist allows him to share his knowledge and experience of dementia care with others. Phil admits that caring for people living with dementia can at times be difficult but to specialise in this career is an extremely rewarding life experience.

Deena Heaney

Deena is a dementia care specialist working as part of the dementia team at Barchester Healthcare. Deena has worked in various roles within the private sector over the past 30 years. A three-time care award winner, Deena has a recognised teaching qualification and has developed

and delivered exceptional training packages, supporting staff teams in enhancing the wellbeing of residents living with dementia.

David Owen

David Owen is currently a dementia care specialist with Barchester Healthcare. He has worked for Barchester for 15 years. His background has foundations as a qualified nurse for over 30 years, working within many roles and responsibilities in the NHS, and private and voluntary sectors of the health industry. He also has qualifications and an interest in talking therapies. His connections with dementia are personal and professional, with a close school friend living with Huntington's disease, and close family members also part of his experience. This experience along with his own health challenges have driven his passion and commitment to developing dementia services and mental health services. The dementia experience, he believes, is always more colourful and positive for an individual who goes into care where family-like relationships are built between residents, family and staff.

Claire Peart

Claire has worked within the care industry since leaving school, initially as a healthcare assistant, and then enrolling as a student nurse in 1992. Since qualifying as a nurse over 20 years ago she has worked in various roles in elderly care within the private sector for a number of different organisations, including as head of a complex dementia unit in North East England. Claire has a keen interest in the implementation of music therapy and technological interventions to support people living with dementia. She currently works as a dementia care specialist for Barchester

Healthcare, supporting care homes throughout Scotland, and North East and North West England.

Holly Rance

Holly Rance started her career in interior design with a Bachelor of Arts Degree in Interior Design from the University of Bournemouth. She then went on to work for various design consultancies specialising in residential interiors, hotels and high-end furniture and yacht design. Holly has worked within the care sector for the past 7 years and has re-developed the aesthetic and brand identity of one of the country's largest care groups. The proven success of this has naturally led on to her creating a dementia concept in conjunction with dementia specialists to develop an environment that is unique and calm, and will enhance the lives of the residents who live in the homes. Holly is passionate about design; her love for creating not only beautiful interiors but ones that are functional and practical is her fundamental approach to design and life.

Leon Smith

Leon has worked within the care industry for just over 25 years; he started out as a carer looking after people with learning disabilities and sensory impairments. He has worked in and managed many different types of care services including a home for people recovering from drug and alcohol dependency, a care home for deaf-blind people, as well as various residential services for the elderly. Leon has always returned to his passion, which is the care of people living with dementia. He has been working as a dementia care specialist for several years and enjoys supporting our homes to offer the highest possible specialist dementia care for our residents, their families and the staff teams.

Introduction

CAROLINE BAKER

From the moment of birth, we are encouraged by others to engage in activity that will provide fun, education, social interaction or individual engagement of the senses. As a baby this may involve a game of 'peek-a-boo', singing lullabies, shaking a rattle or reading a book to entertain, provide comfort or to encourage rest. In our childhood years, we are persuaded to take part in physical activities and sports days, promoting our competitive edge. But we are also exposed to social activity where we learn to make friends and get along with each other; often activities are chosen for us and we have to comply. As we move into adulthood, our choice to be involved in activity becomes less pressured (with the exception of peer pressure!) and our true choice of the things that we wish to be engaged in or actively involved in becomes shaped by our own interests and those aspects that we deem would improve our own well-being, be that physically, psychologically, socially or spiritually. For some of us, activity is high on the agenda. For others, engagement rather than activity is key.

Along with the general view of 'activity', we also all have a role in life (if not several) and part of the function of that role is to fulfil a need for ourselves if not also fulfilling a need for others. Whether that role is a mother, father, sister, employer, employee or a member of the crown green bowling club, we generally carry out our roles as well as we can to maintain our own well-being. The point we are

making here is...why should everything stop if somebody moves into a care home?

10-60-06 dementia care programme

The organisation we work for has just over 200 care homes, 160 of which provide care for people living with dementia in specialist units, called Memory Lane Communities. As a relatively new team of eight dementia care specialists, we really wanted to find a way that we could help staff to deliver the latest evidenced and research-based practices within the care homes and also to implement some of our own ideas that we thought may help in relation to activity provision.

