historical and ideational contexts assists in challenging them, in turn enabling us to improve quality of life and care. This is an essential social investment. We know this; the challenge is to get our leaders listening and acting.

A second dimension of an alternative social framework focuses on how to conceptualise, so as to change where necessary, the relationships which are required to live a good life with dementia. Those with dementia will progressively require more care and support. Framing dementia as ‘decline’ negatively impacts on approaches that aim to enhance the lives of those living with dementia. Adjustments have to be made by all who care for people who are dependent, but in the context of dementia, these are particularly demanding. The fact that carers are forced to change much about their own lives, values and futures is overlooked. They are often profoundly affected by the stigmas that stem from lack of education and training, and negative social attitudes, adding considerably to their stress.

Learning from people with dementia

It is essential to learn from people who live with dementia about the kinds of information, support and insights they require. These discussions involve moral and legal concerns when certain capacities are diminishing, as well as what constitutes acceptable standards of care. Central to this is a critical conversation around personhood and social value. Our value as persons and the quality of our social relationships are influenced by philosophical, social, economic and medical ideas.

Symptoms associated with dementia challenge dominant ideas about the significance of cognition in determining that value. Media coverage of dementia focuses on new research towards prevention or cure, informing the public about its prevalence and symptoms, but even well-intentioned articles exacerbate fear and dismay.

Those diagnosed with dementia are commonly depicted as suffering a loss or deficit of personhood, being lost to a world of relationships, and as a burden for carers. Stories about community efforts to live well with dementia are harder to access. This leads us to ask: what are the taken-for-granted understandings of the good life, and of the abilities required of citizenship, which inform these limited understandings?

The Reframing Dementia project centres on the need for a caring society. Efforts are underway to create community awareness about how to live well with dementia. Such initiatives include Dementia Australia’s dementia-friendly communities program, providing online resources to enable individuals and organisations to begin their journey in becoming a Dementia Friend (see pp 10-11 for details). Another is the Welsh Government’s support for building a ‘dementia friendly nation’ (https://bit.ly/2Js6nr). Initiatives such as these are based on a recognition that living with dementia can be enhanced when the right support systems are in place, within enabling social relationships.

A call for social change

Reframing Dementia is thus a call for social change. We look for inspiration to the growing movement focusing on relational care. In the publications that have stemmed from this project (see box p23), we critically examine the importance of person-centred approaches to care, but move the reader beyond some of the triteness of this phrase to the growing awareness that person-centred care must be relational care. The differences are significant even while they appear similar.

Relational care turns the lens around to engage the carer in the ways in which change is being experienced, meaning that dementia is recontextualised as a social experience, requiring a social response. Relational care explicitly takes up issues of social attitude and morality, and the need to move towards a society in which care is valued as central to all life.

The prospect of a cure for dementia is not close enough to offer support to those living with dementia now and in the immediate future. By challenging the ways in which we think about dementia as a disease experienced by an individual, we can identify the understandings and values that get in the way of the caring society. The changes required to ensure informed and compassionate attitudes and better care for those with dementia that will ensure a better life for us all.

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Helping Hand Aged Care has taken a different approach to delivering exercise for people with dementia, in the process challenging the assumptions of care staff and family members.

Gaynor Parfitt, Megan Corlis, Wendy Hudson, Alison Penington and Dannielle Post report

Two thirds of adults with dementia experience significant functional limitations, particularly individuals living in residential aged care facilities (RACFs). Providing ways for these residents to maintain functional capacity as dementia progresses is important and a key recommendation of the Clinical Practice Guidelines and Principles of Care for People with Dementia (Guideline Adaptation Committee 2016).

