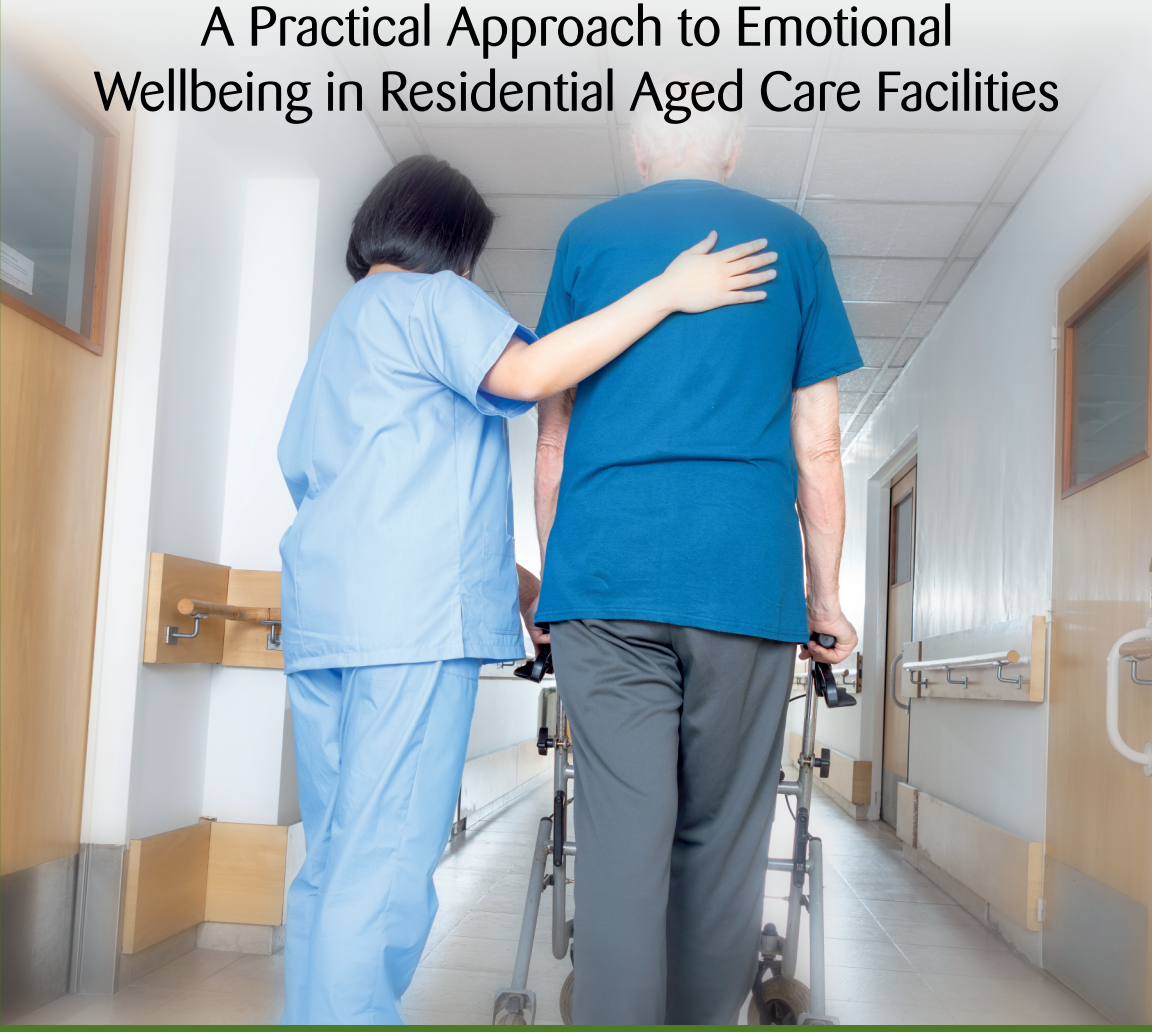
Beyond The Reluctant Move

A Practical Approach to Emotional Wellbeing in Residential Aged Care Facilities



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Dedication

For my children,
Hazel and Henry,
and in memory of my grandparents.