Our starting point was our new mission statement, which led our 10-60-06 programme to have a real focus on activity or engagement for the person living with dementia,

People living with dementia are admitted into our care homes on various stages of their journey, but whichever path they are on in the complex map of cognitive impairment, we need to prioritise the reduction of any distress and the promotion of their well-being.

Our approach underpinning Memory Lane is to help the residents in our care to continue their lives as independently as possible by working alongside them rather than for them and by promoting positive memories wherever we can.

The person is our focus rather than the diagnosis, and when we do this, it allows us to work with the resident in a natural way without preconceptions.

Our staff will be skilled in dementia care interventions and will be chosen for their empathic approach towards people living with dementia.

Our environments will reduce confusion and promote orientation as well as offering evidenced and research-based interventions to assist our residents to achieve fulfilment in our homes.

The 10-60-06 programme itself involves a number of evidence- or research-based criteria that the homes need to implement, along with four levels of training,² but during the pilot phase (across 12 homes) we also decided to implement a number of new activities that had not previously been evaluated by the organisation. During team discussions around which activities we would try, some members of the team initiated their own ideas, which transpired in some amazing activities that had incredible outcomes for the residents involved. The programme and the team (and individuals within the team) reached the finals for six awards last year and we have delivered presentations in the UK, Budapest and Oslo, and in July 2017 will deliver a presentation at the Pioneer Network Conference in Chicago.

This book explores a range of activities that have either been developed by the team or introduced by the team to enhance dementia care within the care home environment, but many of the ideas could also be introduced within any community setting or the person's own home. The book is a real team effort (each team member contributing at least one chapter) and has evolved as a result of the new programme.

Seven domains of well-being

Throughout the book, you will see that most of the chapters refer to the seven domains of well-being and how the

2 The term 10-60-06 derives from the number of criteria within each section. The first 10 criteria apply across the whole home and are key to delivering person centred care. The next 60 criteria apply to the more specialist interventions in dementia care and the last 6 criteria apply to interventions that were tried and tested in the original pilot programme and have been taken forward for all homes now undertaking the programme.

particular activities relate to the seven domains. Our training and the observational tool that we have developed centre around the domains which were adapted and developed by Al Power (2014), a geriatrician based in the USA who is absolutely passionate about the needs of people living with dementia and is highly acclaimed internationally because of the extent of his knowledge and its applicability to changing the culture of dementia care.

What do people living with dementia tell us?

Dementia is more prevalent in older people, and this can often be accompanied by other health issues, including mental health conditions such as depression (Department of Health (DOH) 2016). So if we hope to enhance overall well-being, we need to be mindful to address not only the person's physiological symptoms but also their psychological, sociological and spiritual needs, and thus we can begin to enhance all four areas through a range of activities or interventions that the resident may enjoy.

However, we also need to be mindful that activities really need to be tailored for the person living with dementia and that we don't bring an individual into a large group of people if that is not something that the person has enjoyed in the past. We also need to be acutely aware that within a care home environment specifically, activities are not the responsibility of the lead co-ordinator but the responsibility of us all. Potentially, everything we do can become a meaningful activity.

Within her book, Kate Swaffer (2016) states that being diagnosed with dementia, and living with the symptoms of dementia, are definitely not as much fun as having a birthday party, but having dementia is no reason to give up living or to 'die' straight away. Often the perception of many outside of the direct care field is that care homes are a place of 'no

hope and no future,' particularly if you have a diagnosis of dementia, but we have seen high levels of well-being for people living within our homes because we encourage people to be as involved as they are able (or want to).

I am sure that Kate is not referring to specifically providing a range of meaningful activities to fulfil her needs, but perhaps she is telling us that it remains hugely important to have a sense of meaning in her life following her diagnosis. Kate has been a true ambassador for people living with dementia and has spoken at many conferences and has written several publications and blogs. These particular activities for Kate, it seems, are providing her with strength, ambition and recognition.

However, preferences for involvement or engagement in activity are very different for every individual; some may prefer 'doing', and others may prefer to observe but still remain engaged rather than involved.

