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Review Article

The Community Home Model – Small Scale Community Embedded Residential Aged Care for People Living with Younger Onset Dementia

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Introduction

Until the advent of the National Disability Insurance Scheme, Australia has lacked an appropriate mechanism to provide care and support to people living with younger onset dementia that has resulted in many entering into the aged care system despite its obvious inappropriateness. Many of the inherent negatives of the residential aged care system are exacerbated for those under 65, whose interests, experiences, preferences and needs all clash with the predominate population of over 80's.

Historically, residential aged care in Australia was operated by small not-for-profit charitable organizations and small for-profit entities who provided care in small and medium sized institutions. While many facilities claimed to offer a 'home-like' environment, the majority were more akin to a small, ill-equipped hospital with a clinical environment, multi-bedded rooms accommodating up to 8 residents in one room and ablution block bathrooms more reminiscent of a caravan park.

Since 1997 and the commencement of the Aged Care Act, we have witnessed an increased interest from larger for-profit companies, private equity firms and property developers from both Australia and overseas and the advent of the 'residential aged care facility' with its ever-increasing bed numbers, with some now exceeding 200 beds.

The environment provided in new services now often mirrors that of a five-star hotel with cafes, cinemas, hairdressing salons and large, single occupancy ensuite bedrooms.

Despite these improvements, a number of negatives continue to be experienced and were highlighted in the lived experience of those dealing with the aged care system.

Disconnection with Community

Admission to a residential aged care facility often results in a complete disconnection from the resident's local community. Many facilities still don't provide options for activities external to the facility or own a bus to transport residents into the community. Even where a bus is available, because of the large number of residents housed in each facility, access to bus trips and external activities is limited. Sadly, the vast majority of aged care residents rarely leave the confines of the facility, with some never experiencing the outside world again.

Institutional Environment and Systems and Lack of Person-Centered Care

Despite the obvious improvements to residential aged care facility environments, there continues to be an institutional approach to care and services as providers strive the achieve economies of scale and achieve optimal financial outcomes. Housing 100, 150 or 200+ people in one building can only be institutional. Feeding large numbers daily requires commercial kitchens and rigid fixed menus. Providing personal and clinical care to this number of people requires routines and task lists that drive the day. Individualization is almost impossible at such scale and truly person-centered care is beyond the vast majority of facilities.

Even some smaller scale cottage model homes continue to house between 10 and 15 residents in a facility made to look like a home, and those operated by large, aged care providers continue to have institutional thinking at the core of their operational practice.

Social isolation

A notable change in new facility design is the increasing size of resident bedrooms. Some facilities are now offering single occupancy rooms in excess of 50sq meters complete with lounge and TV spaces and kitchenettes. The result of this is that residents rarely leave their bedroom, often by choice, in an effort to find privacy and remove themselves from other residents presenting with behavioral disturbances.

A physical environment with over 100 single bedrooms is also difficult for staff to cover and results in a reduction in resident and staff interaction and longer response times when assistance is required.

The planning, delivery and built environment in Australian Aged Care is largely a reflection of government policy agenda for decades that have produced and encouraged a system designed to provide care to as many people as possible with the least amount of expenditure and achieve a minimum standard of care that is acceptable to the community designed to avoid electoral defeat.

The system enables little innovation or drivers to achieve clinical and quality excellence, and little has changed in this area in many organizations. Residential aged care regulation is not fit for purpose when a provider wishes to provide flexible, person-centred and driven care, and aged care funding schemes inhibit innovation, appropriate staffing levels and service excellence and as such has been the major reason why as an organization, we have chosen to operate outside of the aged care system.

As a result of this ill-designed and enacted system, providers are encouraged and, in many ways, forced to deliver a level of service mediocrity to all that fails to provide for the individual, their needs and their preferences and exacerbates social isolation.

The Community Home Difference

The Community Home model of care is a nurse developed and driven holistic, multi-disciplinary alternative to traditional residential aged care based around continued community connectedness. It includes aspects of multiple international care models across aged care, disability care and mental health care to produce a person centered, individually driven, human rights-based community of support.

The model was developed in part as a response to the negative effect of the COVID-19 pandemic on aged care residents, in part as an expression of frustration with the current aged care system and in part fulfilling a desire to stop talking and do something better for Australians living with younger onset dementia. The model aims to exceed the minimum standards set by regulators and deliver world-class, person-centered care for people living with younger onset dementia.

Although it was developed prior to the release of the findings of the Royal Commission into Australian Aged Care (and implemented shortly after), the fundamental philosophies of the model represent many of the calls for change that have been articulated by the community and the Commissioners.

The author and his team drew upon decades of health service management and clinical experience across aged, dementia, disability and mental health care and incorporated learning from:

- The report of the Inquiry into Health Services for the Psychiatrically Ill and Developmentally Disabled conducted by David Richmond in 1983. The Richmond Report is recognized as a watershed moment in Australian healthcare history [1].
- The report of the Royal Commission into Australian Aged Care Quality and Safety [2].
- The US Eden Alternative model [3].
- The US Green House Project [4].
- The US Green House Farm model [5].
- The UK Butterfly Household model [6].
- The Netherlands based De Hogeweyk village [7].
- The Netherlands intergenerational programs of Humanitas [8].
- The Austrian Multigenerational House Model [9].
- The German based Mehrgenerationenhäuser Multigenerational Housing Model [10].
- The Danish and Japanese models of deinstitutionalizing the elderly [11].