Contents

Foreword

'If you don't like something change it; if you can't change it, change the way you think about it.'

Mary Engelbreit

A powerful quote – however, it is easier said than done. Moving into an aged care facility is often the final step after all avenues to keep an older person in their own home have been exhausted. Sometimes there are long waitlists to move into a facility, other times the entire process can feel fast and rushed. Either way, in most cases, once an individual moves into an aged care facility they rarely move back home.

Accepting the move can be difficult, as the older person needs to become familiar with their new environment, learn routines, accept external support with personal care needs and adjust to a new way of interacting with their loved ones, which is no longer characterised with care delivery and support in their own home. These changes can impact an older person's emotional wellbeing and that of those who

support them. And, we have not even touched on the older person's health status and changes that may have occurred in their physical abilities or cognitive functioning.

Recognising how to best support an older person and help with the adjustment is important, but it is not always straightforward, and relatives and staff may feel stuck for what to say and do. Certain topics may be avoided, distraction techniques used and isolation and withdrawal normalised.

Over the last decade I have watched the prevalence of mental health conditions in this population slowly rise. In 2018, depression was the most commonly diagnosed mental health condition among people in permanent residential aged care (Australian Institute of Health and Welfare [AIHW], 2019).

Open conversations, preventions, early detection and non-pharmacological strategies are vital in minimising the prevalence of mental health conditions in older adults in residential care. I strongly believe that every older person in residential aged care deserves to be heard, understood and loved. This book is for anyone who supports older people and needs practical wellbeing tips which they can implement today.

The elderly have their voice too – hear them out!

Julie Bajic Smith
Sydney 2020

Introduction

'Mum, we are going out for lunch,' said Helen to her elderly mother Gwen one morning. She was anxiously preparing for her mother to enter residential care that afternoon. Helen felt scared, nervous, yet quietly relieved that Gwen would finally be getting the right level of care, as she was not coping well at home and had already had several falls. The only problem was that she did not know how to tell her mum the plan, as she knew that her mum did not want to leave her home. Gwen was fiercely independent and reluctant to accept her declining physical health, even arguing with her doctor and the geriatrician about her ability to remain living independently. She was adamant she could cope on her own, despite her recent falls which required hospitalisation. Gwen would angrily tell Helen, *'For heaven sake, look at the world today, I am safest right here in my own home'*. Adding to Helen's concern was the feedback from the home care workers, who called in a couple of times a week and helped Gwen with shopping. The workers were concerned about Gwen's health too, her reduced mobility, as well as the impact of isolation on her health.

After lunch, Helen dropped Gwen off at a local, newly refurbished aged care hostel and told her she would stay *'for a night, as requested by the*

doctor'. She eventually told Gwen that she would not be able to return to her home, as she is no longer safe to live on her own. To help with the packing, Helen arranged for Gwen's furniture to be distributed among the family and called a charity to take a significant proportion of Gwen's belongings. Helen only wanted the best for Gwen. Gwen in turn felt rejected, betrayed and upset.

Fortunately, most older adults are in good health and maintain their independence well into their twilight years. Older adults are, in general, happier than younger adults. They are satisfied with family relationships, have meaningful social and recreational involvements and are more emotionally and interpersonally adaptable than younger adults. However, those who have declining physical and cognitive health are more likely to feel isolated, withdrawn and experience depression and/or anxiety. Many of us are uncomfortable broaching the subject of the future with a loved one whose health is declining yet may feel overwhelmed with the responsibilities of day-to-day care.

According to the AIHW, about five percent of older Australians currently live in residential care, with the numbers continually increasing with our demographics and ageing population. Supported accommodation has many negative connotations, despite the increasing trend of low care facilities, such as hostels, which promote independence, outings and social support. Many older adults who move into a hostel experience improved health due to better nutrition, regular exercise and increased socialisation. However, discussing the transition can be difficult, particularly if the person has an impaired perception of independence and is putting themselves at risk of physical harm and emotional withdrawal, due to limited social support.

