

# The benefit and burden of “ageing-in-place” in an aged care community

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## Abstract

Ageing-in-place is usually viewed as a positive approach to meeting the needs of the older person, supporting them to live independently, or with some assistance, for as long as possible. It implies that older people prefer to live in their own home, rather than in an institution or care centre. However, there is little in the literature about the implications of ageing-in-place for the individual or their carers, or the burden this can place on service providers and aged care communities.

In an action research study that investigated the complexities and challenges of change in an aged care community in Western Australia, the implications of ageing-in-place were apparent. The study revealed how residents expressed a desire to age-in-place and identified it as a critical element of quality of life and an important component of social connection. The findings also revealed the burden of ageing-in-place on carers, family and the organisation, and sufficient attention must also be paid to the wider impact on the individual, the family and carers.

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THIS PAPER EVOLVED from the findings of doctoral study<sup>1</sup> that investigated the complexities and challenges of change in an aged care community in Western Australia. The study explored the impact of change on the residents and the senior management team, and explored how

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## What is known about the topic?

Ageing-in-place meets the needs of the older person, supporting them to live independently, or with some assistance, for as long as possible. There is little in the literature about the implications and impact of the concept of ageing-in-place on individuals or their carers, or the burden this can place on service providers and aged care communities.

## What does this paper add?

The paper reports on an action research study that found that while ageing in place was desired it placed burdens on the carers, family and organisations.

## What are the implications for practitioners?

Practitioners must be aware that the carer can become increasingly affected by the role and this can progress to a stage where his or her health is compromised, and the person receiving assistance can feel obligated to “soldier on” because so many people are helping them.

change influenced the redevelopment process and future of the organisation. The study took place with a non-denominational, non-profit, aged care organisation in Western Australia, providing accommodation, services and community lifestyle for some 1100 residents, in low and high care centres and independent living units. This provider had recognised a need for change and elected to embark on a process of redevelopment over several years, to better equip it to meet the needs of current and future resident populations.

Residents and staff described the community as a small country town. Housing varied and included single and double-storeyed units, some like town houses and others more like apartment blocks. There were a number of other buildings, including an art gallery, medical centre, leisure centre, auditorium, grocery shop and chapel. Small streets meandered throughout the

village and one larger road cut through the centre of the site. The trees were well established, as were the gardens, some of which were quite beautiful, and clearly the pride and joy of the owner. The care centres were at one end of the site comprising two multiple-storeyed and one single-storeyed building. The administration building was within the village, with the ground floor a large, well-equipped auditorium used for large public events and activities.

The majority of residents lived independently in a unit or apartment throughout the rest of the village and may have been engaged in activities and services available in the community. Residents lived in a combination of bed-sitter or one-bedroom units and blocks of one- and two-bedroom apartments connected by gardens, paths, internal streets and recreational facilities. Village life might include activity in numerous clubs and social groups, informal gatherings in the coffee shops, film nights and dinner outings. Recreational and therapy facilities were available in both care centres as well as within the village.

There was ready access to public transport and easy access to adjacent roads. Movement throughout the village was safe, as traffic was restricted and roads and paths maintained for safe walking. Gardening and maintenance services were available, along with access to services brought on to the site, such as a pharmacy. Family and friends, and the general public, moved on and off the site at will.

## Methods

Action research was selected as the method because of the need to provide in-depth, detailed understanding of the processes of change in an aged care organisation. A participative approach enabled the participants to be involved in a research process and outcomes that could have a long-term benefit. The research environment and process provided a structure for participative learning and realised new knowledge, with benefit for the organisation for the future. Action research is one approach within a range of critical methodolo-

gies that have a central interest in exploring the relationship between knowledge and action, where knowledge relates to power and power to change.

"Action research is a systematic, participatory approach to inquiry that enables people to extend their understanding of problems or issues and to formulate actions directed towards resolution of those problems or issues."<sup>2</sup> (p. 4).

