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## Dementia Villages: Innovative Residential Care for People With Dementia



*De Hogeweyk, Weesp, the Netherlands*

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## Methods

This bulletin presents an overview of the technology and available evidence; it is not a systematic review and does not include a critical appraisal or a detailed summary of study findings. A literature search was performed by an Information Specialist and consultations with seven Canadian clinical experts and long-term care providers were conducted to further inform the policy section.

### Literature Search

A limited literature search was conducted on the concept of dementia villages using the following bibliographic databases: MEDLINE, PsycINFO via Ovid, CINAHL via EBSCOhost, PubMed, and the Cochrane Library. Grey literature was identified by searching relevant sections of the [Grey Matters checklist](#).

No methodological filters were applied. A second search was conducted using the same databases for the concepts of dementia and care models. The health technology assessments, systematic reviews, and meta-analyses filter was applied to limit the retrieval by study type. The searches were limited to documents published until November 16, 2018. Regular PubMed alerts updated the search until project completion; only citations retrieved before September 1, 2019 were incorporated into the analysis. Additional information was identified by scanning the reference lists of relevant papers, through the websites for the different dementia care models dash – Be the Hogeweyk Care Concept, the Eden Alternative, the Green House Project, and Butterfly Care (Dementia Care Matters) – and further sources suggested by clinical reviewers and the CADTH Health Technology Expert Review Panel.

### Study Selection

Two authors (JH and LAT) screened the literature search results and one or both authors reviewed the full text of all potentially relevant studies. Studies were considered for inclusion if they described the elements or outcomes of dementia village care or other innovative models of residential care for people with dementia. Grey literature sources were used to fill in information gaps where peer-reviewed studies were not available.

### Peer Review

An earlier draft of this bulletin was independently reviewed by two external peer reviewers.

### Limitations

This bulletin is based on a limited literature search that included only English-language publications. Consequently, studies in other languages may have been missed. In addition, no critical appraisal of the identified studies was conducted. Published, peer-reviewed literature has been supplemented by information from grey literature sources, which may not be as reliable. However, the information on dementia villages was reviewed and verified by founders of De Hogeweyk.

## Summary

- Dementia villages (the Hogeweyk Care Concept), modelled after De Hogeweyk village in the Netherlands, have received much media attention as a new way to provide residential care for people living with advanced dementia.
- Dementia villages share some common elements with other innovative models of residential care that emphasize improving quality of life for people with dementia by providing person-centred care in smaller scale, less institutional, more “home-like” environments.
- No comprehensive assessments of dementia villages were identified, but a few qualitative studies of particular aspects, such as staff and caregiver perceptions, have been published.
- Although not unique to dementia villages, benefits associated with many elements of dementia village care are supported by published evidence and some have been integrated into existing care models for dementia; for example:
  - design of the physical environment to accommodate the needs of people living with dementia
  - small-scale, home-like group living to encourage social interaction and participation in activities of daily life
  - ready access to outdoor space and gardens.
- To ensure all residents with advanced dementia are able to participate in the activities of daily life in dementia villages, additional staff are needed.
- Training is needed for all staff and volunteers to encourage empowerment and team work.
- Transforming a traditional long-term care residence into an innovative model, such as the dementia village (the Hogeweyk Care Concept), requires vision and commitment from leadership to sustain changes.

Note: The founders of De Hogeweyk (the first dementia village) prefer not to use the term “dementia village” and refer to the Hogeweyk Care Concept instead. However, as dementia villages is the most widely recognized term, we have used it here.

## Background

Dementia is a broad term covering various conditions that cause cognitive impairment.<sup>1</sup> The most common form of dementia is Alzheimer disease, but other types include Lewy body, vascular, frontotemporal, and dementia associated with conditions — such as Parkinson disease.<sup>1,2</sup> Dementia causes progressive cognitive impairment that affects memory and language, and makes tasks of everyday life — both mental and physical — increasingly difficult.<sup>3,4</sup> Advanced dementia is the main reason for admission to residential long-term care.<sup>5</sup> Long-term care is defined as a residential care setting offering 24-hour care for individuals with complex health needs arising from physical health conditions, dementia, or brain injury.<sup>6</sup>

Beyond the impact of dementia on the individual, the condition affects the family and other caregivers, and results in substantial health care and societal costs.<sup>3</sup> More than 400,000 Canadians are living with dementia, and more than one-third of these people are living in long-term care.<sup>1,7</sup> In Canada, an estimated 87% of long-term care residents have some form of dementia.<sup>8</sup> Most Canadians living with severe dementia (86%) live in residential care.<sup>9</sup>

With Canada's aging population and the corresponding increase in the number of people living with dementia, total annual health care costs for dementia care are expected to double — from \$8.3 billion in 2011 to \$16.6 billion in 2031.<sup>1</sup> Combined direct health care and indirect costs (such as social services and lost earnings) associated with dementia are expected to rise from \$33 billion in 2015 to \$293 billion by the year 2040.<sup>10</sup> Canadian health care and indirect (out-of-pocket) expenditures for caring for people with dementia are estimated to be five-and-one-half times higher than costs of care for those without dementia.<sup>1</sup> Because of the additional care needed, the costs associated with caring for people with advanced dementia are substantially higher than for those living with mild or moderate dementia.<sup>9</sup> The more complex care needs of people with dementia also increase staff workloads.<sup>11</sup>

A 2019 Canadian Academy of Health Sciences report noted that safety, quality of care, and quality of life for people with dementia varies considerably in long-term care homes across Canada.<sup>12</sup> Among its recommendations, the report called for a greater variety of regulated, publicly funded residences for people with dementia, stronger standards to improve the quality of care,

behavioural supports and policy changes to reduce the use of restraints, and increased use of dementia-friendly design and meaningful activities to improve residents' quality of life.<sup>12</sup>

It has been reported that, at the end of their lives, people with dementia may be suffering unnecessarily and not receiving adequate pain medications and other recognized palliative care interventions.<sup>13</sup> They may be transferred to acute care hospitals, which are not set up to provide appropriate care for them.<sup>12,14,15</sup> A Canadian study on dying in long-term care homes concluded that challenging behaviours were more common in people with dementia at the end-of-life.<sup>13</sup> Because of communication difficulties, conditions such as pain and difficulty breathing may not be as readily detected in people with dementia at the end-of-life, and improved management of these symptoms was noted as a priority area for quality improvement.<sup>13</sup> Some modifiable organizational factors were associated with improved end-of-life care, including leadership, staff engagement, and use of best practices to manage responsive behaviours non-pharmacologically.<sup>13</sup>

Over the past 20 to 30 years, alternative dementia care models have been developed.<sup>16</sup> The shift in focus has been to better understand the needs of the person living with dementia.<sup>17</sup> Meeting these needs requires changing the underlying values for the provision of care, adjusting staffing models, redesigning physical care environments, and altering care interventions.<sup>18,19</sup>

The new models share many commonalities and are part of a broader "culture change" in nursing home care — moving away from traditional medicalized, institutional types of care for people living with dementia.<sup>20-24</sup> The focus is on person-centred care and the idea of enabling a "life worth living."<sup>25</sup> Person-centred care:

... focuses on the individual needs of a person rather than on efficiencies of the care provider; builds upon the strengths of a person; and honors their values, choices, and preferences.  
 ... [It] reorients the medical disease-dominated model of care that can be impersonal for those oriented to holistic well-being that encompasses all four human dimensions: bio-psycho-social-spiritual.<sup>26</sup>

Person-centred care practices in long-term care vary and these are affected by funding and the level of privatization of services.<sup>27</sup> Innovative models of residential care for people with dementia have generally introduced changes to improve the quality of

care by creating a less institutional and medical, more home-like environment.<sup>20,28</sup> For example, in addition to care tasks, staff may also undertake domestic work and social and recreational activities with the residents in their care.<sup>28</sup> Examples of innovative care models include:

- Dementia villages (the Hogeweyk Care Concept)
- Eden Alternative
- Green House Project and other types of small-scale, group home residential care
- Butterfly Care (Dementia Care Matters)
- Green Care Farms.

The focus of this bulletin is on the dementia village concept for people with severe dementia developed by Be the Hogeweyk Care Concept in the Netherlands. Brief descriptions of other models are included to highlight similarities and differences, but this bulletin is not a comprehensive review of evidence on these models – some of which are for long-term care in general, rather than dementia villages, which are intended for people with advanced (severe) dementia.

## Policy Questions

This bulletin addresses the following questions:

- What evidence is available on the clinical, behavioural, psychosocial outcomes, and quality of life of residents of dementia villages (e.g., the Hogeweyk Care Concept)?
- What clinical, economic, social, ethical and other issues should be considered by jurisdictions interested in implementing this model of care within the public health care system in Canada?