The Fundamental Principles of the Community Home Model

The Community Home model is based upon the following key pillars:

Respect for the Individual

Our supports are individually designed, and person centered offering a program specifically meeting the wants, needs and preferences of each guest. No two guests' programs and supports are the same and are based upon the wishes of the individual. Our small scale, non-institutional houses offer individualized truly homelike environments where guests are treated like family and maintain their valued roles and status. Past roles and interests form part of our identity, and these are acknowledged and maintained.

Independence

Guests receiving support through our programs are enabled to design and drive their care and are supported to maintain their independence, decision making and risk-taking rights. Our guests choose how their daily routines happen and continue to participate in daily household activities and external programs as they choose. Guests participate in menu development, meal preparation and tend to our vegetable garden, fruit trees and chickens. Both guests and staff eat meals together. Our guests right to autonomy is paramount.

Enablement and Support

Our model is not about staff driven dependency or staff performing tasks upon someone else. Of course, our skilled team members are available to provide hands on support and assistance as required but guests are encouraged and supported to live their best life and remain active participants in life including their personal care, operations of the house, operations of the organization (including staff recruitment) and external activities.

Our generous staff to guest ratios enable us to take the time to make and nurture relationships with our guests and provide a comprehensive, individualized holistic program of support. The appropriate allocation of resources translates to our ability to provide care and support without the use of restrictive practices, despite their prevalence of use with people living with dementia in residential aged care.

We don't see ageing or a diagnosis of dementia as a reason to stop living and we support our guests to achieve their goals and dreams every day.

Community Connection

A defining pillar of our model that sets us apart from many other similar dementia care models. Unlike traditional aged care where residents often never leave the confines of the facility, our guests are encouraged and supported to continue their lives as active participants in the local community.

Instead of creating fake villages complete with internal hairdressers, cafes, shops, gyms, chapels and movie theatres, our model supports our guests to access existing community-based services including medical services, shopping, and the services listed above.

We don't live permanently in our house and ongoing connection to the world around us is important for mental health, physical health, and quality of life. Institutionalization and removal from the world around you are not normal and counterproductive.

Our guests regularly enjoy:

- regular bus trips around the region including to the south coast to the beach
- local community events such as school fetes, festivals, celebrations and sporting events
- community resources such as art galleries, museums, parks, and libraries
- intergenerational programs with local preschools and playgroups
- access to a full range of community based allied health practitioners
- activities including gym, yoga, book club, art classes, music programs, gardening, woodworking, cooking, movies, church services (in a real church with the local congregation), walking programs, cafes, and restaurants.

Community connectedness also includes connection to family and friends and our model extends to the spouses and loved ones of our guests. Families and friends are included in activities and celebrations and become an integral part of our care and services. Where family are unable to visit, we enable our guests to visit them … even when they live 600km away.

Through our partnership with a local Pilates company, we now offer free Pilates sessions for carers and family of our guests.

Expertise

Education, training and evidence-based practice are an important part of our model's success, as well as our comprehensive internal education programs we also support team members to undertake ongoing professional development beyond our organization. All team members, regardless of role, are enabled to complete qualifications appropriate to aged care, disability and dementia including all modules of the Wicking dementia program through the University of Tasmania. Training in first aid, CPR, and advanced life support (including the use of a defibrillator) is included in our annual training program and paid for by the organization.

Clinical staff continue to maintain their currency of practice through our partnership with the Canberra Hospital. Fully funded by Community Home Australia, team members are paid to complete supernumerary shifts in the acute geriatrics wards in what has proved to be a valuable experience for both our staff and those employed at the hospital.

Additionally, through our partnership with the University of Canberra we actively participate in research programs and have fully funded a PhD scholarship commencing in 2023 to explore our model of care and establish an evidence base for others to follow.

Staff Value

We celebrate and support our staff in recognition of their valuable role in providing the highest quality of care to our guests. Without our team members our organization would not be a success and as a mark of respect, Community Home Australia has made a commitment to support each team member in achieving their dreams.

Through productivity and efficiency gains, we now offer staff at all levels wages 15% above award, additional annual and personal leave entitlements (6 weeks and 20 days per year respectively) and 12% superannuation contributions. All staff are enabled and encouraged to pursue educational and personal opportunities and we offer inclusive and supportive HR practices that offer flexibility and support.

Acknowledgements

It is important to acknowledge that the Community Home model of care was successfully established because of the multi-million-dollar financial contribution of the author and the determination of Registered Nurse and Gerontologist Nicole Smith, who with the author and a small team has built and driven a culture of person centeredness, community connectedness, enablement and inclusion that is supporting our guests to live their best lives. The model was established without any government or external business funding or grants.

It is also acknowledged that this model provides an exceptional level of individually focused care and services unprecedented in traditional residential aged care because of the foresight and hard work of those who developed and successfully implemented the National Disability Insurance Scheme (NDIS) which is, in many ways, the complete opposite of the aged care system. People who are diagnosed with dementia prior to the age of 65 have access to the NDIS and its optimal system of support.

The NDIS represents a truly person-centered system of supports that allows providers to tailor care and services to individual participants. It strives for excellence within a participant driven system and allows providers to actively engage with support recipients to plan and deliver their care in a way that meets their individual needs and preferences.

Conflict of interest

None.

Acknowledgement

None.

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