



# Exercising Choice in Long-Term Residential Care

Edited by Pat Armstrong and Tamara Daly

# **Exercising Choice in Long-Term Residential Care**

**Edited by  
Pat Armstrong and Tamara Daly**

Exercising Choice in Long-Term Residential Care

Edited by Pat Armstrong and Tamara Daly

Copyright © 2017

ISBN 978-1-77125-367-3

Typesetting and design: Nancy Reid

Printed in Canada by RR Donnelley, 1500 Saint-Patrick, Montréal QC H3K 0A3

---

The opinions expressed in *Exercising Choice in Long-Term Residential Care* are those of the authors, and do not necessarily reflect the views of the Canadian Centre for Policy Alternatives.

# CONTENTS

**ACKNOWLEDGEMENTS** 5

**PROJECT RESEARCHERS** 7

**INTRODUCTION** 11

*Pat Armstrong and Tamara Daly*

*Chapter 1*

**YOU'VE GOT TO GET UP IN THE MORNING!... OR DO YOU?** 37

*Ruth Lowndes and Tamara Daly*

*Chapter 2*

**SMALL BITES AND FOOD IN SIGHT** 45

*Susan Braedley and Pat Armstrong*

*Chapter 3*

**MAKE MINE A DOUBLE** 55

*Sally Chivers*

*Chapter 4*

**SPONTANEOUS ACTIVITIES** 59

*Christine Øye, Gudmund Ågotnes, James Struthers  
and Frode Jacobsen*

*Chapter 5*

**LET'S TALK ABOUT SEX... IN LONG-TERM CARE** 69

*Tamara Daly and Susan Braedley*

*Chapter 6*

**OPPORTUNITIES TO PROBLEM-SOLVE: CONDITIONS FOR  
DEMENTIA CARE** **77**

*Susan Braedley and Marta Szebehely*

*Chapter 7*

**A FLEXIBLE DIVISION OF LABOUR: POTENTIAL FOR CHOICE** **85**

*Jacqueline Choiniere*

*Chapter 8*

**APPRENTICES: MORE HANDS ARE NECESSARY BUT NOT  
SUFFICIENT** **97**

*Beatrice Müller, Monika Goldmann and Hildegard Theobald*

*Chapter 9*

**FAMILIES AND CHOICES** **105**

*Pat Armstrong*

*Chapter 10*

**DEATH WITH DIGNITY IN LONG-TERM RESIDENTIAL CARE** **111**

*Shauna Zinnick, James Struthers and Malcolm Doupe*

*Chapter 11*

**EXERCISING CHOICES: IDEAS WORTH SHARING** **121**

*Pat Armstrong and Tamara Daly*

## ACKNOWLEDGEMENTS

*First, we would like to thank all those who live, work and manage in the 27 long-term residential care homes we studied. They were generous with their time, their resources and their trust, demonstrating to us their dedication to making care as good as it can be.*

*Second, we would like to thank Wendy Winters, the person who keeps this large and often unwieldy project together, and who has made multiple valuable contributions to this publication. We would also like to thank Jane Springer for her thoughtful and careful editing of the manuscript as well as for her patience with our disrupted work.*

*Third, we would like to thank the Canadian Centre for Policy Alternatives for their support and most specifically Nancy Reid, who handled the production so effectively, and Erika Shaker, Director of Education, for her ongoing support of publications from our project.*

*Fourth, none of this would be possible without financial support from the Social Sciences and Humanities Research Council of Canada and the European Research Area in Ageing 2 (in Canada from the Canadian Institutes of Health Research).*