## Who Might Benefit?

More than 419,000 Canadians older than 65 years have been diagnosed with dementia.<sup>14</sup> In addition, an estimated 16,000 Canadians under the age of 65 are living with dementia and many other Canadians have the condition but have not been diagnosed.<sup>14,29</sup> About 76,000 Canadians are diagnosed with dementia each year.<sup>1</sup> Two-thirds of seniors living with dementia are women.<sup>1</sup> Dementia rates among Indigenous peoples are 34% higher than elsewhere in Canada, with an earlier onset of disease and more men than women affected.<sup>10</sup>

With the aging population and population growth, the number of Canadians living with dementia is expected to almost double over the next 20 years.<sup>1</sup> In Canada, dementia affects more than 23% of men and 70% of women older than 80 years of age who live in residential care.<sup>30</sup>

## Current Practice

Most cases of dementia occur in individuals older than 65 and, as expected in an older population, multiple comorbidities such as heart disease, hypertension, diabetes, chronic obstructive pulmonary disease, and musculoskeletal disorders are common.<sup>31</sup> Some of these conditions (diabetes and hypertension, for example) also increase the risk for developing dementia.<sup>5,12,32,33</sup>

In the earlier stages of dementia, most individuals can remain in their own homes, with support from family, friends, or home care services.<sup>10</sup> As dementia progresses, it affects the ability to carry out activities of daily living, including eating, bathing, dressing, and toileting.<sup>10</sup> In the later stages of dementia, individuals may be disoriented and unable to communicate verbally, walk, chew, or swallow food.<sup>10,12</sup> Individuals with advanced dementia need considerably more care, and caregiver burnout often leads to the person with dementia being placed in residential long-term care.<sup>10,17</sup>

People with dementia may also exhibit responsive behaviours such as agitation, anxiety, wandering, or aggression.<sup>34-36</sup> These behaviours may be in response to frustration at their inability to communicate; to psychological distress, physical pain, or discomfort; to the environment; or to boredom, loneliness, or other unmet needs.<sup>17,34,37,38</sup>

Physical restraints and drugs (chemical restraints) have been used to manage responsive behaviours, but in light of evidence of significant adverse events and ethical concerns associated with restraint use, current best practice is to minimize their use.<sup>32,39-41</sup> In Canada, more than a quarter of seniors in long-term care who do not have a diagnosis of psychosis have been inappropriately prescribed antipsychotic drugs.<sup>39</sup> Psychotropic drug use is associated with worse quality of life and higher risk for serious adverse events and death.<sup>42-44</sup> Recent initiatives have successfully reduced the use of physical restraints and inappropriate use of antipsychotic medications in several jurisdictions – with demonstrated reductions in the rates of adverse events (falls) and cost-savings as a result.<sup>39,40</sup> Increasing staff, staff training, policy changes, and behavioural and other interventions have been effective in reducing the use of restraints.<sup>1,17,34,39,40,45</sup>

Long-term residential care in Canada is provided through three types of facilities: publicly owned care homes supported by municipal, provincial, or territorial government funding; voluntary (non-profit) care homes run by charitable or religious organizations; and private (for-profit) care homes.<sup>11,46</sup> Levels of funding, the types of care provided, and the mix of public, non-profit, and private facilities vary across the country.<sup>5</sup> Most of the care in these facilities is provided by unregulated care aides.<sup>5,11</sup>

Long-term care in Canada is governed by provincial and territorial legislation and regulations.<sup>47,48</sup> In a number of jurisdictions, this includes regular quality and safety audits and mandated critical incident reporting.<sup>49,50</sup> Most jurisdictions mandate that a registered nurse must be on duty at all times, and some have an established minimum number of hours of direct care that must be provided per resident.<sup>49,51</sup>

In most jurisdictions, individuals are assessed for long-term care placement by care coordinators using a standard assessment tool, the interRAI Resident Assessment Instrument–Home Care (RAI-HC).<sup>52</sup> The RAI-HC assesses health, behavioural, and environmental risk factors that predict one’s need for care services, including changes in decision-making behaviour, medication management, nutritional status, performance with activities of daily living, and changes in behaviour that present a risk to the person or a caregiver (such as, wandering, physical abuse, or socially inappropriate behaviours).<sup>53</sup> Given that there are wait lists for long-term residential care services in most jurisdictions at any given time, RAI-HC data can also be used to categorize individuals by their care needs and prioritize those with the highest needs.<sup>54</sup>

## Overview of Innovative Models of Dementia Care

### Dementia Villages (the Hogeweyk Care Concept)

The first dementia village, De Hogeweyk, was developed in Weesp, in the Netherlands. Before its transformation, De Hogeweyk was a traditional nursing home. In 1993, managers of De Hogeweyk began introducing changes; for example, creating a shared kitchen and dining and living spaces. In 2009, the fully redesigned De Hogeweyk opened, with townhouse units and the amenities of a small village.<sup>55,56</sup>

The guiding principles of De Hogeweyk are to “deinstitutionalize, transform, and normalize” care for people with advanced dementia. The founders asked: “What is important at this stage in life? Is it important to have the best treatment and be sitting in a chair all day waiting for the doctor or is it important to do things you like to do?”<sup>57,58</sup> The premise of dementia villages is to enable people with advanced dementia to live an ordinary, normal life, as much as possible.<sup>57</sup> This is based on the understanding that life in traditional nursing homes confuses residents with dementia, and that in a supportive, more familiar home-like environment, they can still live a good life and engage in activities that are meaningful to them.<sup>21,59,60</sup>

The average age of residents at De Hogeweyk is 83, and all residents at De Hogeweyk have advanced dementia.<sup>23,55,59</sup> Residents typically live at De Hogeweyk for two to two-and-one-half years — and they die there.<sup>61</sup> About 60% of De Hogeweyk residents are ambulatory, but those who are not are still included in household and other activities (Jannette Spiering, *Be the Hogeweyk Care Concept*, Weesp, the Netherlands: personal communication, 2019 Aug 12). According to a news report, about one resident per year does not adapt to life in De Hogeweyk, either because of psychiatric issues or because they are unsuited to small-group living.<sup>55</sup>

The six “pillars” of the dementia village / the Hogeweyk Care Concept follow.<sup>59</sup>

#### 1. Favourable surroundings:

- living a normal life, on a human scale, with support from professional staff, as needed
- a house, with a front door, a living room and kitchen, and one’s own bedroom, with household furniture, tasks, and daily routines that accommodate personal preferences shared with a small group of people with similar backgrounds or lifestyles
- outdoor space (streets and gardens) to walk in

#### 2. Life’s pleasures and meaning:

- freedom to wander
- social life (clubs, restaurant, concerts, day trips, shopping)

#### 3. Health:

- staff to support quality of life (to be able to enjoy family and community, freedom, environment, culture)
- well-being through social relationships rather than medical interventions

#### 4. Lifestyle:

- recognizing the individual is the same person they were before they had dementia (i.e., their preferences, behaviour, daily routines, and values)
- offering lifestyle groupings based on Dutch culture (these will differ in other countries)

#### 5. Staff and volunteers:

- employees and volunteers work as a team and all understand and work toward the vision (volunteers always work under the supervision of an employee responsible for their work)

- training is provided through an initial introductory day, on-the-job learning and coaching, and workshops
- there is one team for every household (six to seven residents); each team has six to eight employees, including professional caregivers and assistants
- caregivers are responsible for nutrition, daily care, health, and contributing to each resident's care or life plan, with input from the other team members and the family
- in addition to each team, support is provided, as needed, by a nurse, geriatrician, psychologist, social worker, physiotherapist, and occupational therapist

## 6. The organization:

- all policies and organizational structures, procedures, etc., are based on the vision
- professional staff are there in the service of the resident to ensure they live a normal, healthy life
- centre stage or onstage in De Hogeweyk is "living life as usual," backstage or behind the scenes is the provision of nursing home care.<sup>57,59</sup>

Staff at De Hogeweyk do not wear uniforms and medical supplies are stored out-of-sight.<sup>56,57</sup> This is intended to minimize medicalization and contribute to the sense of normalcy, rather than to deceive residents.<sup>62</sup>

De Hogeweyk is run by a Dutch government-owned nursing home agency (Vivium Zorggroep) and funded by the national social security system.<sup>59</sup> The dementia village comprises a 1.6 hectare (3.7 acre) site, about half of which is outdoor space.<sup>59,63</sup>

As of 2018, the 169 residents at De Hogeweyk live in 27 townhouses (Jannette Spiering: personal communication, 2019 Aug). The townhouses are designed with seven different Dutch lifestyles in mind.<sup>23,58,59</sup> Lifestyle options include homemakers, trades and crafts people, Dutch upper class, religious, cultural, urban, and Dutch-Indonesian.<sup>23</sup> The most suitable lifestyle choice is made in consultation with the resident and their family.<sup>64</sup>

Residents choose their own daily schedules for meals and activities.<sup>55</sup> Each of the households functions independently; for example, groceries are bought at the village supermarket and meals are prepared together in each home.<sup>34,55</sup> Or, residents may choose to dine at the village café or restaurant, which are also open to the public.<sup>34</sup> The type of food prepared in the households also reflects lifestyle preferences; for example, residents in the Dutch-Indonesian households may eat Indonesian cuisine.<sup>56</sup> Each of the different households has an outside sitting area and garden.<sup>34</sup>

De Hogeweyk is a secured residential care home; the residents cannot leave the village unaccompanied. However, unlike traditional dementia care homes, there are no disguised exits, dead ends, or locked doors that can confuse and frustrate people with dementia (other than the main entrance to the village).<sup>56,65</sup> Design features to accommodate people with dementia are incorporated into all aspects of De Hogeweyk. For example, the elevator senses when people are waiting and runs between the ground and first floors without the need to push buttons.<sup>65</sup> Safe, circular pathways, with outdoor lighting at night, seating areas, water features and gardens encourage the residents to be active and spend time outdoors.<sup>23,56,65</sup> Dr. Habib Chaudhury, a Canadian expert in design for people with dementia, noted that "... Villages can provide a much wider range of movement compared to a typical dementia care unit."<sup>64</sup>

In addition to the lifestyle choices in the households, many different social groups are available. Residents are supported by trained volunteers and staff to participate in their choice of activities.<sup>34</sup>

Regular staff are assigned to each residence, but they do not live there.<sup>23</sup> (A study of a German dementia village noted there were three staff shifts — day shift, afternoon, and night.<sup>23</sup>) All staff, including those working in the restaurant, café, and store, are trained in dementia care.<sup>56</sup>

Some potential issues identified with small-scale, group living have been addressed in the De Hogeweyk dementia village. For example, the low social density in some small group homes could conceivably reduce social interaction.<sup>4</sup> However, in De Hogeweyk households, residents are matched with other people who have similar backgrounds and interests to encourage interactions, and the households are part of the larger village community.<sup>59,66</sup>

There are almost no bedridden residents in De Hogeweyk and only occasionally is a resident bedridden for a long period of time. The residents are elderly and, in addition to severe dementia, have other health issues. About 40% of De Hogeweyk residents are disabled and require regular wheelchairs, and these, as well as specialized wheelchairs, are used to ensure that all residents can be in the living room of their residence, participate, socialize, and go outside (Eloy van Hal, Be the Hogeweyk Care Concept, Weesp, the Netherlands: personal communication, 2019 May 12).