Beyond the Reluctant Move was written in consultation with aged care experts, facility managers, allied health professionals, diversional

therapists, recreational activity officers, personal care staff, registered nurses and, most importantly, with older adults who entered residential care and their families and friends. The aim of the book is to dispel the common myths associated with the transition into residential care and help you consider the needs for each individual, regardless of their health status or life stage. Through evidence-based tips, practical strategies and guidance, you'll learn how to openly communicate and assist older adults to make a successful transition into care when the time is right.

Moving into residential care is challenging – but access to the right information and helpful tips from others who have already made the move themselves can enormously assist with the process. You are not alone. Many families report a sense of relief once a loved one enters residential care, as they are receiving the right level of support for their needs and are in the appropriate place for the amount of care needed.

Unfortunately, a lot of people think it is normal to get depressed as you get old – and that it is even more normal to experience cognitive changes, most notably dementia. Some research has even revealed that doctors often overlook mental health in the aged and fail to diagnose and treat it (Uncapher & Arean, 2000). This trend has significant implications for the older person, and for those who support them, as it may mean that the level of support needed is higher as the individual's mental health has not been addressed. If an older person has symptoms of depression and is reluctant to engage in physical activities, they are more likely to experience changes in their mobility, be at a greater risk of falls and experience isolation.

In the chapters that follow, we disentangle the issues that arise for older people when they move into residential care. How can the process be managed better to ensure a smooth transition and adjustment to the new environment? What is the role of families in supporting the

elderly and how can they help their loved one adjust? There are many different approaches that can be implemented, and the focus of this book is to share simple and effective strategies and practical tips that can help anyone who works in aged care or supports an older person in an aged care setting.

Humans are social creatures with emotional needs for relationships and positive connections to others. Humans are not meant to survive, let alone thrive, in isolation. Therefore, when individuals find themselves isolated, due to changes in their health status or support network, it is important to look at ways their connections can be enhanced, as it is the key to improving emotional wellbeing. Human connection includes conversations taking place face-to-face, the tone of voice being heard, facial expressions seen and energy being felt. Phone calls and video calls have their place, but nothing can beat the stress-busting, mood-boosting power of quality face-to-face time with other people.

Creating emotionally supportive and healthy aged care environments is not a process completed in isolation by health professionals. Emotionally insightful aged care providers are not 10 times more funded, 10 times more experienced or 10 times more staffed. The approach has nothing to do with the size of the provider, it has everything to do with five skills that make an organisation stand out from the rest and lead the industry in raising the bar to improve emotional wellbeing in their residents.

This book is underpinned with five skills that emotionally aware aged care providers focus on, which are:

- Emotional Wellbeing
- Identifying Strengths
- Establishing Social Goals
- Resilience Boosting Activities
- Integrated Collaboration

Emotional Wellbeing

Emotionally aware aged care providers have a screening process to check the wellbeing of their residents down pat. They have good systems in place to review admissions and to escalate concerns to health professionals for any residents who appear to have ongoing difficulty adjusting to the new environment. This does not mean that they just tick the box and await feedback from health professionals – instead, they continue to work with the individual to identify ways the older person's emotional wellbeing can be nurtured, such as providing opportunities for one on one time and implementing reflective listening. If the provider does not have a clear system in

place for resident reviews and escalation of concerns, they cannot measure progress.

Identifying Strengths

Resilience and confidence grows when we focus on the strengths, not the weaknesses of older adults. They do not need regular reminders of activities they are no longer able to complete independently, such as accessing the community, driving, going to the beach or bushwalking. Emotionally aware aged care providers are innovators in identifying individual strengths which can greatly assist older people adjust to living in residential care.