The field of action research is varied, and in practice choices may be made as to how implementation is interpreted. However, there are five broadly shared features: participation and democracy; knowledge-in-action; practical issues; human flourishing; and emergent developmental form.<sup>3</sup> There are varying definitions of action research within the literature, all of which capture these key features in some way. The following definition is one of the most comprehensive and is particularly relevant to this study.

Action research is a period of inquiry, which describes, interprets and explains social situations while executing a change intervention aimed at improvement and involvement. It is problem-focussed, context-specific and future-oriented. Action research is a group activity with an explicit critical value basis and is founded on a partnership between action researchers and participants, all of whom are involved in the change process. The participatory process is educative and empowering, involving a dynamic approach in which problem identification, planning, action and evaluation are interlinked.<sup>4</sup> (p. 11).

The study occurred predominantly over 2002 and 2003, with some continuation into 2004. The study had three phases with two action research cycles and a critical reference group, comprising the senior management team and researcher. It adopted a broadly qualitative method, using data from participatory observation and semi-structured interview; it also included quantitative and qualitative data from two "quality of service" surveys of independent living residents, and a staff satisfaction survey.

## Ageing-in-place

Ageing-in-place and the associated benefits are not new concepts. For example, Heumann and Boldy<sup>5</sup> stated, “interpreted correctly, ageing in place has the potential to provide more appropriate care at less cost than a move to a more specialised and sheltered facility”.

However, they followed this by, “Alternatively, ageing in place can cause great harm if it becomes an excuse not to build and fund long-term care facilities” (p. 2).

The term implies that an older person is provided with the option of staying in their (own) home and out of a care institution, implying a sense of independence. To enable the older person to “age in place” services must be available to meet their needs and to assist them to live independently, so as to avoid or prevent a costly, often traumatic and inappropriate move to a more dependent facility. This means that services need to maximise the person’s level of independence through support, management and physical adaptation and respond to increasing dependency over time.

Ageing in place has advantages for service providers. It can prevent expansion of over-caring in costly institutions, facilitate coordination of an often complex and fragmented network of support services and assist older people to remain actively engaged in their own support to the full extent of their ability. However, ageing in place is not an option for everyone. In some cases, such a desire (by the individual and/or their family) can delay access to necessary services and accommodation and diminish quality of life. Wilken et al<sup>6</sup> describe the “two sides” of the term, that is, the possibility of individuals staying in their own homes as long as it signifies something positive to the individual, relatives and society.

In Australia, the desire to assist older people to age in place has guided government policy and funding for services. It has resulted in a greater emphasis on community care, enabling people to stay out of an institution longer, and resulting in decreased numbers in low care facilities (hostels) and higher levels of dependency in high care facilities (nursing homes). It also introduced

multidisciplinary aged care assessment teams and the development of a residents’ rights charter. It has also had an impact on community and health professionals’ attitudes who perceive ageing-in-place as synonymous with care at home, to be fostered and encouraged regardless of individual circumstance.

This study revealed that the process to support someone to age-in-place is not straightforward. While staff supported ageing-in-place in principle, they identified a concern that some residents were staying in the village (independent living) for too long, so that when they moved to the low care centre they in fact needed a higher level of care than they would have, had they moved earlier. Some residents also indicated they may have tried to cope at home for too long and this had led to physical and mental exhaustion for both them and their carer. By “missing out” on a transition through low care, with its balance between support and independence, the adjustment to high care was harder for all parties.

With community expectation that most older people want to age-in (their)-place, there is a risk that those who choose not to do so will be judged unfairly, by family, friends, health professionals and others, including themselves. This perception of being judged for not coping was shared by some residents: as expressed by one, “I should have kept her [wife] at home longer and felt badly when I couldn’t cope any longer.” This highlights the importance of a flexible approach to services, and viewing need as associated with the individual, not the accommodation or label. Understanding the desire to age-in-place along with the possible outcome of ageing-in-place for too long, with implications for residents, carers, staff and services, was a significant finding in this study.