Residents remain at De Hogeweyk until they die. The period of dying is quite short (an average of four days) and their final days are supported by a palliative care team, including geriatricians, that are all employed by De Hogeweyk (Eloy van Hal: personal communication, 2019 May).



## Eden Alternative

The Eden Alternative is a US care model developed in the early 1990s by Dr. Bill Thomas.<sup>67</sup> Eden Alternative uses the slogan, “It can be different.”<sup>67</sup> The model is intended for residential, home, or community care for the elderly, and for those with mental health, cognitive, or developmental challenges, including those with dementia.<sup>25,67</sup> Eden is based on the following ten principles:<sup>25,67,68</sup>

- Institutional care of the elderly using a medical model results in suffering caused by the “three plagues of loneliness, helplessness, and boredom.”
- A community centred on the residents (elders) should be a “Human Habitat” that includes close contact with plants, animals, and children. This engagement makes life meaningful.
- Companionship is an antidote to loneliness, and human and animal companionship must be readily available.
- Rather than an institutional model focused on staff tasks, a community that enables elders to give care (not just to receive it) can relieve helplessness.
- Boredom is alleviated by creating an environment that encourages spontaneous events and interactions.
- Undertaking meaningful activities is essential to health.
- Medical care should be guided by genuine human caring.
- Rather than top-down decision-making, as much as possible decisions should be made by the elders themselves or by their loved ones.
- Creating an elder-centred community is a continuous, unending process.
- “Wise leadership” is needed to guide the fight against the three plagues.<sup>25,67,68</sup>

## The Green House Project

Like the Eden Alternative, the Green House model was developed by Dr. Bill Thomas.<sup>68,69</sup> The first Green House opened in the US in 2003 and, as of 2015, more than 174 Green House homes have been in operation.<sup>22</sup> An adaptation of Green House — Best Life — is intended for people with dementia. The Green House Best Life approach stresses seeing the person with dementia as a whole person rather than as a medical label. The core values of Green House are based on:

- enabling a meaningful life (according to the individual's needs and abilities)
- empowering staff (through dementia care training)
- creating a real home environment.<sup>70</sup>

Each Green House is an independent residence for approximately seven to 12 residents.<sup>71-74</sup> The house may be situated in a residential neighbourhood or among multiple houses placed on a “campus,” but the intent is to avoid creating an institutional complex.<sup>72</sup> Every resident has a private room and bathroom, and these are arranged around a shared central living area with a fireplace, communal dining room, and kitchen.<sup>71,73</sup> The Green House deliberately avoids elements such as nursing stations, medication carts, and public address systems.<sup>72</sup>

Green Houses are run by specially trained, certified nursing assistants called Shahbaz (Shahbazim plural), who provide personal care, as well as housekeeping, meal preparation, laundry, and arranging activities.<sup>71,74</sup> Residents can participate in housekeeping and other activities as they choose, and flexible daily routines (time to get up, meals, etc.) accommodate each resident’s preferences. Shahbazim are supported by clinical teams that include nurses (each nurse typically supports two homes during the day shift, and three homes at night), social workers, occupational therapists, nutritionists, pharmacists, and a medical director.<sup>71,75</sup> The clinical teams visit, but are not based, at the Green House.<sup>22,73</sup>

As in other small-scale residential care models, mealtimes are recognized as important for their nutritional and social aspects, and for their role in quality of life. Meals are jointly prepared in the household by the Shahbazim, residents, and family members.<sup>73</sup>

Although the Green House model does not include a village, the residences are intended to be linked to the local community in various informal ways, led by a volunteer “sage” from the larger community.<sup>73</sup> The individual Green Houses are also intended to be linked to other facilities to minimize the level of administration and bureaucracy involved.<sup>73</sup>

Tabor Village in Abbotsford, British Columbia, is studying how the Green House model of small households would enhance the redevelopment of their complex care residences. Their new complex care centre is planned to accommodate 154 people, including those with advanced dementia (Dan Levitt, Tabor Village, Abbotsford, BC: personal communication, 2019 Jul 8).

## Butterfly Care (Dementia Care Matters)

Developed by Dr. David Sheard in the UK during the 1990s, the Butterfly Care model uses the slogan, “feelings matter most.”<sup>76</sup> The Butterfly Care focus is on staff training to encourage empathy and recognizing the individuality and emotions of the person with dementia.<sup>20,77</sup> The *Feelings Matter Most* series of publications outline the different elements of Butterfly Care.<sup>78,79</sup>

The Butterfly Care model promotes the use of bright, home-like environments. Residents are encouraged to participate in everyday activities and staff focus foremost on the people in their care rather than on assigned tasks.<sup>80</sup> Residents typically live in households of 10 to 12 people at similar stages of dementia.<sup>81,82</sup> Staff do not wear uniforms, and residents and staff interact throughout the day (not just during structured activity periods), eating meals together.<sup>81,82</sup>

Butterfly Care is currently used in more than 100 residential care homes worldwide, including in the UK, Ireland, the US, Australia, and Canada.<sup>77,82-84</sup> In Canada, five Alberta centres have adopted the Butterfly Care model and one new care home that will use the model is being established in Calgary.<sup>77,85</sup> Malton Village in the Region of Peel, in Ontario, adopted the Butterfly Care model in 2017, and five other long-term care facilities in the region plan to adopt the model over the next three years.<sup>77,81</sup>

Staff training for Butterfly Care involves eight days over a four-month period.<sup>81</sup> The staff-to-resident ratios are higher with Butterfly Care, but fewer nursing staff may be needed.<sup>81</sup>

## Green Care Farms

Not to be confused with greenhouses, these farms are based on small-scale, home-like living residences, where residents are encouraged to undertake agricultural activities within their capabilities that are enjoyable and meaningful for them.<sup>86</sup> Initially, the farms were intended as a type of day care, but farms with 24-hour care are now available — particularly in the Netherlands, France, and Norway.<sup>87</sup> The intent is to encourage social interaction and autonomy in a safe care environment. Being outdoors, exposed to daylight, and able to interact with plants and animals, giving care, and participating in activities of everyday farm life are important elements.<sup>86-88</sup>

Green Care Farms and small-scale group residences share the same underlying aim of normalizing life for people with dementia, which may explain why results were similar for Green Care Farm residents.<sup>88</sup> Given the different backgrounds and interests of people with dementia, Green Care Farms may provide an important lifestyle option for some.<sup>88</sup>

## Other Types of Small-Scale, Group Home Residential Care

Several studies have reported on small-scale, group home care residences, but these have not specified following any particular model of care. These types of residences appear to be used most widely in the Netherlands and Scandinavia, but the Green House model in the US is also an example of this type of care.<sup>21,89-91</sup> What constitutes a small-scale, group home is not always clearly defined, but there are common characteristics:<sup>21,89-92</sup>

- typically, six to 16 residents in a household
- staff live in the residence
- households can be stand-alone houses or units within a larger complex
- daily life centres around household tasks and other activities organized by residents, staff, and family
- staff do not wear uniforms and in addition to caregiving they perform non-medical tasks, such as meal preparation, alongside the residents, who participate as much as they are able
- the residence resembles a home, rather than an institution, with private bedrooms and bathrooms, and communal living spaces (kitchen, dining room, living room, laundry), and without long, hospital-like corridors, nursing stations, and medication carts.

## Similarities in Innovative Dementia Care Models

There are many similarities between the newer models of dementia care. Some of the similarities identified in the information reviewed for this bulletin are shown in Table 1.

**Table 1: Elements of Novel Dementia Care Models**

	Dementia Villages (the Hogeweyk Care Concept)	Eden Alternative	Green House	Butterfly Care
Focus on person-centred care	✓	✓	✓	✓
Vision and leadership needed to implement changes	✓	✓	✓	✓
Staff training, team work, and empowerment are needed	✓	✓	✓	✓
Environmental design aspects to support people with dementia	✓	?	✓	✓
Small group homes or household units within larger facilities	✓	✓	✓	✓
Strive to create a non-institutional, familiar, home-like environment	✓	✓	✓	✓
Access to the outdoors	✓	✓	✓	?
Opportunity to participate in meaningful activities	✓	✓	✓	✓
Recognizing the cultural and lifestyle preferences of residents	✓	?	?	?
Autonomy of residents, flexible daily schedules	✓	✓	✓	✓

Note: This table is intended to draw attention to the similarities between different models, but it does not capture all aspects of each model.