Establishing Social Goals

It's no longer enough to simply focus on day-to-day activities, it's also essential to plan activities ahead and review each individual's social goals. Emotionally aware aged care providers assist older people to develop and achieve their unique individual goals. They work collaboratively to help clients maintain those goals, ensuring the lives of older people are rich, meaningful and engaged.

Resilience Boosting Activities

Emotionally aware aged care providers intrinsically understand the types of activities that boost wellbeing in older adults in care and offer these activities on a regular basis. Each activity is evaluated and its effectiveness is measured. This does not necessarily mean that activities are more expensive, time consuming or demanding, they are simply better ways to provide engagement and fulfillment in residents.

Integrated Collaboration

Emotionally aware aged care providers do not work in isolation. They collaborate with families, internal multidisciplinary teams, external providers and health professionals to achieve the best outcomes for their residents.

Looking closely at a number of providers who apply this approach, it can be noted they are consistently in the upper bracket of their field. It does not take years, it does not take luck and it does not necessarily take hard work. It is about focusing on the things that matter most – the emotional wellbeing of residents.

Part I

Emotional Wellbeing in Late Life

CHAPTER 1

Late Life Changes

To be old and wise; what a privilege denied to many. Of course, with positive ageing comes a number of rewarding benefits, such as sharing special memories with loved ones and being able to travel. Then again, there can be some challenges, such as reduced endurance, a higher risk of sensory impairment, no longer driving and an increased need for support.

The last century has seen many medical advances and scientific findings on how to improve our physical health and wellbeing. We now better understand the relationship between physical activity, dietary intake and social connection, and how this impacts our wellbeing and longevity. We no longer attribute all the negative effects of our poor health outcomes on genetics and better understand the

role we all play in our own health. The food we eat can either be the safest and most powerful form of medicine or the slowest form of poison. However, not everyone who enters late life requires nor receives support. In fact, most older adults remain fairly independent, sometimes even caring for others, until their death. For some, the need for an increased level of support may arise in mid-life, such as diagnosis of early onset dementia. For others, it may happen later in life following the death of a spouse, falls or poor mobility. If in-home support is not available, or has been exhausted, these health changes may result in admission to residential care, a process that's not often discussed or favourably looked upon.

In the period between 2017–2018, the aged care sector provided services to over 1.3 million Australians. Almost 1 million individuals received support in their own homes, and about 300,000 received support in residential care. The average age on admission to permanent residential aged care was 82 years for men and 84 years for women. Many of those admitted to residential care had previously received a home care package, which included government subsidised support for daily living activities (AIHW, 2019).

There is often the assumption that older people become automatically eligible for residential care, based on their age alone. However, the admission is met with stringent eligibility criteria following a formal assessment by an independent assessor relying on medical evidence and a review of daily living activities in the older person's home. Subsequently, there are various reasons for admission into residential care, including frailty, significant cognitive decline, mental health support needs and exhaustion of home care services due to declining health status. Once admitted to residential care, the average length of stay for a permanent resident in residential care is around two years, and women tend to stay longer than men. Some residents move to another facility, some move back home (which is rare but still possible), but most stay at the facility until their death.

Late life changes do not always occur slowly, such as the gradual decline in mobility and sensory impairment. Sometimes they can be quite sudden. Betty, aged 94, was walking to an art exhibition in downtown Sydney, when she suddenly slipped and heard a little 'crack'. Betty was determined she was fine, but passers-by called the ambulance and she was transported to a hospital where she was diagnosed with a hip fracture which required surgery. Betty never again laid eyes on her immaculate two-bedroom apartment which she called home for over four decades. The stairs in her rustic building prevented safe access and subsequently Betty's family decided the best option was for Betty to move to an aged care facility. This decision is one that Betty has never fully accepted and she still holds some resentment with her family, which she has been working hard to put behind her.