Exercise is identified as a key component, with studies showing exercise programs for aged care residents with dementia are beneficial (Brett et al 2016) and associated with maintenance of independence (Csosznek et al 2017). Exercise is reported to improve performance of activities of daily living (ADLs), as well as balance and mobility (Poulos et al 2017). Exercise is also recommended as a comprehensive reablement approach for people living with dementia to help maintain physical functioning and mobility with potential benefits on cognition, mood and quality of life (Poulos et al 2017). The typical approach to exercise is to support individuals one-to-one in gyms; however, this approach or environment may be a barrier for many. Exercise programs in gyms or group sessions may not suit people with cognitive decline and it is frequently challenging for older people living in RACFs to participate in community activities.

Another approach is through exercise prescribed by Accredited Exercise Physiologists (AEPs) and delivered in RACFs. AEPs are allied health professionals specialising in the delivery of exercise for the prevention and management of chronic diseases and injuries. They are equipped to design personalised exercise programs to suit individual needs and abilities.

Helping Hand Aged Care (HHAC) in South Australia has just completed a two-year trial exploring the service that AEPs provide to enhance the cognitive and functional capacity of residents with
Changing hearts and minds

dementia in RACFs through an exercise prescription approach. The Exercise Physiology (EP) in Aged Care Project involved personalising physical activity using participants’ lived experience to motivate and engage them. The project is being independently evaluated by Associate Professor Gaynor Parfitt (co-author here) from the University of South Australia, with funding from the Cognitive Decline Partnership Centre (CDPC).

This article discusses the successful implementation of EP services for people with dementia in four HHAC residential units, perceptions of the program’s impact from family members and care staff, and how aged care organisations can apply such evidence-based practice to sustain and embed exercise into care.

Lived experiences

The EP in Aged Care Project was developed by HHAC in 2015 and led by Megan Corlis and Alison Penington (both co-authors here). The project built on initial work by University of South Australia EP students working under supervision during placements within HHAC care units. They began using the previous life experiences of residents to help motivate them to exercise and observed that this approach seemed to have some relationship with residents’ level of engagement in the exercise.

Collaboration between CDPC funding partners HHAC and Brightwater Care Group with UniSA, as part of the CDPC-funded evaluation, led to the project team incorporating aspects of the wellbeing mapping approach used by Brightwater. Wellbeing mapping is an individualised approach to support and care planning that places the person at the centre of care, recognises and includes family, carers and residents as ‘partners in care’, and involves discovering and documenting the personal history, needs, strengths and abilities of each individual (Jarrad & Hudson 2017). The EP in Aged Care Project used this personalised approach in assessing participants’ exercise needs and tailoring exercise to meet those needs.

Personalising exercise

Identifying and responding to the individual needs, goals and preferences of a person living with dementia, their carers and family is a fundamental principle of personalised care (Guideline Adaptation Committee 2016). The act of gaining professionals, care and nursing staff, and family, to help plan exercise sessions. Gathering information from partners in care ensures EPs understand what is important to and for the individual in relation to health and exercise.

The following example, involving Maggie, a participant in the EP in Aged Care Project, demonstrates how this personalised approach occurs in practice.

Maggie

Maggie (not her real name) is living with younger onset dementia within a HHAC memory support unit. Through discussions with her partners in care, the EP learns that horses and horse riding are important to Maggie.

Engaging Maggie in exercise is important for Maggie, to reduce her risk of cardiovascular disease and other chronic conditions. Maggie grew up in the country and loved to ride horses as a child; she is a mother, worked in health care, and enjoys walks.

Maggie is not keen on exercise, so the EP adjusted programs to try to get the best outcomes by using horse riding, important to Maggie, as a motivator for her to exercise. Maggie was seated in front of a computer tablet which played a YouTube video of people on a horse ride. The video was filmed from the point of view of the horse rider and, from Maggie’s perspective, it seemed like she was riding the horse. Maggie was given a set of bike pedals to use while watching the video. This theme was applied throughout the exercise sessions with Maggie; images of horse riding were used as a cue for her to exercise. In addition to pedaling, Maggie seemed motivated to participate in upper limb strengthening exercises, including bicep curls and rowing movements, using cables or dumbbells for resistance, as this related to horse handling and improving and maintaining her balance for riding. Maggie participated in these EP-led sessions once or twice a week in her care unit, in addition to walking sessions.