## Summary of the Evidence and Additional Information

Improving the quality of life of people with dementia – person-centred care – requires multidimensional changes in residential care philosophy and care delivery. For some interventions, such as creating a more home-like environment with the opportunity to participate in daily activities, the evidence suggests that these are beneficial.<sup>4,93-96</sup> There is also evidence to support the use of specific interventions, such as access to gardens or outdoor space, which can reduce agitation and improve quality of life.<sup>95,97</sup>

People with advanced dementia may not be able to provide self-reports of quality of life, and proxy reports from family and staff caregivers are often used, but these may differ.<sup>98-99</sup> Studies suggest positive impacts on residents’ quality of life and staff satisfaction, but comparisons are difficult because of differences in study populations, terminology, outcome measures, and the introduction of selective changes rather than more comprehensive, holistic models of care.<sup>18</sup>

## Dementia Villages

The literature search for this bulletin identified four published studies of dementia villages in Europe.<sup>23,34,99,100</sup> No published evaluations of the De Hogeweyk village were identified. Further information on dementia villages included in this bulletin is from conference presentations, media reports, and correspondence with the co-founders of De Hogeweyk.

The first study, published in 2013, reported on a research visit to De Hogeweyk and possible lessons for dementia care in the UK.<sup>34</sup> The researchers noted that the village is designed to minimize the disability of residents, supporting them to carry out everyday activities in a safe environment and maximizing their quality of life.<sup>34</sup> In addition to everyday activities, various social groups were offered, and trained volunteers work with staff to help the residents participate.<sup>34</sup>

The other three studies, all published in 2018, describe family and health care providers’ perspectives on “everyday life” for residents of a Danish dementia village,<sup>99</sup> and two ethnographic studies describing one researcher’s impressions of the first German dementia village and health care staff interactions.<sup>23,100</sup>

The Danish study noted that family members and staff in dementia villages may have different views on what constitutes a meaningful day or real-life activity.<sup>99</sup> For some family members, an activity was more of a special event, whereas some staff caregivers noted that, for a dementia village resident, a walk to the dining table might be an activity in and of itself.<sup>99</sup> Other family members in this study described the importance of taking their relative out into the “real” world — even if the services were available within the dementia village — to ensure they still felt part of the outside world and maintained connections to activities they enjoyed earlier in life.<sup>99</sup> But, health care providers had a different perspective on activities beyond the village, noting that it may cause confusion for the resident and impact staff and other residents in the village on their return.<sup>99</sup> Regarding activities and services within the village, some relatives noted that their family members with advanced dementia were not able to take advantage of these services unless a staff or family member could accompany them.<sup>99</sup>

The two papers on the German dementia village found some differences from the Dutch De Hogeweyk, notably that residents in Germany were not matched by cultural backgrounds or lifestyles.<sup>100</sup> The researcher also commented that family expectations may not align with resident autonomy.<sup>23</sup> For example, a family member may expect their loved one to be up and dressed at a certain time each day, whereas the resident may prefer to stay in their pyjamas all day.<sup>23</sup> As a care provider commented, “... some relatives don’t seem to get the concept at all.”<sup>23</sup>

The German study also found that initially staff providing different levels of care (non-clinical, care assistant, and nurses) had similar aims and focuses on the welfare of the residents.<sup>23</sup> Over time, though, relationships between the different providers became “strained,” with a lack of clarity over the responsibilities and scope of work for each provider.<sup>23</sup> In part, this may have been due to leadership changes with the manager and head of care both leaving the organization.<sup>23</sup> Staff at the German dementia village also noted concerns regarding the extra burden and possibly unhygienic effects of being required to wear (and take home to launder) their own clothes rather than having uniforms provided.<sup>23</sup>

A 2018 conference presentation on De Hogeweyk noted that the primary objective is to preserve and improve residents’ quality of life despite the progression of dementia.<sup>66</sup> The presentation summarized findings of a literature review conducted by the organization to identify individual and environmental factors for which there is evidence of a positive impact on quality of life.<sup>66</sup> These factors were mapped to the elements of dementia village care embodied in the De Hogeweyk Care Concept.<sup>66</sup>

Individual characteristics that affect quality of life include self-esteem, spirituality, medications, mental and physical health, and financial security.<sup>66</sup> External factors that affect quality of life depend mainly on the care environment. These factors include the ability to live a meaningful life, enjoy life’s pleasures, have privacy and safety ensured, have social contact and something to do, maintain autonomy, and live in an aesthetically pleasing environment.<sup>66</sup> The conference presentation cites studies of environmental design and small-scale, home-like, group living care facilities that support improved quality of life for people living with dementia. For example:

- social interaction and engagement with caregivers and residents<sup>4,101,102</sup>
- functioning and physical exercise<sup>28,103</sup>
- way-finding or orientation<sup>104</sup>
- reduced agitation and behavioural disturbances.<sup>103</sup>

Other reviews have found that higher staffing levels, home-like, small-scale, group living facilities, and environmental design practices (both indoors and outdoors) increase physical activity levels of residents in long-term care.<sup>105,106</sup>

Information provided by a founder of De Hogeweyk noted that antipsychotic medication use at the residence has decreased from approximately 50% of residents before the dementia village was introduced to approximately 12% in 2019 (Jannette Spiering: personal communication, 2019 Aug).

No information on safety issues in dementia villages was identified. There is a recognized need to balance quality of life and freedom of movement for residents with potentially increased risks (such as for falls).<sup>96</sup> Safety protocols and residential care regulations may deter facilities from introducing enabling activities that could increase risks, such as using wheelchairs to reduce the risk of falls rather than encouraging residents to walk, or using large-scale, institutional food services rather than supporting residents to help caregivers prepare meals in their residence.<sup>86,107</sup>

No studies of clinical care outcomes for residents of dementia villages were identified. In future studies, clinical outcomes, such as pressure ulcers, could be used as a measure of quality of care. Residents who are encouraged to move about freely, as they are at De Hogeweyk, would be expected to have fewer pressure ulcers than residents in traditional long-term care facilities; however, to date, no published studies have confirmed this.

## Eden Alternative

A study of the impact of the Eden Alternative in six Texas residential care facilities found an overall decrease in behavioural issues, pressure ulcers, use of restraints, and a decrease in staff absenteeism, as well as an increase in the residents' levels of movement.<sup>108</sup> However, the results varied between facilities, perhaps reflecting differences in leadership and resident health status.<sup>108</sup>

A two-year quality of life study, also conducted at several Texas care facilities, found no significant improvement in quality of life in Eden Alternative nursing home residents. But it stressed the difficulties inherent in longitudinal studies given the progression of dementia throughout the course of the study and the high rates of morbidity and mortality.<sup>109</sup>

A 2013 systematic review on the impact of person-centred elder care found that the Eden Alternative was the only model that incorporated all elements of person-centred care.<sup>18</sup> Other facilities included in the review had implemented a few changes but not a complete overhaul of care. (Note that this review did not focus on dementia care and no studies of dementia villages were included.) Evidence on the Eden Alternative was based on three studies. One of the studies found that residents' feelings of boredom and helplessness were reduced, while the second study found that levels of depression were reduced.<sup>18</sup> However, the third study noted a higher rate of falls associated with environmental changes in one Eden care home — which may have been because the residents were more ambulatory than those in the control group of residents.<sup>18</sup> Overall, despite noted limitations in the studies, staff reported improved job satisfaction and the ability to meet the needs of individual residents.<sup>18</sup>

## Green House

No studies specifically of the Green House Best Life model for dementia care were found, but several US studies have compared Green House residences to traditional nursing care facilities.<sup>22,71,72,110-113</sup>

Studies of Green House staffing compared with conventional nursing homes found a higher ratio of certified nursing staff to residents in Green Houses; however, total staff time (nursing and non-nursing) was slightly less with Green House care.<sup>71</sup> Green Houses also had fewer administrative and support staff than conventional nursing homes.<sup>111</sup> The Shahbazim nursing assistants engaged in a wider variety of tasks, in more direct care activities, and spent more time with the residents than did nursing assistants in traditional nursing homes.<sup>71</sup>

Some Green House homes did not adopt all the recommended practices; for example, many homes did not give the elders the freedom of when to get up in the morning or when to bathe.<sup>22</sup> In addition, care staff interpreted their “empowerment” differently, and medical care staff involvement also differed between homes.<sup>22</sup>

One US study examined the capital and staffing costs associated with Green House residences.<sup>111</sup> Capital costs were higher with a Green House residence, but the per resident square footage of space was almost double (650 square feet per resident in Green Houses versus 350 square feet per resident for a new build, traditional nursing home.)<sup>111</sup> In the US for-profit model, some of the additional costs for Green House care could be offset by higher occupancy rates (i.e., because Green House care is sought after, their occupancy rates are higher), and by extra fees charged for private rooms and bathrooms.<sup>111</sup>

A study of a Green House development in Mississippi noted that building costs were less than those associated with a traditional nursing home building. Where possible, residential building materials were used. Together with additional safety features and assistive technologies, such as lifts, residents and their families were able to bring their own bedroom furnishings.<sup>73</sup> The authors noted that costs may be redistributed, rather than increased, in the Green House model. The Green House Project in the US has developed financial tools for implementing this model.<sup>73</sup>

A US study that assessed Medicare costs for residents of Green Houses compared with those for residents in traditional nursing homes found that Green House care may reduce hospitalizations and hospice care.<sup>112</sup> Although the results were not statistically significant because of the small study population, the authors concluded that substantial cost-savings may be achieved if this type of care was implemented more widely.<sup>112</sup>