Understanding Emotional Wellbeing in Late Life

The vast majority of older adults enjoy better mental health than younger people. They are resilient, financially secure and less stressed than the working population. Many engage in vocational activities, such as paid employment and volunteer work, travel, hobbies and sports. However, challenges tend to arise when the older person experiences health setbacks, which may affect their ability to maintain social engagement and attend to the activities of daily living. These experiences can affect an older person's confidence, emotional wellbeing and view of themselves and their abilities. Although many people age without significant changes to their own health, they are likely to experience inevitable changes around them. This may include, more frequent grief and loss in late life, such as the death of their spouse, siblings, friends and acquaintances. Cessation of driving and the subsequent reduced access to their local community and social interactions can have an accumulative effect on their wellbeing, as can the side effects of medication, chronic pain and reduced mobility. The more isolated the older person feels the more likely they are to

experience changes in their emotional wellbeing. Older people may become more reliant on their children and relatives to attend to daily activities and social interactions. This can assist in reducing the older person's isolation and wellbeing, however, the increased need for support may put strains or carers, stretching their commitments and ability to provide support on an ongoing basis.

Historically, our understanding of the emotional needs of older people has been predominately based around those who live in their own homes. Research studies examining factors associated with wellbeing in late life and have found that many older people do not seek support for their emotional wellbeing (Bagley et al., 2000; Davison et al., 2012; Eyers et al., 2012). Stigma, ageism and the lack of mental health professionals who specialise in supporting this age group are some of the contributing factors of this trend. In residential care, the access to mental health professionals is even more limited, as there are very few organisations who employ mental health professionals and many external providers are not experienced in conducting clinical work outside of their consulting rooms. On top of this, limited funding for mental health support results in out-of-pocket expense for the older person which can further hinder service accessibility. Aged care providers then find themselves in a position where they have residents who are isolated, withdrawn, emotionally distressed and reluctant to participate in activities on offer at the facility.

However, the transition to residential care is not always a negative experience and one that triggers negative changes to emotional wellbeing. For some, it can mean better social connection, more access to nursing support, improved physical activity, social engagement and access to hot meals and warm showers. In those instances, residents may have been exposed to an unsuitable environment prior to admission into residential care. There may have been a history of social isolation, neglect or even elder abuse. These examples highlight the importance of skilful support and guidance prior to, and on the

day of, admission. The first few days in the new environment need to be carefully managed with a balance between alone time and encouragement for social engagement which can assist in boosting the overall health and wellbeing of an older person. Older people who are well supported during the admission may be faster to adjust to the new environment and be more willing to engage in activities and form new friendships.

Statistics on an Ageing Population

Statistics from the World Health Organisation reminds us that with increasing age, numerous underlying physiological changes occur, and the risk of chronic disease rises. By age 60, the major burdens of disability and death arise from age-related losses in hearing, seeing and moving, and noncommunicable diseases, including heart disease, stroke, chronic respiratory disorders, cancer and dementia (World Health Organisation [WHO], 2011). However, the presence of these health conditions says nothing about the impact they may have on an older person's life. There is a significant difference between individuals and how they respond to changes in their physical health and emotional wellbeing.

In Australia, the population of people aged 65 and over has increased significantly in the last 100 years and is predicted to continue growing. In 1901, the proportion of people aged 65 years and over represented 4% of population, in 2011 the same age bracket represented 14% of the population and in 2101 it is predicted that people aged 65 plus will represent 25% of the population (AIHW, 2019). This significant growth is resulting in increasing demand for services and awareness of the needs of older people. Statistically, only about 5% of older adults will move into an aged care facility. In 2019, that percentage is almost 300,000 individuals.

Onset of Mental Health Conditions

In defining mental health conditions, it is crucial to distinguish the language used, address negative stigma and have a better understanding of labels used. Often terms can be thrown around which can be misrepresentative and hurtful.

So how do we define the difference between mental health and mental illness? Easy – every person needs to have good mental health and resilience when faced with the challenges of daily life. However, our mental health can decline for various reasons and affect our wellbeing. For some individuals, they may have been first diagnosed with a mental health condition in early life, which is defined as early onset, whereas others may not have had any significant emotional disturbances until late life, which is defined as late onset mental health condition(s).