The shift to increased funding for community and home-based services has been part of Australian health and aged care policy for some years. While this philosophy is commendable, the “industry” is sometimes critical of the way this is unfolding and there is concern that “governments” do not really understand what ageing-in-place means or the resources it demands.<sup>7</sup> The study revealed that, though individuals and pro-

viders support the principle of ageing-in-place, it is a complex, multifaceted concept and needs to be managed well.<sup>1</sup> The Australian government considers ageing-in-place a preferred approach to care and supports it through current funding schemes and service allocation.

The lines of demarcation between low and high care accommodation, and between independent living and low care, in relation to levels of dependence and the need for care, are not well defined and becoming increasingly blurred. This highlights the importance of having flexibility in the way that services are funded and delivered. An emphasis on “need” rather than accommodation classification may encourage a more timely progression through the care system.

### **Ageing-in-place and social connection**

As well as taking account of dependency, successful ageing-in-place requires social connection. The importance of social connection as a key element of quality of life, regardless of social situation or personal health status, was revealed in this study. The literature on social connection has focussed more on community-based older people, equivalent to those residents living in independent units in this community.

Social connection, that is, meaningful involvement in social activities and making a contribution to others, was identified by residents as a significant element of wellbeing. Older people report social involvement and encouragement to be significant factors in leading healthy lives and contributing to feeling good about oneself, even if they are experiencing illness and disability. The key is to continue activities and relationships that are important, and to have social support. Feeling valued and appreciated has a critical bearing on wellbeing.<sup>8</sup>

Both activity (including paid work and volunteering) and the social environment are major influences on the health and wellbeing of older people. With the ageing of the population, participation in the labour force and volunteering are becoming increasingly important issues for indi-

viduals and the economy. The Australian Institute of Health and Welfare document “Older Australians at a glance”<sup>9</sup> identifies a number of categories of activity. When compared with younger people, older people (65 years or above) spend more time on passive leisure activities (reading, watching television, audio-visual media, relaxing). They spend less time in social and community interaction, but still 10% of their time visiting, entertainment, socialising, and attending sporting or other events related to community participation. If, because of illness or disability, an older person can no longer participate in those activities that have become part of their life, they may experience increasing feelings of isolation and loneliness.

Residents in this community identified a number of different social and recreational activities that they participated in and, for many, social clubs and events were a major part of their life. Some were involved in volunteering at the care centres, while others enjoyed the companionship of friends at meal times and in other informal settings. For others, family interaction was more important as evidence of social connection. Recognising a range of interests and needs, and how they create and maintain social connection, is important.<sup>10</sup>

The literature discusses the importance of social connection in planning and design, but pays little attention to its relevance to models of care. A particularly strong criticism of the first site development plan for this community that was the focus of the doctoral study<sup>1</sup> was that it failed to place sufficient importance on environmental and social connections across the community. With its focus on buildings, it neglected to address those elements of quality of life identified by the residents. The accepted site plan, as well as the model of care developed by the senior management team, were both informed by the findings of this study and recognised the importance of social connection as an element of quality of life. The redevelopment plan that was adopted aimed to enhance social connection through buildings, recreational areas, access and pathways, social centres and activity venues. The

model of care placed its emphasis on meeting the needs of the residents regardless of physical location or designated dependence category, and planned services to meet need and connect the residents with available resources to increase the attractiveness and viability of the ageing-in-place option.

### **Ageing-in-place and quality of life**

Ageing-in-place should imply congruence with concepts of quality of life. Understanding what residents considered to be elements of quality of life was a major feature of this study. Quality of life for older people is a concept that is extensively discussed in the literature, particularly as it relates to residential aged care.<sup>11-19</sup>

Many attempts have been made to define quality of life. While there is no one consistent definition, there is agreement that it is multidimensional, has subjective and objective components and is often defined in domains. Such an approach is supported by this study, in which elements of quality of life were found to vary across sub-populations of residents. Ball et al<sup>11</sup> defined quality of life as, "the ability to enjoy life and feel that it has meaning" (p. 305).

While elements of quality of life varied between the three sub-populations of residents in the aged care community (independent living, low and high care), those revealed as common related to both the individual and the individual's connection to a community environment. The significance of the issues revealed within the elements of quality of life became a driving force behind the rejection of the first site redevelopment plan and informed the foundations for the new one.