Images of horse riding were used as a cue to motivate Maggie to exercise. She pedalled while watching a YouTube video of people on a horse ride.

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We do not yet have outcome analyses for the EP in Aged Care program’s impact on participants’ physical functional capacity; however, Maggie’s story demonstrates how the personalised approach (i.e., understanding Maggie’s likes and needs) validates her past role as a horse rider and was key to engaging her in the exercise.

Maggie’s family reported they were encouraged by her memories of horse riding and considered arranging visits to stables so that she could reconnect with horses.

**The EP in Aged Care Project**

The 12-week EP in Aged Care exercise program was implemented within four residential units across two HHAC sites between 2016 and June 2018. Participants, with varying levels of dementia, had one-to-one sessions with an EP each week, plus two group sessions during the 12-weeks. The intention was to empower residents by providing a sense of purpose; increasing their engagement and opportunities to socialise; and contributing to improved physiological function.

Key features of the EP in Aged Care Project:

- The use of portable exercise equipment, which could be moved around the RACF on a trolley. The equipment included: bike pedals and arm ergometers; weights such as dumbbells and ankle weights; balls; exercise resistance bands; and balance training equipment.

- Engaging participants in the environment where they felt most comfortable and safe, rather than in a gym or other place outside the RACF. For the one-on-one sessions this was their room or outdoors in the garden. The group exercise sessions were held in lounge areas of the residential units – not only to maximise participation from residents who felt comfortable in this space, but also to encourage participation by those who might be influenced by seeing others exercising. Residents were also exercising where care staff could see them, which helped change their perceptions of the residents and challenged assumptions that people with dementia are unable to participate in reablement activities.

- In the one-on-one sessions, which lasted 30 to 45 minutes, exercises were individualised to suit participants’ physical and cognitive needs and abilities. They focused on challenging proprioception, balance, strength, and incorporating dual task activities, such as throwing and catching a ball while pedaling. Moderate-intensity interval training was used for some individuals to improve cardiovascular health.

To support sustainability, 12 weeks after the exercise intervention participants were encouraged to attend the regular HHAC lifestyles activity program and take part in two exercise initiatives – 5-Minute Moves and Movement With Benefits (circuits) – supported by their partners in care.

5-Minute Moves was designed as a short, chair-based exercise program delivered by trained lifestyle staff, EP students or volunteers. The exercises were done when residents were sitting together, such as before regular activities and/or before meal times.

The Movement With Benefits circuit program was co-designed by the EPs and HHAC lifestyle staff for more active residents who wanted to participate in structured exercise activities and didn’t require one-on-one assistance to exercise. Once a week a circuit comprising individual exercise stations (with colour-coded instructions on how to perform the activities) was set up in the RACF’s living area. Exercises were done while seated and included leg raises, arm raises using weights, and arm stretches using bands. Each participant was partnered with a fellow resident and they moved between the stations, helping each other to complete the exercises. Partners in care assisted throughout the circuit when needed. After five sessions participants received a voucher to use at the RACF’s café.

**Outcomes**

Outcomes of the project to date challenge assumptions that people living with dementia, including those with advanced dementia, are unable to participate in and benefit from prescribed exercise activities. Evidence also suggests that the perception of families and care staff around the likely benefits of participation for residents with dementia can shift as a result of observing the residents participating in the program.

While the majority of family members and care staff perceived that there were benefits for participants with respect to physical function (physical strength, mobility and flexibility, and ADLs), they also reported improvement in communication, contentment, and social involvement, with little to no deterioration perceived by family members or care staff. Socialisation opportunities and outcomes for participants were perceived to be particularly beneficial. It was reported that there was a great deal of enjoyment expressed by individuals involved in the program, and for the care staff who saw the participants exercising. For example, care staff reported that they saw people doing things they did not expect them to, as indicated by comments such as, “I got really excited about it, we’d all stand around going ‘oh look, oh look’.”