For individuals diagnosed with early onset of mental health conditions, genetic factors and life experiences can contribute to an increased risk of developing a chronic serious mental illness, such as schizophrenia and bipolar disorder. Whilst the purpose of this book is not to examine chronic serious mental illness in early life, it is important to recognise the role of such experiences in late life and how they affect individuals in residential care. Individuals with chronic serious mental illness often have higher risk factors for developing mild cognitive impairment, are more frequently single and come from lower socio-economic backgrounds. These individuals are likely to age prematurely with high rates of obesity, vascular disease, diabetes and have a history of alcohol and drug misuse. Some of these factors, such as a history of bipolar disorder or depression, may be a risk factor for dementia in late life and these individuals are more likely to require maintenance psychotropic medication.

Late onset mental health disorders include depression, anxiety, bipolar disorder, late life psychoses and alcohol/drug misuse.

These conditions often have organic, in particular neurological factors in their presentation as well as psychosocial factors, which can include financial status, support networks and physical health. Late onset mental health disorders can be associated with mild cognitive impairment, and without professional mental health support and thorough assessment (including discussion with family and relatives), it can be difficult to establish if the cause for cognitive impairment is due to a mental health condition or early symptoms of dementia. Typically, individuals with late onset mental health disorders are more likely to have family supports and have reasonable socio-economical background than those with early onset disorder.

Cognitive Decline in Old Age

Many older people fear experiencing cognitive decline such as dementia in late life and often seek support from health professionals in how to enhance their memory. Those who experience mild cognitive changes may not have insight into their impairment. This can result in short-term memory loss including repetition, forgetfulness around routine and getting lost. There are a number of reasons for cognitive changes in late life and dementia is just one of them. Diagnosis of dementia can have a significant emotional effect on the individual and their family, while for others it can be a sense of relief to finally know the cause of the symptoms. Other reasons for cognitive changes may include emotional status, side effects of medication, disruption in routine and sleep deprivation.

Cognitive decline due to emotional changes can be reversed and outcomes can be improved – but not treating emotional changes which may be due to mental health conditions can have serious consequences for the older person and their physical health.

The effect of untreated mental health conditions includes:

- reduced quality of life
- unnecessary suffering for the older person
- increased burden for the family and service provider
- social and economic impact as the person requires more care and support
- increased use of health services
- increased physical morbidity
- increased risk of mortality and suicide.

These effects are significant and there are a number of ways in which addressing the mental health needs of this population is important, as outlined in later chapters.

Cognitive decline due to a neurological condition, such as dementia, is far less likely to reverse and improve, however, with a structured routine the effects can be slowed down. In a 2001 study, researchers examined memory in almost 900 individuals aged 70 to 93 years. The study found that crystallised abilities (factual information such as age, family dynamics and information about major life achievements), remained largely intact, but that cognitive speed and memory performance tended to decline with age (Christensen, 2001).

It is normal to experience some cognitive decline in older age, for example, taking longer to recall information or remember some details. However, the presence of dementia in old age is not a normal part of ageing. Prevalence rates for dementia across the world are relatively low, being only around 5–8% of the population aged 60 and over (WHO, 2017), with the risks increasing with age. For adults aged 70–74 the prevalence of dementia is only 1–3%, however, the prevalence of dementia increases to 10–21% for adults aged above 85 years (Hendersen et al., 1994).

Medical Comorbidity

Medical comorbidity refers to experiencing multiple health problems at the same time. Common comorbidities in late life include arthritis, hypertension, reduced visual acuity, hearing impairment, diabetes and cardiovascular disease. Changes in emotional wellbeing can be caused by changes in physical health status, for example, if an older person had a stroke or reduced fine motor skills due to arthritis, their ability to engage in recreational activities may be impaired and this can affect how they feel. Similarly, emotional wellbeing can also affect physical health. Those who feel sad or down may be less inclined to exercise and keep active, which can then affect their physical bodies and (in late life in particular) may reduce mobility.