### **Supporting a desire to age-in-place**

This paper suggests that ageing-in-place is a state of mind, a preference and that it implies a sense of empowerment. It is not just where someone lives. The study found different aspects to be particularly important in each of the three sub-populations.

### **High care**

Ageing-in-place implies a perception of quality of life described as *personal care and communication* that can be realised for residents in a high care centre. Residents or their family members highlighted personal care, cleanliness, meals, medications and treatments as important elements of their life experiences. They also rated friendly, "good" (skilled) staff as important, along with communication and interaction with others. Being able to solve problems when they arose was important to family members, and visitors, especially family members, were important to residents.

For one high care resident, confined to bed unless she had assistance, the staff made the difference to her quality of life. "I like the staff to be kind and gentle to me. I am a bit slow you know." For another, a lady with a complex medical condition and considerable physical disability, "Just my room and my bed and someone to look after me, dear. That's all I want."

Another resident was a lady of 82 years with a sharp mind but dependent on staff to assist her with all daily activities of living, including showering, dressing, walking, meals and medications. This lady had been in this facility for several years. When asked what contributed to her quality of life and gave it meaning she said, "I just need someone to look after me, dear. I don't do much anymore."

One daughter, who participated because her father could not communicate, said during the conversation, "Dad doesn't really know what is going on anymore, but I need to know he is clean, well fed and cared for with kindness and compassion."

In summary, residents in the high care centres revealed elements of quality of life related to their physical health and medical condition that determined a level of functioning. Their "home" was mainly their bedroom and surroundings within the centre and the people they shared this with, their family and staff. These residents described matters of personal care as very important, as was personal comfort. Communication and interaction with staff and contact with family also played

an important part in their quality of their life and its meaning. Any change that altered the ability of the staff to meet their personal care needs or interfered with communication affected their quality of life. Change may not directly affect them, but if staff, the physical environment, or their family were affected, then there was greater likelihood that change would also affect them. It was important not to disregard this population because they were less visible, less vocal and appeared not to be directly affected by change. They were part of this aged care community and their needs and quality of life were as important as the needs and quality of life of any other group of residents.

### **Low care**

Ageing-in-place realised quality of life for residents in the low care centre, but the elements and events that contributed to or affected quality of life, and gave it meaning, were expressed differently. The key elements were also relevant to their personal situation, described as *a balance between independence and assistance*.

Personal space and belongings were important. One lady in low care said, "I feel safe here and I get assistance with my shower and dressing." Another explained, "Enough space for my personal belongings but not too much to look after."

During a conversation with one lady who needed assistance each day, she said, "I need assistance every morning and night with showering and dressing and my meals. Without that I could not manage and would not be very well. I watch TV a lot, especially the sport, and I have family here all the time. But I cannot live alone anymore. I feel safe here and I don't worry about what other people are doing."

A fit, well-travelled, eighty-five-year-old gentleman who could see very little and could no longer read, but was still independent and active, explained:

I need to walk everyday. I am a great walker. I need to feel safe to walk all over the village each day. My room is clean and tidy and the meals are really good. I can get help when I need it but they don't bother me either. I

leave my door open all the time and people often just call out and say hello when they pass by. I listen to my talking-books and my family call me on the phone a lot.

His comment illustrated the importance of achieving the balance between help when it was needed, but independence when it was still possible.

Another resident had other thoughts. This lady walked with two sticks for support, had multiple medical conditions and was very short of breath when she talked for any length of time. When visited, she was watching the television while knitting. During the conversation she talked of her family, her deceased husband and some of her life experiences. For her, quality of life was about a balance between assistance and independence.

I know I need help now but I don't need to be in a nursing home yet. It is important to me to do as much as I can for as long as I can. I mean, if I give up on myself then everyone will give up on me too. It is still my life and I want to be in control. It drives my family mad sometimes [she laughed]. They want to do everything for me and I won't let them.