# PROJECT RESEARCHERS

## PRINCIPAL INVESTIGATOR

Pat Armstrong, York University

## CO-INVESTIGATORS

Annmarie Adams, McGill University

Hugh Armstrong, Carleton University

Donna Baines, University of Sydney

Susan Braedley, Carleton University

Sally Chivers, Trent University

Jacqueline Choiniere, York University

Tamara Daly, York University

Megan Davies, York University

Malcolm Doupe, University of Manitoba

Monika Goldmann, Technische Universität Dortmund

Charlene Harrington, University of California San Francisco

Frode Jacobsen, Bergen University College

Robert James, York University

Monique Lanoix, St. Paul University

Paul Leduc Brown, Université du Québec en Outaouais

Joel Lexchin, York University

Liz Lloyd, University of Bristol

Martha MacDonald, St. Mary's University

Margaret McGregor, University of British Columbia

Kathryn McPherson, York University

Allyson Pollock, Queen Mary University of London

James Struthers, Trent University

Marta Szebehely, Stockholm University

Hildegard Theobald, University of Vechta

Pauline Vaillancourt Rosenau, University of Texas

## **SITE VISIT PARTICIPANTS**

Gudmund Ágotnes

Albert Banerjee

Rachel Barken

Suzanne Day

Sara Erlandsson

Ashley Heaslip

Krystal Kehoe MacLeod

Alexis Kezirian

Margrethe Kristiansen

Ruth Lowndes

Tone Elin Mekki

Christina Meyn

Penny Miles

Beatrice Müller

Anders Næss

Derek Newman-Stille

Justin Panos

Marius Schulze Beiering

Sandra Smele

Renita Sörensdotter

Palle Storm

Anneli Stranz

Mia Vabø\*

Shauna Zinnick

*\* Mia Vabø is a partner (the Norway group leader) on the CIHR-funded complementary project.*

## **PROJECT PARTNERS**

Canadian Federation of Nurses Unions

Canadian Union of Public Employees

National Union of Public and General Employees

Ontario Association of Non-Profit Homes and Services for Seniors (now AdvantAge Ontario)

Service Employees International Union Healthcare

Swedish Association of Local Authorities and Regions

The Council on Aging of Ottawa

Unifor Canada



# INTRODUCTION

*Pat Armstrong and Tamara Daly*

Expanding choice has long been a central feature of health care reforms, with a focus on choices for individual patients or residents. However, choices are structured by conditions that are often beyond the control of individuals or even particular care homes and involve how the system is structured, how funding is allocated, who is eligible for care, and who is available to provide that care.

Fieldnotes from a Swedish home demonstrate the crucial link we observed between choices for residents and choices for care providers. They also point to structural factors that make it possible for those who live and work in long-term care to exercise choice.

Sonja<sup>1</sup> comes in in her dressing gown and bare feet (she had slippers on earlier for breakfast). Pavel [an assisting nurse] greets her warmly with a big hug and she immediately looks much happier. I don't know whether he knows that she has already had a proper breakfast but as I hear later in the reflection meeting it doesn't matter — if someone asks for breakfast they just serve it instead of arguing that the person just had been eating. He offers her coffee; she asks for tea and gets that, sits at the same spot in the kitchen as before. Happy with another cup of tea and a toast (doesn't eat much of the latter as she just finished her first breakfast). Now Signe [assisting nurse] is sitting there, too, and Pavel sits down with the two ladies and serves himself a yogurt from the fridge. Sonja discovers that she has no shoes and Pavel goes to her room and gets them. After breakfast he offers to

help Signe [to assist Sonja] with her shower and to get dressed (she had been dressed already but obviously only temporarily). They leave for her room. (Fieldnote, Sweden)

The reflection groups mentioned above are both regular and ad hoc meetings held by and for direct care staff. The meetings allow staff to problem-solve and brainstorm together as well as provide support to each other.

Pavel gives me a piece of paper (half a page) about the reflection group. It says that it is demanding to work with people with dementia, that we use ourselves as important tools, that it is common to be involved in difficult ethical situations or that we have different opinions about how best to treat residents or their family members. The aim of the reflection group is to improve our knowledge and become even better at understanding and handling difficult situations in order to improve the care and make the environment more stimulating for both the residents and those working together. (Fieldnote, Sweden)

These conditions shape the extent to which staff or unpaid providers can build relationships with residents, families and other workers, relationships that provide the basis for appropriate decision-making. Moreover, there is a fundamental tension between the need for routine, for evidence-informed decision-making and for safety on the one hand, and on the other, the need to respond to individual choices and deal with the events that often disrupt routines, such as an unexpected death or sexual aggression. In long-term care, this tension is complicated by several conditions.