Studies of Green House residences found improvements (i.e., reductions) in three of eight Minimum Data Set (MDS) quality indicators (bedridden, catheter use, and low-risk pressure ulcers).<sup>22,113</sup> Improvements in other MDS quality indicators (such as incontinence or restraint use) were not seen, but neither was a decline in quality for any of these measures.<sup>22</sup> Hospital readmissions were also lower in Green House homes.<sup>113</sup> The specific aspects of the Green House model that contributed to the improvements could not be determined, but the researchers speculated they may be related to the smaller scale of care, the consistency of regular staff caring for the same residents, and the presence of the central, communal area of the home that allowed staff more frequent interactions with residents.<sup>22</sup> The Mississippi Green House study also found that many residents were able

to stop using their wheelchairs, as the shorter distances in the household unit were easier for them to navigate.<sup>73</sup>

## Butterfly Care

Other than a report on three Alberta residences that adopted Butterfly Care,<sup>85</sup> no further independent evidence on Butterfly Care was identified. Anecdotal reports and the Alberta report noted improvements in residents' social engagement, with less unintended weight loss, fewer falls, reduced behavioural symptoms, a lowered use of antipsychotic drugs, and less staff absenteeism, together with improved staff and family satisfaction with the care provided.<sup>81,85</sup> In Ontario, the Region of Peel plans to collaborate with the Sheridan College Centre for Elder Research to assess their Butterfly Care homes.<sup>77</sup>

## Green Care Farms

Studies of Green Care Farms reported that residents were more physically active, had a wider range of activities to engage in, spent more time outdoors, and interacted more socially compared with residents in traditional nursing homes and those in other small-scale group homes that may lack the facilities to encourage activity.<sup>24,87</sup> One study compared quality of care and quality of life of residents of Green Care Farms, small-scale group homes, and traditional nursing homes.<sup>88</sup> Although quality of care was comparable across the three settings, quality of life for residents of Green Care Farms was higher than for residents of traditional nursing homes.<sup>88</sup> Residents of the Green Care Farms also scored higher in three particular aspects of quality of life: engagement in activities, social interactions, and positive mood.<sup>88</sup>

## Other Reviews and Studies of Small-Scale, Group Home Residential Care

A 2010 Dutch study that compared small-scale group homes with conventional nursing home care for people with moderate-to-severe dementia found no differences in residents' overall quality of life or behavioural symptoms.<sup>89</sup> The main differences were that nursing staff in group homes had slightly higher job satisfaction, and family caregivers reported less burden and more satisfaction with group home care.<sup>89</sup>

A 2012 study in Japan compared quality of life in people with dementia in small-scale group homes to residents in conventional nursing homes.<sup>114</sup> The group home units housed up to 24 residents (larger than most small-scale group care facilities elsewhere), with a communal area and the same regular staff. Staff-to-resident ratios were higher in the group homes than in conventional nursing homes. Residents' quality of life (assessed by staff caregivers and based on interaction with the environment, self-expression, and negative behaviours) was also rated as higher in the group home residents.<sup>114</sup>

## *Interventions to manage behavioural symptoms of dementia and reduce use of restraints and antipsychotic medications*

People with dementia experience anxiety and restlessness, but some of this arises from their environment. A more normal, home-like environment supports the resident and reduces their feeling of being "trapped."<sup>64,94</sup> A 2017 systematic review of person-centred care interventions for people with dementia (not specifically dementia villages) concluded that these can reduce behavioural symptoms of dementia and improve quality of life.<sup>115</sup>

A 2013 systematic review funded by the US Agency for Healthcare Research and Quality found limited, low-to-moderate-quality evidence to support some dementia care interventions.<sup>3</sup> Interventions that reduced agitation included person-centred approaches to bathing and showering, and pleasant sensory stimulation, such as music, hand massage, and offering food.<sup>3</sup>

A recent *Lancet* review suggested that the use of restraints is one measurable outcome of dementia care.<sup>32</sup> The review noted that, "Good evidence is available that person-centred care reduces use of restraint in care homes and hospitals and should be implemented."<sup>32</sup> And a study that compared restraint use in small group homes to traditional nursing homes in the Netherlands found that restraints were used much less for residents of small group homes (10% of residents in group homes compared with 50% of residents in nursing homes).<sup>116</sup>

A small 2019 Dutch study found no reduction in psychotropic drug use in people with dementia who moved from a larger special care unit to a small-scale group living unit during the first six months of follow-up<sup>45</sup> — although an earlier study by this same research group found residents who moved into a small-scale group living residence had reduced levels of anxiety, perhaps because of the more home-like, familiar environment.<sup>117</sup>

A 2014 study of small-scale, home-like residential care in the Netherlands found more social engagement, and significantly less use of physical restraints and psychotropic drugs, in the small-scale group homes compared with conventional nursing homes.<sup>118</sup>

A 2014 systematic review of interventions to reduce the use of antipsychotic drugs for people with dementia in residential care found that, in the short-term, the interventions were effective in curbing the use of these drugs.<sup>119</sup> However, there were two main issues: first, difficulties in changing residential care practices, in part due to insufficient staffing and staff training; second, an overall lack of good-quality studies in long-term care settings.<sup>119</sup> The authors concluded that, to sustain changes, "the culture

and nature of care settings and the availability and feasibility of nondrug alternatives needs to be addressed.<sup>119</sup>

## ***Social interaction and engagement in activities***

Social interaction, positive relationships with others, and participating in meaningful activities are associated with improved quality of life and reduced behavioural issues in people with dementia, and with improved family satisfaction with the quality of care.<sup>44,120</sup> Studies of residents living with dementia in small-scale, home-like residential care found increased levels of social interaction and participation in activities compared with residents in traditional nursing homes.<sup>116,118 28,120</sup>

Authors of one study reasoned that this may be because the small-scale group homes provide more opportunities for small activities of daily living, such as watering plants or domestic tasks, and that staff in group homes may be more aware of the activity levels of individual residents in their care and able to encourage their involvement.<sup>28</sup> The study also found that people with more advanced dementia, particularly older residents and men, were less involved in activities overall and that extra attention is needed to determine their abilities and preferences for activities.<sup>28</sup>

Key predictors of increased involvement in activities include staff education and training, reduced staff workload, and higher staff-to-resident ratios, such as is found in small-scale, group home residential care.<sup>120</sup>

## **Ethical Issues**

A 2009 Nuffield Council on Bioethics (UK) report on ethical issues in dementia care provides a framework for understanding the ethical implications of interventions in this field.<sup>121</sup> The framework takes a case-based approach to decision-making (i.e., assessing the facts and applying appropriate ethical values). While acknowledging the harm dementia causes to the individual, the framework also recognizes that, given appropriate supportive care, a person with dementia can have a good quality of life. Foremost, the framework takes a relational approach to the interests of the person with dementia — in particular, it promotes their autonomy and asserts that well-being requires enabling self-expression and fostering relationships with others. It also recognizes the interests of their caregivers.

Social solidarity principles stress our mutual interdependence and the need (both familial and societal) to support people with dementia. Respect for the personhood of the individual with dementia — regardless of their cognitive or physical impairment — is a central premise of the framework.<sup>121</sup>

## **Deception**

The concept of deception is an important ethical issue in dementia care. Deception is a broad concept that encompasses withholding information, in addition to “truth-telling.”<sup>122</sup> Although deception may be acceptable in some circumstances and for some individuals (e.g., when in the best interest of the person with dementia), deception may be considered by some to be contrary to respecting the personhood of the person with dementia.<sup>123</sup> Recent descriptions of the ethics of deception in dementia care distinguish three options:

- reality orientation, where the truth of a situation is repeated, regardless of whether this causes distress to the person with dementia
- therapeutic lying, where a lie is used to protect the person with dementia
- validation therapy, where a confirmatory statement is used to empathize and recognize the feelings of the person with dementia, without insisting on stating facts.<sup>122</sup>

One criticism of dementia villages is that they are deceptive or “make-believe,” presenting a “fake normality,” “feigned reality,” or “manufactured utopia.”<sup>64,100,124,125</sup> But, as a proponent of dementia villages noted, “There’s a difference between a Potemkin village where everything is just a façade [and] a place like Hogeweyk.”<sup>126</sup> Unlike artifices, such as fake bus stops (intended to reduce agitation and wandering), the dementia village is carefully planned but the village elements are real.<sup>60,127,128</sup>

A 2013 UK description of a visit to De Hogeweyk noted that there was no evidence of “reminiscence materials” and the village store stocked the same items found in any modern supermarket.<sup>34</sup>

Rather than expecting people with dementia to adapt to their surroundings, the physical and social environment is adapted to meet their needs. This was seen as “enabling” and the researchers commented, anecdotally, that De Hogeweyk residents with advanced dementia were functioning at levels beyond what they would expect to see in the UK.<sup>34</sup> However, other news reports note that De Hogeweyk also accepts and integrates distinctive dementia behaviours, such as pacing and wandering: the behaviours do not disappear but are treated as legitimate.<sup>60</sup>

## **Stigma and Segregation**

There is a perception that dementia villages may stigmatize people with dementia, particularly with the use of derogatory terms used in the media, such as “dementiaville.”<sup>129</sup> Another viewpoint is that the residents have been segregated — “deported or marginalized” into a “ghetto” or a “zoo.”<sup>100,124,130</sup> The Nuffield

Council on Bioethics framework notes the need to normalize dementia in our society so that people living with dementia are accepted, included, and able to participate in their usual activities.<sup>121</sup>