Following the 12-week sustainability period, the majority of care staff perceived that, on the whole, participants had maintained benefits from the exercise program; however, only a quarter of family members perceived the improvements associated with participation in the initial 12-week program had been sustained. The likely explanation for this difference in perception is that family members’ responses were specific to one resident; their own family member. In contrast, the perspectives of care staff accounted for all participants in their care, and as such, they may be more likely to perceive sustained benefit when considering individuals overall.

An emerging theme from our evaluation of this project is that sustainable benefits are only likely if a concentrated, long-term program is in place. Further, people who were cognitively aware that the sustainability activities were available in their RACF, and physically able to access these exercise activities, were perceived to be more likely to sustain any positive benefit than those who were cognitively unaware of the activities, or physically unable to attend them.

Accommodating the specific exercise needs and requirements of participants based on their circumstances reinforces the importance of understanding what is important to a person in terms of outcomes for a community of people living with dementia and related functional decline in aged care homes.

Observations from the EPs indicated
that residents were able to remain focused on a task and activity for longer periods of time during the exercise sessions compared to other times, suggesting the task-oriented exercise created a sense of purpose and that achievement was important to the person. Group sessions were reported to create a sense of togetherness and unity among residents.

**Challenges and sustainability**

There are challenges in prescribing exercise to people living with dementia and related functional decline in RACFs. Some of these include: negative connotations around the use of the word ‘exercise’; participants’ cognitive and physical limitations; and the environment. Circumventing these can be achieved through applying principles of the wellbeing mapping approach. For example, the EPs used several techniques to accommodate individual capabilities in attempts to improve exercise outcomes for residents. These included:

- Using language that focused on getting people “moving” or “warming up in the cold”, rather than exercise, which can be perceived as an unpleasant activity.
- Considering cognitive limitations by demonstrating the activities for residents; using simple cues such as “heels up, toes up”.
- Adapting activities to suit individuals with physical limitations.
- Increasing staff engagement in exercise delivery to enhance their awareness of individual residents’ capabilities; using portable exercise equipment.

Despite the positive reports associated with this EP intervention, it can be hard to sustain positive outcomes. Recommendations to sustain the EP in Aged Care Project, based on the observations of the EPs involved, include participation by EP students and family members in facilitating exercise delivery.

Student involvement would increase the number of people available to deliver exercise and therefore the opportunities for residents to exercise. Teaching simple exercises to family members would enable them to deliver exercise when they visit their relative, leading to greater involvement in their relative’s care.

**Recommendations**

Based on the evaluation findings to date, we would recommend educating care staff and family members about the benefits that exercise can have for residents, regardless of their level of cognitive or functional decline.

For long-term sustainability of exercise programs it is recommended that care organisations put in place processes to gather information about an individual’s previous experiences, likes and dislikes that can be used by partners in care, so that there is a shared understanding of what is important to and for the person in their ongoing care.

Indeed, in the last HHAC care unit to receive the EP intervention, we compiled a ‘one-page profile’ for each participant (see example p25). This records what is important to the person and what is important for the person (based upon the activities and their abilities over the previous 12 weeks of the exercise program). The profile was then shared with the resident’s partners in care to support sustainability of exercise activity.

**Evaluation**

Evaluation of data from the EP in Aged Care intervention is continuing, with outcomes to be reported in 2019 including the program’s impact on participants’ physical and cognitive functional capacity.

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**References**


**EPs in aged care**

Despite the success of Exercise Physiologists’ (EP) input for many people within the community, there appears to be little information about the EP role with older people, particularly for those living with dementia and related functional decline in residential aged care facilities (RACFs).

EP interventions are a largely underused resource in the Australian health setting (Deloitte Access Economics 2018). This is in part due to EPs not being recognised as allied health professionals under the current Aged Care Funding Instrument (ACFI) model. Recent recommendations have been made to include EPs in an updated funding model (Stoyles 2017). The current ACFI arrangements mean that RACFs are responsible for funding EP roles; an obvious barrier to the employment of EPs in RACFs.