With more than half of the residents diagnosed with a form of dementia, some choices residents make may be inappropriate or even harmful to themselves or others. Non-routine events or irregular requests from residents may occur any time during the day or night and a resident's designated decision-maker may not be available to negotiate the response. Furthermore, the designated decision-maker may not agree with either the resident or the care provider. In addition, many residents have complicated health issues that prompt medical

regimes that may run counter to quality-of-life choices, such as salt consumption. A significant proportion of residents require help to dress, dine, bathe, and use the toilet, but individual preferences for the timing of these daily activities may run counter to workers' schedules or other residents' preferences. Increasingly, residents and workers come from a range of cultural practices that may conflict with established routines based on a common background. Moreover, although the majority of residents and workers are women, there are growing numbers of men in long-term care, creating new challenges in terms of both what decisions are to be made and who makes them. Finally, interruptions because of non-routine events or new preferences — from residents and families — can affect schedules and create new dynamics.

All these factors raise questions about what exercising choice means for residents of long-term residential care. They also raise questions about the conditions that allow such choices to be made and to be made as smoothly as possible when they do not fit into routines or prescribed practices.

Enabling resident choice requires responsiveness from those who are paid to provide or manage care. The majority of paid care providers, especially in North America, have extensive experience but limited formal training, raising questions about whether they have the skills to exercise choice when responding to individual resident preferences and to unplanned events. At the same time, managers increasingly operate in conditions that limit their decision-making. Although professional and managerial staff with more credentials may have more leeway to respond to challenges and interruptions based on their recognized skills, questions remain about the extent to which they can exert control and deviate from the confines of system rules that too often standardize but do not personalize care and carers. Although the majority of paid workers in five of the six countries in our study belong to unions, even these organizations are restricted in terms of their capacity to protect decision-making on the job or to prevent the privatization of services that can undermine some working conditions.

Increasingly, the labour of paid care providers is supplemented by privately paid companions who may or may not have formal

education or experience in care and may not have much oversight from managers, staff or families.<sup>2</sup> The same can be said about volunteers. Moreover, families — and especially the women in them — often supplement care and intervene when paid or unpaid workers respond to resident choices. These other care providers too may be limited in their ability to respond to residents' choices and to situations outside the expected.

### **The context for exercising choice**

In this short book, we seek to identify conditions that set the context for exercising meaningful choices in long-term residential care. We start from the assumption that there will be events and choices that do not conform to routines and standardized patterns; there will also be choices and preferences that are impossible without routines. And we assume that the conditions of work are the conditions of care. In other words, without appropriate working conditions it is difficult to provide the care residents need, want and deserve.

Each chapter asks what conditions allow for meaningful choices to happen as smoothly as possible, contrasting these to responses that do not work as effectively for at least some of those who live, work and visit in long-term residential care. To illustrate this work and these care conditions, we offer examples from our research on long-term residential care in six high-income countries.

**By long-term residential care**, we mean places that provide around-the-clock nursing and personal support, are subject to some government regulation, and have some form of public funding. Most commonly called nursing homes, they provide residents with more than what is usually understood as nursing care. In addition to meals, housekeeping and laundry services, they also offer assistance with the activities of daily living such as dining, bathing, dressing and using the toilet, as well as social, physical and recreation programs intended to stimulate and engage residents. The people who live in these homes have chronic conditions — ones that cannot be cured by modern medicine — and most have some form of dementia.