The continuum of dementia care can involve both integration in the community, where possible, and specific services to meet needs, where necessary (appropriate therapeutic care). The Swiss Alzheimer association noted that different types of care are needed at different stages of dementia, and the dementia village is a “good solution for people in advanced stages of the disease.”<sup>124</sup> Moreover, the founders of De Hogeweyk have highlighted that, could they redesign their village, they would integrate it more closely with the outside community. This is what is planned for the Korongee village in Australia.<sup>131</sup> Currently, at De Hogeweyk, nearby community residents come into the village to use the coffee shop, restaurant, and other amenities that are open to the public.<sup>60</sup>

Others involved in planning for dementia villages in Norway point out that it may not be easy for people with dementia in residential care to use facilities in the local community, but that the local community may be attracted to visit the dementia village through coffee shops, pubs, restaurants, and other amenities it can offer.<sup>130</sup> They note that “... at all events it must surely be better for residents to be able to move about freely in a ‘village’ environment, rather than wandering around the corridors in a nursing home.... Many Norwegian care homes are built with an overriding focus on providing medical care, while provision for the benefits and opportunities gained by being able to move around freely outside the buildings has received very little attention....”<sup>130</sup>

## Cultural Differences

One important principle in establishing De Hogeweyk was to recognize and accommodate cultural and lifestyle differences between residents based on their background and interests, on the premise that people with similar backgrounds will be more likely to socialize together. The Danish dementia village used cultural themes and Danish rather than Dutch values to accommodate their residents.<sup>99</sup> However, in the German dementia village, segregation by background was not considered acceptable and the residents in the four houses were not matched to those with similar backgrounds.<sup>100</sup> Experience with the Butterfly Care model in Alberta noted that matching residents by cultural backgrounds may be difficult to achieve in Canada, given the shortage of long-term care facilities.<sup>85</sup> However, in some parts of Canada, denominational care homes and care homes for residents with similar cultural backgrounds are available.

The national dementia strategy for Canada recognizes the importance of equitable access to culturally safe and appropriate dementia care, and recommends that Indigenous peoples’ organizations and communities be involved in developing dementia care programs for First Nations, Métis, and Inuit people.<sup>14</sup> Recent Canadian reviews have highlighted that residential dementia care outside of the community may not be acceptable to Indigenous people.<sup>132,133</sup> Other groups in Canada, such as ethnic minority populations, LGBTQ2 (lesbian, gay, bisexual, transgender, queer and Two Spirit), younger people with early onset dementia, and those in rural and remote communities may also experience barriers to accessing culturally appropriate dementia care.<sup>14,15,33</sup>

## Costs

### Canada

A 2018 news report on plans for a dementia village in Vancouver, run by Providence Health Care seniors’ care and palliative services, estimated the cost of constructing the village as between \$200 million to \$300 million.<sup>134</sup>

During the consultations for this bulletin, Duncan McKercher provided information on the costs of the Crossmount dementia village near Saskatoon that is planned as part of a larger retirement village. The total budget for construction of the Crossmount dementia village is \$55 million. Once it is fully operational, the Crossmount Village will accommodate 184 people with severe dementia, with a staff of 160. Crossmount is privately financed and owned, and the anticipated cost per resident, per month, is \$9,350 (Duncan McKercher, Kenmore Land Corporation, Crossmount, SK: personal communication, 2019 Mar 28).

A 2019 news report cites costs of from \$7,300 to \$8,300 per month, per resident, for the private dementia village that opened in Langley, British Columbia in the summer of 2019.<sup>128</sup>

### International

A 2018 news report on the construction of an Australian dementia village, Korongee, in Tasmania cited a cost of AUS \$25 million.<sup>131</sup> This village will be about half the size of De Hogeweyk, with 12 houses, each with eight bedrooms. The Korongee village is being jointly funded by private, non-profit, and government financing, and is expected to be no more expensive than other residential care in Australia.<sup>131</sup>

In a 2017 interview, a founder of De Hogeweyk observed that the Dutch dementia village cost no more than conventional, publicly funded nursing homes in the Netherlands.<sup>57</sup> A 2012 news report cited a total cost of €19.3million to build De Hogeweyk, of which



the Dutch government funded €17.8 million, with the remainder from charitable donations and sponsorship.<sup>135</sup> Another news source noted that De Hogeweyk generates revenue through opening its facilities — such as the restaurant, café, and theatre — to the local community.<sup>136</sup>

In 2019, the cost per resident at De Hogeweyk was €7,200 per month, which is the same government rate provided for all non-profit nursing homes in the Netherlands through the *Long-term Care Act* (Jannette Spiering: personal communication, 2019 Aug).<sup>137</sup>

## Implementation Considerations

### Long-Term Care Beds

The 2019 Canadian Academy of Health Sciences assessment on dementia care concluded that the quality and availability of long-term care facilities may be inadequate.<sup>12</sup> A capacity planning study for dementia care in Ontario estimated that, by the year 2020, 39,789 people with dementia in Ontario will be awaiting placement in long-term care (an increase of 80% over 2010 numbers).<sup>138</sup>

It has been reported that approximately 15% of patients in Canadian acute care hospitals are waiting for long-term care.<sup>10,139</sup> These patients are sometimes designated as alternate level of care, or ALC, meaning their care needs could be met in a setting other than an acute care hospital.<sup>139</sup> Operating costs for long-term care beds are considerably lower than costs for acute care hospital beds — approximately \$74,200 per year for a long-term care bed compared to \$495,900 for a hospital bed (in 2017 dollars).<sup>46</sup>

A 2017 Conference Board of Canada report estimated that, to accommodate the aging baby boom demographic, an additional 199,000 long-term care beds will be needed by the year 2035 — approximately double the number currently available.<sup>46</sup> Meeting this need will require approximately \$64 billion in capital costs, while the operating costs (from 2018 to 2035) are projected to be approximately \$130 billion.<sup>46</sup> The Conference Board report included an economic cost-benefit analysis that found that the likely economic spinoff from adding this bed capacity could exceed the anticipated cost.<sup>46</sup>

A recent study of length-of-stay in nursing homes in Alberta and Manitoba from 2008 to 2015 found that residents in some jurisdictions were entering residential care with more complex care needs than in the past, perhaps due to aging-in-place strategies and community care services that help to avoid or delay the need for long-term care.<sup>140</sup> Although on average, resident

length-of-stay had decreased to about 1.5 years, their care needs were greater. Meeting these more complex needs may require changes to long-term care funding to address care staff workloads and ensure quality of care.<sup>140</sup>

## Staffing, Job Satisfaction, and Training

### Staffing levels

In 2018, there were 169 residents at De Hogeweyk, living in 27 townhouses (Jannette Spiering: personal communication, 2019 Aug). A 2014 conference presentation noted that De Hogeweyk had 291 employees (167 full-time employees, including therapists, nurses, doctors) and 140 to 160 volunteers.<sup>59,65</sup>

The Danish dementia village study found that, for residents with advanced dementia, additional staff and volunteers are needed to help residents participate in activities and use the services in the village.<sup>99</sup> However, staffing may be reduced in some areas and increased in others. For example, in a 2017 interview, Eloy van Hal explained that a care residence of De Hogeweyk's size would typically need three physiotherapists, whereas at De Hogeweyk residents help with laundry, grocery shopping, and other household tasks and are more physically active. As a result, only one physiotherapist is needed.<sup>57</sup>

A 2017 study that assessed changes to a more person-centred care model (not a dementia village) in one UK care residence noted that the number of professional nursing staff needed was reduced, but that more support workers were hired to provide care.<sup>141</sup> A review of the Butterfly Care model experience in three Alberta residential care homes also noted a need for additional staff — particularly health care and recreation aides — after the model was implemented.<sup>85</sup>

Canadian researchers report that, although the complexity of residents' health needs has increased, long-term care funding has not been allocated accordingly, and that Canada lacks national standards for minimum staffing requirements.<sup>5,8,142</sup> A 2019 report on models of long-term care in Toronto stressed that a clear message from their consultations was that staffing levels in care homes must be increased to maintain and improve quality of care.<sup>20</sup> In addition to higher staffing levels, having consistency of staff (i.e., the same staff caring for the same residents) is recognized as beneficial.<sup>107</sup>

### Staff job satisfaction

A comparison of nursing staff in small-scale group living homes and conventional nursing homes in the Netherlands (not De Hogeweyk) found those working in small-scale group living homes reported greater job satisfaction from lower demands,

having greater control, and having more social support from colleagues.<sup>143</sup>

Researchers have noted that staff burnout affects both staff health and the quality of care provided to residents.<sup>5</sup> Consequently, any improvements to the working environment, including higher levels of staff training, will also improve the quality of care.<sup>5</sup>

## Training

The need for staff education and training is key in achieving the necessary culture change to provide truly person-centred dementia care. Adopting a new care model may require staff to develop different skill sets (e.g., social and communication skills) to complement their clinical expertise.<sup>21</sup>

Staff empowerment also requires training and clarity to enable staff to practice confidently within their scope of practice.<sup>22,73</sup> The report on the German dementia village noted that it was difficult for staff to maintain more collaborative ways of providing care and over time they tended to revert back to more hierarchical models of care.<sup>23</sup> An evaluation of the Butterfly Model in Alberta also noted the need for staff training, especially in terms of team building.<sup>85</sup>

A recent Canadian review of interventions to reduce the behavioural and psychological aspects of dementia in long-term care found moderate-quality evidence to support benefits from staff training, such as specific training in person-centred dementia care.<sup>144</sup>