Residents in the low care centre recognised that they needed care when they could no longer manage on their own, but, at the same time, they wanted to maintain their independence. Their personal world was wider than the residents in the high care centres but also restricted by their level of dependence and health status. They were far more aware of the world outside their room and still interacted with that world in various ways. Interaction with other people was important and access to social activities and participation in clubs was important for some. Having room for personal belongings and everything accessible was more important for others and contributed to quality of life. These residents were more aware of change and more likely to react to it than the residents in high care. They wanted to be kept informed and have the opportunity to express an opinion and provide feedback. But quality of life came with a balance between independence and assistance and was

more likely to relate to personal situation and surroundings than the larger community. It was important to listen to these residents and to recognise the elements of quality of life that gave meaning to them, and to monitor the impact of change on their quality of life.

### **Independent living**

Ageing-in-place realised the key elements of quality of life for residents living independently in the village related to *stability and security* and also included factors associated with the physical environment, their personal situation and the desire to remain in their own homes. Because these residents were mobile and far more involved in activities within the community, they were far more aware of change, and some were very aware of the dislocation that came with the demolition of some of the old accommodation. Some were also more aware of the changes to the business of the organisation, the Board and Chief Executive Officer, and were very affected by what they saw as a change to the focus of the business. This section outlines the lived experiences and factors that contributed to quality of life and gave it meaning for residents living independently, and the impact of change on their quality of life.

During conversations and in their responses to the annual resident survey some residents indicated that the physical environment of the village, the gardens and pathways contributed to quality of life. Although many of the units were old, small and rather close together, the ability to walk around the village, to stay in their own unit and tend to their own garden, was important to them. Security and safety were very important, and many residents talked of the fear of strangers wandering through the village and the importance of having a security service after hours. Many residents in the village still drove a car and used this or public transport to take them to shops, services, friends and family. The availability of public transport was also identified as a factor in their quality of life.

Many residents had lived in this community for a long time, mostly in the same accommodation, and identified additional important ele-

ments. One woman who had been living in the village for twelve years said, "Security is very important to me because I live on my own." Another couple explained, "We have lived here for years — this is our home. All our friends are here, there is lots to do and we can go out whenever we want to."

Stability was important and living in the same unit for years achieved this. One resident explained, "I have been in this unit for 16 years, had the same neighbours most of the time and we look after each other. I didn't want to move really because this place is my home now. You know, it is a bit like my home is my castle."

One woman, who had been on her own for many years wanted stability and comfort with her environment and said, "My eyes are failing and I know where everything is — I don't worry about falling or getting lost."

For these two residents, quality was related to the security and predictability of their home, the unit they had been in for many years, and the life that they had developed around that home. Other residents expressed quality in terms of safety, security and friendship.

A very independent woman in her nineties, who had been a resident for many years, felt she was being looked after and made this comment, "I like knowing someone is keeping an eye on me. I had regular visits from the welfare staff — just keeping an eye on me. She is too busy now and only visits me when I call for help. What if I can't get someone?"

The availability of some assistance and other accommodation options on the same site was very attractive to some residents. One eighty-five-year-old resident who had been living in the village for many years, initially with her husband and alone since his death, explained why this was important. She had multiple medical problems and limited mobility, but still played cards twice a week and took a taxi to the local shopping centre once a week. During conversation, she said that it was important for her to keep doing as much as she could but to also know that help was available if she needed it. She'd had several falls in the previous 12 months and needed some help for a

while, but was still obviously very proud that she could cope most of the time. She commented:

I am not as bad as some of them yet and I don't want to go into the home. I have to keep trying to do things for myself, proving to myself that I am still all right. It would be easy some days to give up, but I seem to bounce back most of the time. My family would like me to be over at the care centre but this is my home and I aim to stay here for a while yet.

Some staff indicated concern that the drive to keep going for as long as possible sometimes put an individual at risk and resulted in exhaustion of their partner, who might be the carer at home. In other cases it resulted in the individual not getting help until too late. In both cases, quality of life suffered. One staff member described this situation well when she said:

Sometimes they [residents] stay in the village too long. By the time they come to low care, they really need high care. If they accepted their need for assistance earlier, it may have been possible to support them to maintain some independence in low care longer.