As admission criteria have become increasingly restrictive in all high-income countries, more and more nursing home residents require high levels of assistance with daily living as well as some medical care.<sup>3</sup> A growing number of residents die within six months of entering a home due to how advanced their frailty is by the time they can finally move in. Although still mainly a place for older women, the closure of chronic care, rehabilitation and psychiatric hospitals in many jurisdictions means that more residents are male, younger and have significant physical or behavioural needs. And especially in North America, the resident population has also become more racially and culturally mixed.

These residences are called homes because many people live in them over the long term and because the emphasis is intended to be on the kind of care one could get at home, often described as social care rather than as medical care. It remains the case even though admission is increasingly limited to those with significant health care needs. Not incidentally, calling them homes also allows governments to require residents to pay for their accommodation as they would at home.

The combination of a jump in fertility rates following World War II, developments in medicine, and the social and public health measures provided by welfare states has contributed to a rapidly growing elder population. Often described in alarmist terms such as “silver tsunami,” there are multiple warnings that the aging population will swamp health care systems. These concerns are raised in the context of austerity measures, attacks on taxation, support for profits and commercial sector involvement in government services, and the promotion of individual or family responsibility for the payment and provision of care. At the same time, media and social movements critique the quality of care and the limits on choice in care homes.

The solution to these pressures in most high-income countries is an emphasis on home care or on what is often called “aging in place.” Although this strategy provides a way of reducing costs and shifting care work onto families and especially onto the women in families, it is often presented as what people want — as their choice. When, for example, a study in New Zealand asked older people about their ideal

place to grow old, aging in place was “related to a sense of identity both through independence and autonomy and through caring relationships and roles in the places people live.”<sup>4</sup>

But choice often implies an older person has a safe, secure place to live out their old age and that this place has all the supports they need, including unpaid care by relatives or volunteers. It does not consider that this choice for older people with extensive care needs may mean little choice for their families in terms of providing care, given that no governments provide 24-hour care at home or a full range of services in the home. And this is particularly the case for the women in those families.

This emphasis on aging in place as a first choice does not consider how home care services restricted to specific tasks and times can limit autonomy and independence. Nor does this framing of choice consider the social isolation that often comes with living in a private home or the alternative of long-term care. The choice to remain in one’s home is not surprising if you have a home, sufficient income to pay for additional services, a family and a supportive community, and if you are relatively physically and psychologically well. It is particularly understandable if the long-term care homes in your area are understood as the worst options, ones that provide little opportunity for individuals or families to exercise choice.

Although there is little evidence to indicate that the aging population will overwhelm the health care system, in part because the baby boom generation is much healthier than previous ones, there are still a significant number of people who now need and will need residential care.<sup>5</sup>

Exercising choice if you have extensive care needs means having options beyond aging in place. Yet constructing long-term care as an attractive option for either the older population or for those who provide care has not been a high priority in most countries. As the World Health Organization points out, “strategies for providing long-term care have been low on government agendas everywhere.”<sup>6</sup>

Especially in Canada, the number of places in care homes has not kept up with the number of people defined as needing care, even as those defined as eligible has become more and more restricted to people with complex health issues combined with dementia and little possibility for care in their own home. For example, in February 2017, six of the 36 nursing homes in the city of Toronto had estimated wait times of over a 1,000 days for nine out of 10 applicants.<sup>7</sup>

It is not only the number of places that matter in terms of options but also the kind of care that is provided. The media regularly report on scandals related to care<sup>8</sup> and reports on the quality of care often paint a depressing picture, contributing to the notion that these are places of last resort for older people.