## Implementing Change in Dementia Care

The literature reviewed for this bulletin identified the following elements as necessary for improving dementia care:

- a focus on person-centred care and the individual resident's psychosocial well-being rather than only providing medical or physical care<sup>86</sup>
- a willingness of managers or leadership to introduce changes<sup>86</sup>
- involving staff in the "processes of change"<sup>86</sup>
- providing staff with education and training (particularly in aspects of person-centred care for people with dementia), problem-solving, decision-making, and team work<sup>22,86,115</sup>
- balancing risk, safety, and freedom for the individual with dementia — performing "risk-benefit assessments" that consider the individual's well-being rather than just risk assessments<sup>121</sup>

- a need for changes to government funding, and financial support or incentives to facilitate new models of care<sup>21,22</sup>
- attitudes — it is not just the environment that needs to be changed, but the "attitudes" of the people involved. A vision that is shared by all levels of staff, and a "can do" rather than "cannot do" attitude is needed.<sup>67</sup>

Researchers involved in planning the Norwegian dementia village projects noted that the following issues need to be considered:<sup>130</sup>

- adequate service provision
- how to recruit volunteers
- how to meet the needs of people with dementia throughout the stages of dementia
- if and how non-residents will use the facilities of the village
- whether the village concept is in keeping with the concept of inclusivity.<sup>130</sup>

## Leadership

Vision and strong leadership is recognized as essential in making changes to residential care.<sup>32,79,141</sup> Leadership is also needed to ensure sustained changes, promote values for care, establish quality standards and procedures, and to support staff training and transitioning to a collaborative, team-based approach to care.<sup>32,141</sup> Conversely, resistance from leadership is the most often cited barrier to changing nursing home culture (followed by concerns about possible costs and regulatory compliance).<sup>18</sup>

## Dementia Strategies in Canada

### Provincial Strategies

Nearly all provinces have dementia strategies in place or in progress, and several provinces — including Alberta, Ontario, and British Columbia — have recently updated earlier dementia strategies.<sup>12</sup> In general, provincial dementia strategies have focused on five key aspects to address the rising incidence and prevalence of dementia, as follows.

- **Lifestyle and prevention:** Recognizing the influence of lifestyle factors such as diet, physical activity, and social activity on reducing dementia risk, many dementia strategies include a focus on these and other modifiable risk factors.
- **Dementia-friendly or age-friendly communities:** The dementia-friendly communities movement aims to create communities in which individuals with dementia are safe and supported to fully participate, including in accessing community services and having the ability to travel safely within the community.<sup>10</sup> Creating dementia-friendly communities involves addressing public stigma

and misconceptions about dementia, as well as investing in improved accessibility. Initiatives to support dementia-friendly communities might include education for first responders and other public servants (e.g., bus drivers) on what dementia is and how to interact with people with dementia, and on enhanced signage and way-finding in public spaces.

- **Funding for research:** Most provincial dementia strategies include a commitment to fund both basic and applied dementia research through provincial granting agencies.
- **Access to diagnosis and early clinical management:** Obtaining a diagnosis of dementia allows individuals and families time to plan, and to receive adequate care and support. However, dementia is difficult to diagnose definitively and primary care providers may not have the training or experience to provide early diagnosis. Many dementia strategies focus on this existing diagnostic and early clinical management gap.
- **Continuing care for individuals with dementia:** Dementia strategies generally have focused on improving care for individuals with dementia, as well as enhancing caregiver supports across the full continuum of care, including community supports, day programs, home care, assisted living, and residential long-term care for those who can no longer live safely at home. Strategies also tend to focus on having a workforce that is adequately trained and supported to address the unique needs of individuals with dementia.

## Federal Strategies

In June of 2017, the Parliament of Canada passed the *National Strategy for Alzheimer's Disease and Other Dementias Act* committing to the development of a national dementia strategy.<sup>145</sup> In June of 2019, the Public Health Agency of Canada released the national dementia strategy.<sup>14</sup> One of the priority areas it identifies is the need to improve the quality of life for people living with dementia and their caregivers — in fact, improving quality of life is emphasized in the vision, principles, and national objectives of the strategy.<sup>14</sup> In particular, the strategy calls for evidence on person-centred, “effective innovative and alternative care models that support quality of life...” and for “innovations and strategies that enhance integrated dementia care, focused on the safety,

quality of care, and quality of life of people living with dementia in long-term care.” The strategy also noted that a skilled workforce providing “evidence-informed care” will be key to achieving improvements in quality of life.<sup>14</sup>

The strategy was based, in part, on the work of the Ministerial Advisory Board on Dementia and the National Dementia Conference to establish priorities for the development of the national dementia strategy.<sup>146</sup> Through this conference, potential federal roles in supporting residential care for those with dementia were identified, including:

- investing in improving and/or replacing aging long-term care facilities and homes across the country that were not built to support people living with dementia
- using federal levers to build the needed infrastructure to support the spread and scale-up of promising practices in integrated dementia care
- supporting the establishment of evidence-based dementia care guidelines.

## Uptake of Dementia Villages

Dementia villages modelled after De Hogeweyk have been established in several countries, including Denmark (Bryghuset — Svendborg Dementia Town, established in 2015),<sup>99</sup> Switzerland (Wiedlisbach, opened in 2017),<sup>147</sup> Ireland,<sup>148</sup> two villages in Germany,<sup>64,100</sup> and one in France (expected to open in 2019).<sup>148</sup> Plans for a French dementia village include a research centre that will provide opportunities for researchers to evaluate this model of care. Ten other Danish municipalities have plans for dementia villages<sup>62</sup> and Scotland, Japan, Norway, and Italy are also planning villages.<sup>34,126,130,149</sup> New Zealand's CARE Village, modelled after De Hogeweyk, opened in Rotorua, in 2017.<sup>150</sup> Australia has the microtown NewDirection Care dementia village, in Bellmere, Queensland (Jannette Spiering: personal communication, 2019 Aug). Construction of the second Australian dementia village Korongee, in Tasmania, is underway.<sup>131</sup>

## Dementia Villages in Canada

Several dementia village facilities are planned for or are currently under construction in Canada (see Table 2).

**Table 2: Canadian Residential Care Modelled After De Hogeweyk**

Province/ Territory	City	Residence	Public/ Private	Year Operational / (Under Construction)	Number of Residents
British Columbia <sup>63,128,134,151-153</sup>	Comox	The Views at St. Joseph's, Providence Health Care	Public	(2020)	150 (126 publicly funded beds)
	Langley	The Village Langley	Private	2019	76
	Vancouver	St. Vincent's Hospital, Providence Health Care	Public	(Info. not available; a preliminary pilot project funded by private donation of \$3.3 million will have two households with 12 residents in each)	300
Saskatchewan	Saskatoon	Crossmount Village	Private	(Construction anticipated to begin in the summer of 2019)	184

Note that the term dementia village is often applied incorrectly – for example, to facilities that offer reminiscence therapy with facades to invoke memories of earlier days.<sup>128,154,155</sup> Other facilities report being “inspired” by De Hogeweyk, but they have not incorporated all aspects of the Dutch dementia village.<sup>58,156</sup> For example, The Village Langley is situated on a five-acre, suburban site, with six residences each housing 12 to 13 people – a larger group than the six to seven people in De Hogeweyk residences.<sup>128,157,158</sup> Unlike De Hogeweyk, the Langley residents will not be matched by lifestyle or shared interests, although each house will have a distinct theme.<sup>128</sup> The Village Langley will include amenities such as a grocery store, barber shop, beauty salon, pub, and coffee shop.<sup>153</sup> It will accommodate up to 76 residents, with a contingent staff of 72 and further support from nurses and other trained “facilitators.”<sup>128</sup> The residents will wear smart bracelets to indicate their location and issue an alert if they fall.<sup>125</sup> Information on The Village Langley website indicates that the village has been influenced by both the De Hogeweyk and Green House models.<sup>159</sup>

Eloy van Hal explained that few facilities worldwide have adopted all of the critical elements of the De Hogeweyk Care Concept. Elements that may often be missing are the involvement of residents in household activities, matching lifestyles, group size of the residences, the outside living environment, and access to life's pleasures both inside and outside (Eloy van Hal: personal communication, 2019 Feb).

In Canada, only the Crossmount Village in Saskatchewan has worked directly with the De Hogeweyk Care Concept to develop its dementia village. The Crossmount Village located

just outside the city limits of Saskatoon is a privately funded and operated seniors' community that will be home to a total of 1,200 seniors, including residences for 184 people with severe dementia. The Crossmount Village is intended to provide “de-institutionalized” living across a continuum of care needs, from independent living to supportive care, to dementia care for residents who need it. The Crossmount community is situated on 400 acres of pasture land and housing will be designed to resemble traditional housing common in Prairie farm communities, unlike the row houses and walk-ups common in the Netherlands. The village will include a medical services building, restaurant, coffee shop, gym, hairdressers, and other amenities for the residents, as well as a daycare, cidery, and events hall for the public. The residents will be matched by common interests and backgrounds, such as farming or academia. The dementia village group homes will each house six residents, with shared common living areas, and a private bedroom and bathroom for each resident. Crossmount will also include apartments for couples to stay together. Construction for the Crossmount dementia village is expected to begin in the summer of 2019 and may take from 24 to 30 months to complete (Duncan McKercher, Kenmore Land Corporation, Saskatoon, SK: personal communication, 2019 Mar 28).