One gentleman interviewed illustrated this well. He was living independently in a unit in the village, but his wife was in one of the high care facilities. When talking in his unit, he described their long life together and how devastated he was when his wife had a stroke.

I cared for my wife for 10 years after she had her stroke. It was hard work sometimes but I just had to do it. At times I was exhausted. I had to stay well and just keep going because I said I wanted to keep her at home. I felt like I had let her down when she moved into the high care centre, but I just couldn't lift her on my own. I know she understood but I would have liked to have kept her home longer. The family told me I was crazy to wait for so long and the staff say I am wonderful [laughs]. Now I visit her twice a day and help her with her meals and other things. It gives me a bit of time for myself. I

didn't realise how exhausted I was until she went. It took me ages to feel well again.

For him, quality of life and meaning was having his wife looked after, being able to visit her and participate in her care, but also to look after his health and maintain some independence.

Understanding the elements that contributed to quality of life for residents in the village brought greater understanding of the concept of quality of life for older people. The key elements were identified as stability within their personal situation (financial and health) and security within the community environment. Many residents were keen to remain in their own home but to have ready access to recreational and other services, if they chose to access them or needed them. The knowledge that assistance was accessible within the community, either in their home but at a later stage within the care centres, was also important. These residents revealed that they were most directly affected by the redevelopment and associated change and were very keen to be kept aware of, and in some cases, involved in, decisions. Many were confident that their future was secure and had confidence in the management. Others did not and were very critical of "how things had changed" in recent years.

## Conclusions

The literature reveals the importance of wellbeing, expressed as quality of life, empowerment, ageing-in-place and social connection.<sup>1</sup> This study expands the knowledge base regarding the complexities of ageing-in-place among older people in different settings within an aged care community.

The concept of aging-in-place has implications for aged care providers and the retirement village industry as it relates to an individual's preference to live independently in his or her own home, rather than enter into residential care. Residents expressed this view and talked about the importance of staying "out of care" for as long as possible. This is achieved by many older people, but many others find that they need an increasing level of services to enable them to live "in their



own place", provided either by an external agency or agencies, or by a family member, friend or spouse.

While recognising the relevance of this concept, this study highlights two interesting complications of a preference to age-in-place. First, the spouse, family member or friend who may be providing assistance to enable the individual to live at home can become increasingly affected by the role, and this can progress to a stage where their health is compromised. Second, the person receiving assistance to stay at home can feel obligated to "soldier on" because so many people are helping them, when they may be feeling exhausted. In both situations, there is a risk of creating feelings of guilt when the situation becomes untenable: "I failed her because I couldn't cope any longer"; or, "I am a failure because I can't cope any longer, even with all this help". This study alerts the "industry" to review all situations individually, to recognise when gentle intervention in a situation might be the best outcome for all concerned, and cautions against placing over-riding emphasis on the importance of ageing-in-place when residential care might improve the health status of one or all parties. Balancing the ideals of ageing-in-place with the realities and impact of caring in personal situations is also a message for a wider audience.

Finally, Hudson illustrates an outcome that should be achievable: "In a cultural environment that favours productivity over disability and dependency, in a medical research environment devoted to postponement, if not abolition of old age, is there a place for creative communities where we may age gracefully?"<sup>20</sup>

Let us create aged care communities where people can age-in-place on their terms, not aged care communities where ageing-in-place is an expectation or a burden, a policy directive or a service category. Ageing-in-place might mean my place and on my own with minimal assistance — but my place might be a bush camp, a two-bedroom apartment, a house, a bed-sitter, a caravan or a shared room in a high care facility.

In this paper we have argued that, while ageing-in-place should be a desirable option for

older people, service providers need to ensure that sufficient attention is paid to the wider impacts on the individual, the family and carers. Ageing-in-place has become "common language" with policy makers, within the industry, and in the wider community without real understanding of the implications of its favour. It is a commendable ideal — but should not become a burden.

## Competing interests

The authors declare that they have no competing interests.

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