Increasingly, they may also be places of last resort for those who work in them because pay is lower than in hospitals and the working conditions are often inferior.<sup>9</sup> Based on our survey of those paid to work in care homes, we concluded that:

The low staff levels, the hectic work pace, the low level of control and unequal pay take a toll on the workers' bodies and in their homes. Too many feel inadequate and lose sleep at night as a result. They are physically and mentally exhausted, injured and ill. They face violence, racism and unwanted sexual attention on a regular basis.<sup>10</sup>

But exercising choice means more than having the option of living in or working in a nursing home. It also means understanding that choices are built on conditions that promote care as a relationship and that provide as much autonomy as possible for both those who provide and those who need care. Care necessarily involves more than one person and those persons are embedded within social structures characterized by pressures that restrict options in unequal ways. Opportunities for choices happen every day and every night because health issues do not always follow a single pattern, because individual residents or visitors often respond in variable ways and because new incidents happen on an irregular basis. Responding to these opportunities for choice means continual adjustments to the established routines. Working conditions shape responses to

these disruptions, influencing the extent to which staff and residents exercise some choice.

Care choices must be understood not only in terms of the individual but also in terms of the relational context. In explaining at an Ontario Health Coalition Conference<sup>11</sup> what is meant by care as a relationship, Margaret McGregor turned to the Canadian Aboriginal AIDS Network. This organization defines relational care as “an interactive, caring, respectful path for culturally competent services leading to the well-being of the whole person.”<sup>12</sup> In keeping with the perspectives in our research project, she added “and their formal and informal circle of care” to the definition.

### **External factors that shape working conditions**

Multiple factors outside a care home shape working conditions and thus the possibilities for exercising choices within them. **Ownership** is particularly important. It takes three basic forms: public, not-for-profit and for-profit. There are significant differences in ownership patterns among the six countries in our study but in recent years, we have seen a growth in for-profit ownership and especially in corporate ownership in all six countries. This growth has been particularly obvious in North America and the UK.

A host of studies, including ones by our team members, indicate that ownership matters for working and living conditions in long-term residential care. For-profit, and especially corporate, nursing homes are associated with inferior care.<sup>13</sup> For example, residents in for-profit homes are more likely to be hospitalized,<sup>14</sup> not a first choice for many, given that the transfer is disruptive to residents, staff and families, and often puts residents at risk of additional health problems. Staffing levels are lower in for-profit homes, resulting in time pressures that reduce options for both staff and residents. And there are more complaints to government that are verified as serious, indicating the incapacity to deal with them within the nursing home.<sup>15</sup>

**Regulations** and their enforcement are undoubtedly critical to care<sup>16</sup> but much depends on the subject and nature of the regulations as

well as on their enforcement. Regulations tend to focus on homes and on the staff within them rather than on larger structural factors such as ownership and staffing, even though both matter significantly in quality care.<sup>17</sup>

Regulations also structure possibilities for choice and ownership has an impact on the type of regulations and on how they are enforced. A review by our team of the audit and inspection process in our six countries found that “countries with higher rates of privatization (mostly the liberal welfare regimes) have more standardized, complex and deterrence-based regulatory approaches.”<sup>18</sup> There are more regulations and more detailed regulations in the countries with the highest rates of for-profit ownership. In the United States, we were repeatedly told that nursing homes were more highly regulated than the nuclear industry.

Many jurisdictions require that a Registered Nurse (RN) be present on every shift, and those with an RN on shift are less likely to transfer residents to hospital.<sup>19</sup> Although research indicates that care homes need to have staffing levels equivalent to at least 4.1 hours of direct care provider per resident per day, only a few jurisdictions establish minimum staffing levels. None of those in Canada with minimum requirements set the minimums at the level recommended by experts based on the research.<sup>20</sup>

Moreover, some regulations are mainly prescriptive, setting out what must be done, when and by whom, while others are more interpretive, setting guidelines that allow for choice and adaptation to particular places and people. Research from our team found that “prescriptive regulatory environments tend to be accompanied by a lower ratio of professional to non-professional staff, a higher concentration of for-profit providers, a lower ratio of staff to residents and a sharper division of labour.”<sup>21</sup> In contrast, “interpretive regulatory environments tend to have higher numbers of professionals relative to non-professionals, more limited for-profit provision, a higher ratio of staff to residents, and a more relational division of labour that enables the work to be more fluid and responsive.”<sup>22</sup> While prescriptive environments tend to focus on punishment, interpretive ones tend to provide support for altering

the factors that contribute to violations or complaints. "The implication of a prescriptive environment, such as is found in Ontario, Canada, is that frontline care workers possess less autonomy to be creative in meeting residents' needs, a tendency towards more task-oriented care and less job autonomy."<sup>23</sup> Standards are obviously necessary to help ensure quality care but standardization implies a single way of providing care that leaves few options for staff, residents or families and little opportunity for making care relationships a priority.