## Policy Considerations

### Who Pays?

In our review, not much objective information was identified on either capital or operational costs associated with dementia villages. Media sources report that the De Hogeweyk village costs no more to operate than standard long-term care facilities

elsewhere in the Netherlands.<sup>57</sup> The Hogeweyk Care Concept confirmed that De Hogeweyk receives €7,200 (about \$10,700) per resident per month— the same government funding provided to other nursing homes in the Netherlands in 2019. This covers care, housing, food, medical supplies, and recreation (Jannette Spiering: personal communication, 2019 Aug).

Limited information available on staffing in other European dementia villages<sup>34,99</sup> suggests that the staff-to-resident ratio is higher than that in current Canadian long-term care. Even though the staff-to-resident ratio is an identified issue in Canadian long-term care facilities, with much attention focused on increasing staffing, there would still likely be an incremental operating cost increase for Canadian dementia villages adopting the De Hogeweyk model when compared with standard long-term care facilities providing care for those with dementia. Additional capital costs could be expected in constructing community spaces like grocery stores, cinemas, or cafes that are not part of existing guidelines for new residential care facilities.

The potential for incremental capital and operating costs associated with the dementia village model is a consideration for policy-makers as they weigh how to include dementia villages in the continuum of continuing care for older adults. This issue is further complicated by the mix of public, private not-for-profit, and private for-profit long-term care facilities across most Canadian jurisdictions. To date, some dementia villages planned or under construction in Canada, including The Village Langley in Langley British Columbia and Crossmount Village in Saskatchewan are being built by private developers. In the case of The Village Langley, no publicly subsidized spaces were available when the village opened — meaning that residents and families will be responsible for paying the full monthly rate of \$7,300 to \$8,300, depending on the level of care needed.<sup>157</sup> Future dementia villages in Vancouver and Comox, however, are being planned by Providence Health with the involvement of regional health authorities and will have spaces for residents receiving a public subsidy.

Given the public interest in dementia villages as a care model, it seems likely that the private sector will continue to respond to this demand. Public sector funders of long-term care should consider how and if they wish to integrate dementia villages into the continuum of elder care, and whether this model can be adopted for publicly owned and operated facilities.

## Equity

Care at De Hogeweyk is covered by the Dutch social insurance system. The Netherlands has a social insurance model for residential long-term care and provides a much higher level of

public funding than in Canada, and the monthly per diem includes care, housing cost, food, medical supplies, and recreation (30 minutes per week, per resident). In the Canadian context, public funding and subsidy is available for residential care facilities that provide 24-hour care for residents with complex care needs, whether as a result of physical health conditions, dementia, or brain injury.<sup>6</sup> However, Canada also has private retirement homes and assisted living facilities that are not publicly subsidized, where monthly accommodation costs are considerably higher than in publicly funded long-term care facilities. These facilities generally are best suited for residents who may require some support in their daily lives, but who do not require 24-hour care or supervision. However, given that at least some of the planned Canadian dementia villages plan to operate outside of the public system, questions remain about how these facilities will be regulated.

Questions also remain about affordability, particularly given the initial monthly rates of \$7,300 to \$8,300 at The Village Langley. Although this may be reflective of the high cost of providing individualized dementia care, this cost is likely prohibitively expensive for many individuals and families who may benefit from the unique care environment provided by a dementia village. The current “two-tiered” system creates the risk that access to dementia villages will be based on one’s ability to pay rather than need. There may also be geographic equity issues if the development of dementia villages is predominantly driven by economic considerations rather than population need.

## What Determines Care Quality?

Media coverage of De Hogeweyk has captivated the public, at least in part because it presents an alternate vision of what life for individuals with dementia can look like in a supportive environment. This review identified a number of elder care models that are currently in practice and present a similar vision of creating a home and community-like environment, prioritizing meaningful activity, and encouraging resident autonomy and choice.

A seminal framework for measuring quality in health care, the Donabedian framework, posits that both the factors that affect the context in which care is delivered, and the processes by which care is delivered, influence outcomes.<sup>160</sup> In the context of dementia villages, the unique physical environment is only one structural factor; others include staff-to-resident ratio, staff mix (i.e., registered nurses to practical nurses, to care aides), and the acuity and care needs of residents living in the residence. Processes include the procedures for how care is provided within the residence and could include daily processes including routines around waking, bed, and meal times, medication

administration procedures, and regularity of visits with allied health professionals such as physiotherapists and occupational therapists.

Applying a systems-thinking lens such as the one provided by the Donabedian framework, one can conclude that building a facility based on the De Hogeweyk “blueprint” will not necessarily mean that the outcomes will be exactly the same. This message is consistent with what the founders of De Hogeweyk have said about piecemeal adoption of their care model being inadequate. Policy-makers considering regulating or adopting the dementia village model should consider not only the physical environment, but also the other structural and process factors required to deliver high-quality care in the Canadian context.

## The Future of Dementia Care

Dementia villages have captured significant media and public attention, perhaps because this concept challenges popular perceptions about life with dementia and the kinds of care people living with advanced dementia need. The De Hogeweyk concept is grounded in the belief that, with proper supportive care and within a controlled environment, individuals in relatively advanced stages of dementia can experience a good quality of life and meaningfully participate in their communities.<sup>59</sup> This more person-centred model is in contrast to the traditional model of long-term care facilities that are often seen as institutional, impersonal, and risk-averse.

Conceptually, dementia villages are highly aligned with existing dementia strategies at the provincial and national levels in Canada. However, given the broad focus of dementia strategies, little attention is paid to the policy specifics of the funding and delivery of residential long-term care in these documents. It is widely recognized that existing long-term care bed supply is inadequate to meet the needs of an aging population and that older facilities lack “dementia-friendly” design elements. Still, dementia strategies tend to focus more on the demand side of this equation and assume to some degree that robust community supports for aging in place can delay or prevent the need for residential long-term care.

Assumptions about the future demand for long-term care beds in Canada, including for specialized dementia care, are based on a status quo understanding of the resources available for elder care and how and why individuals come to require 24-hour care. However, much emphasis is currently being placed on creating age- and dementia-friendly communities, supporting unpaid family carers, strengthening home and community care, and providing respite care options for older adults. While there

are likely to be individuals with advanced dementia for whom specialized, 24-hour care is the best option, even in a world with strong and equitable access to home and community-based supports these supports could considerably reduce demand for residential care. Planning for future long-term care capacity, including dementia villages, should include a realistic assessment of the future supply of services that may prevent or delay the need for residential care. However, such planning should also consider the potential implications of increased reliance on community-based dementia care for unpaid carers who may be expected to take on additional care responsibilities. The bulk of unpaid care tends to fall to women, and this has important implications for labour force participation.<sup>161,162</sup> Nearly half of unpaid carers for older adults with dementia exhibit symptoms of caregiver distress, which is almost double the rate for unpaid carers for older adults who do not have dementia.<sup>1</sup>

During our consultations with Canadian experts, we heard that, whether because of long waiting lists for long-term care beds or because of enhanced home and community supports, individuals with dementia tend to enter long-term care later in the disease trajectory and have shorter overall lengths of stay than in previous years. Planning for new long-term care capacity, which will include new models of dementia care, should account for new assumptions about lengths of stay, level of care required, and available community supports that can potentially delay long-term care admissions.

If dementia villages based on the Hogeweyk Care Concept were to be implemented at scale in Canada, a number of policy changes would need to be considered. Capital funding formulas and design guidelines for long-term care facilities would likely need updating to ensure that design elements currently viewed as non-essential could be integrated into building design. Further, higher levels of public operating funding would likely be needed to support individualized care by a variety of different health professionals. Lastly, as discussed elsewhere in this bulletin, culture change in residential care would be needed to ensure residents may live at greater risk, and to support care that is truly team-based and person-centred.

## Final Remarks

There are many similarities between the various innovative models for dementia care.<sup>67</sup> Some changes appear to have developed “organically.”<sup>141</sup> The focus of care has changed to person-centred care and the intent is to enable the person with dementia to live an “ordinary life” with as much autonomy as possible, in a safe environment.<sup>18 141</sup>

Canadian researchers suggest that, as the care needs of people with dementia change with the progression of the disease, a “life course perspective” for person-centred care is needed.<sup>163</sup> The recent Canadian Academy of Health Sciences report noted:

The quality of life of persons living with dementia and their caregivers can be improved across all stages of the condition through a complex combination of person-centred, high quality health and social care.<sup>12</sup>

A 2019 report on models of long-term residential care for the City of Toronto concluded that the:

...limited research has produced uneven and sometimes contradictory results.... Nevertheless, all the research shows models resulting in some improvement in the quality of both care and work, although there is some suggestion that models can become more rigid over time. In addition, all the models imply significant costs.<sup>20</sup>

The authors conclude that, rather than adopting a single model, adopting best practices from each to suit local needs may be a reasonable approach.<sup>20</sup> (Note: The Toronto report did not include dementia villages but did look at other models, including Butterfly Care, Eden Alternative, and Green House, as well as models not discussed in this bulletin.)<sup>20</sup>

Not all facilities fully adopt all aspects of the De Hogeweyk or other care models. Identifying which elements are most beneficial could be useful, as well as which elements work best in combination with other elements.<sup>22,118</sup> One assessment of the Green House model suggested that it could be considered a framework for organizational change in nursing home care within which evidence-based practices to improve care can continue to be introduced.<sup>22</sup> This is also true of the Hogeweyk Care Concept for dementia villages — an important transformation of care for people with advanced dementia and a model of care that can continue to be refined as new evidence becomes available. As Canadian dementia villages are established, it is important to ensure good-quality evidence is collected on the benefits and costs of this type of care.

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