One of the most common comorbidities for an older person in a residential setting is presenting with symptoms of depression and cognitive impairment. It can be difficult to establish the primary disorder – did the person first experience changes in their mood or in their memory? At times, it can be changes in mood and reduced activity levels which can affect memory, particularly if the older person is isolated and not regularly engaging in interpersonal activities and interactions. On the other hand, for some individuals who first experience cognitive changes, depression can come secondary, particularly if they have insight into their memory changes and this affects their confidence and self-esteem. Many older people with early cognitive changes report feeling ashamed that their memory is not as good as it used to be. They can also experience grief and loss, as their future and prospects have changed and they are now facing a different life path to the one they envisioned.

Loneliness

Loneliness refers to the discrepancy between the number and quality of the relationships that an individual wants and those they actually have. Some individuals only have two friends, but if those friendships are deep, meaningful and meet the all their needs, then they are not lonely. Others could be in a crowd of people and feel lonely, as they do not meaningfully relate or connect to any of those individuals. Loneliness is common in residential care, especially if residents are not encouraged to socialise and interact or if during the initial settlement period their solitude and withdrawal is normalised and accepted as a personality trait.

Loneliness is a common condition affecting around one in three adults (Eyers et al., 2012). It affects people of all ages and is particularly common in adults who find it difficult to interact with others due to declining physical health and sensory impairment. The effects of loneliness are widespread. Research indicates that loneliness can damage our brain, compromise our immune system, and lead to depression and suicide (Eyers et al., 2012). Loneliness has also been found to increase the risk of dying prematurely, and it can be as detrimental to our health as smoking 15 cigarettes a day (Tiwari, 2013). Individuals who experience loneliness tend to feel more tired, even if they get sufficient sleep, and feel stressed in situations that others cope better in. This has been attributed to the effects of reduced interactions with others and the lack of access to connect with others to problem-solve issues on a day-to-day basis.

Interestingly, loneliness is not just about how individuals feel but reflects also on their behaviours. In older people this can include changes in eating patterns, skipping meals and opting for less healthy options, due to lack of motivation to prepare a healthy and fulfilling meal. Individuals who experience loneliness in a residential setting are also less likely to engage in activities such as exercise and group

activities, which are important for physical and mental health. They may feel uncomfortable and unfamiliar in the environment and be self-conscious of their efforts, not wanting to put themselves in situations where they may get embarrassed if they say or do something incorrectly and are perceived as being 'silly' or 'stupid'.

It is easy to assume that the best way to overcome loneliness is to simply talk to a few more people or to put complete strangers in the same environment and presume they will become the best of friends and overcome their loneliness. These strategies can help, but will not necessarily result in the formation of meaningful relationships. However, the addition of an experienced facilitator who can make introductions and start discussions based on common interests can be highly beneficial. In residential care the addition of careful planning of reminiscence activities, skill-building activities as well as strength-based programs which focus on the resident's abilities rather than losses can also help.

When people become lonely, they can start to act and see the world differently. They may begin to notice the threats in their environment more readily, expect to be rejected more often and become more judgemental of the people they interact with. People they talk to can feel this, and as a result, it can drive them away, which further perpetuates their loneliness cycle.

Better interactions can be formed by starting a discussion asking the older person about their pleasant memories, such as favourite holidays and family traditions, rather than talking about the reasons for admission to aged care and the help and support they require. The facilitator will also need to be mindful of sensory impairment and incorporating written cues into the program. In the Be Well Group Program this is accommodated with scripts for each session. More details about this program can be found at the end of the book.

DIGGING DEEP

1. What are some of the common misconceptions about ageing introduced to you by your parents, teachers or elderly family members when you were growing up?

2. Do you ever notice yourself making similar misconceptions in your day-to-day conversations? For example, if you are a parent, do you share those misconceptions with your children? Do you say them to your friends?

3. When you reflect on your life and key older people that inspired you, what characteristics did those people have? What set them apart from others their age?