Christine Bryden (2005) informs us that, 'With the stress of many activities at once, I become very focused, trying with all the brain I have left to concentrate. Telling me to rest won't help, but helping me to complete the task will.' She goes on to say that the most important factor for improving care is the environment, as this can be changed quite easily to ensure that it enhances the person's sense of safety, value and well-being. She elaborates further by informing the reader that it needs to validate the person's experiences and emotions, facilitate the person's actions, celebrate the person's abilities and provide sensory pleasures.

Content

It is helpful to read Chapter 1 before the other chapters, as the subject of this chapter – getting to know our residents really well – underpins everything we do in dementia care. Other than that, feel free to dip in and out of any chapter.

In Chapter 1, Ann Marie Harmer talks about two new life story activities that have been developed by her and her colleague, David Owen, which have since been professionally produced and rolled out across the organisation. The first is a book called 'Getting to Know Me' that helps residents to document the key memories that can be shared with staff to help them to deliver person-centred care. The second is a board game, also called 'Getting to Know Me', that staff can play with the residents to obtain the information to complete the book with them.

In Chapter 2, the readers are introduced to an intervention designed and developed by the author, Claire Peart, which encompasses a digital approach to reminiscence therapy. Rolling slide shows categorised into either the 1950s or the 1960s are picture shows with accompanying music and text which are placed predominately in 'rest areas' within the corridor. The slide shows have had a phenomenal impact on some of the residents within our care homes, so much so that although this intervention was originally only intended for the homes that Claire was working with, it was also implemented into many of the other pilot homes.

In Chapter 3, David Owen explores the use of the Namaste approach in care homes and how the use of Namaste has helped to improve well-being and increased nutrition within the care home. Namaste Care involves a blend of sensory approaches and is carried out with a small group of residents in a dedicated area. The Namaste programme is carried out for two hours each morning and afternoon over a seven-day period, with staff receiving training in sensory activities. The staff working within the home have really enjoyed being involved in delivering Namaste Care and again, this will also be delivered in many other of our care homes as we roll the programme out.

In Chapter 4, Jason Corrigan-Charlesworth talks about the implementation of empathy dolls within the care home setting and how their use has really helped the residents to

engage, reminisce and improve their well-being. There is much more written about the use of doll therapy now but it was so important within our programme that we just couldn't leave it out!

In Chapter 5, Jason Corrigan-Charlesworth's second chapter, he talks about the implementation of Memory Cafés within the care home setting. Sometimes hard to implement and maintain, Memory Cafés can be incredibly helpful not only to those living with dementia but also to the families and friends who may want to find out more about dementia or simply to gather support from others living with the condition or supporting those who do.

In Chapter 6, Phil Harper shares with us the insights and observations he made when introducing programmes of physical activity into several care homes for people living with dementia. Having witnessed one of these sessions when accrediting a home, I could clearly see the joy and laughter as residents (and relatives) engaged in the sessions.

In Chapter 7, Leon Smith shares a story of something that we have not often seen used in dementia care. His chapter focuses on guided imagery accompanied by smells, sounds and sometimes visual images to help residents to relax, draw on their memories and chatter to each other about their experiences.

In Chapter 8, Deena Heaney talks about the importance of maintaining daily living skills and how these can be incorporated into everyday life in the care home, helping people to maintain a sense of purpose and increase their well-being. Some of our residents simply want to relax when they come into our care homes but, for others, keeping busy is really important to maintain their self-esteem.

In Chapter 9, Caroline Baker and Holly Rance write about the importance of the environment in enhancing dementia care. Often our residents are transferred from hospitals where they may already have had several transfers (of wards or bays) and we need to ensure that we try to

reduce any further confusion or frustration as much as we can. Additionally, we aim to provide engagement on the journey for people who wish to walk around and places where they may stay and rest.

In Chapter 10, Caroline Baker will summarise the results of the programme and discuss further interventions or activities that were implemented to enhance well-being.

Although we were confident at the beginning of the programme that some of the interventions or activities would make a difference, we have been absolutely delighted with the results that they have brought: so much so, that we felt we had to share them with you all. Anybody who works in dementia care really only has one major goal, and that is to improve the lives of people living with dementia; so it is only fair that if we have found something that works well, we share best practice.

We all really hope that you enjoy reading about this collection of activities that we have tried and tested.

Please note that names have been changed throughout the book to protect the identity of service users and care staff.