Regulations increasingly include prescriptive instructions on care plans and on how to monitor care. The most popular of these, at least in North America, is a system called RAI-MDS (Resident Assessment Instrument-Minimum Data Set). It is intended to provide data on the health care needs of those in long-term care and to measure the quality of life in long-term care, as well as contribute to accountability by providing indicators of quality in homes.<sup>24</sup> However, the focus is on standardized clinical measures instead of residents' routines and preferences where "knowledge of individual preference, style, and vocational history is critical to accurately deciphering the meaning of behavior."<sup>25</sup>

This type of regulation often reinforces the hierarchy that undermines collaborative teamwork and decision-making by allowing only those high in the hierarchy to input data that are collected by those providing direct care. It limits options for both staff and residents, while taking time away from care. It limits autonomy and standardizes care, as a nurse practitioner in Canada eloquently explained:

[I]t's weird. It almost is robotic, mechanical. Yeah, that's really how I want to describe it. It's robotic mechanical nursing care. If this happens then you do this. If this happens then you do this. The computer is thinking for you and the humanity is lost in it.... [T]he thing is people are feeling incapacitated to make their own clinical judgments without having the "I don't know everything about it but the indicator came up." You shouldn't need to have the computer tell you what the problems are with your person. It just seems ridiculous to me because you're the one telling the computer so then the computer can then tell you.

The result of these types of systems is that staff, residents and families can find it difficult to exercise actual choice.

One alternative to such accountability systems is reporting based on exceptions. For example, instead of recording how much a resident drinks at each meal, as is the case in Ontario, reporting can be required when there is concern about dehydration, based on the judgement of the care provider, as we saw in Germany. Norway offers another example of accountability based on knowledge, this time in the case of resident falls. In Ontario, any fall must be reported and may lead to repercussions for the individual worker responsible and for the home, while in Norway only falls with injuries are reported, and the result is consultation on how to prevent such falls for this person in the future. Working in teams can also contribute to accountability, not only by providing support and advice but by offering checks on the quality of care provided by all.

There are other regulations that limit or promote the exercise of choice. In North America especially, regulatory bodies set out the scope of practice for many of those paid to provide care. Although these regulations and their enforcement are important in helping to ensure that staff have the skills they need and that they practice in appropriate ways, the regulations can also enforce rigid hierarchies and make it more difficult for all paid providers to work as a team to share knowledge and reflect together on their choices.<sup>26</sup>

Government employment regulations and those related to health and safety as well as to unionization also play a role. For instance, some regulations allow workers to say no to unsafe practices such as lifting heavy residents alone and make work in care a reasonable choice by protecting wages and benefits. In Germany and the Scandinavian countries, unions operate at the national level to support worker choices and in Canada, they do so at the level of the home. By contrast, non-unionized workers in the US homes we visited had no right to protections such as paid sick leave.

Government minimum employment standards in many jurisdictions tend to be set quite low and are not always enforced. Moreover, part-

time, agency and casual workers are often excluded from protections, leaving them limited options for exercising choice.<sup>27</sup> Paid companions hired directly by families are almost always excluded from both protection and teams.<sup>28</sup>

**Funding** also plays a part in establishing working conditions and the capacity to exercise choice. All six countries charge for what are usually called accommodation fees in publically funded long-term care, although these fees vary significantly from country to country and even within Canada.<sup>29</sup> However, such fees provide only a small part of the costs, given that the major expenditure in health services is labour.

As we show in *Promising Practices in Long-Term Care: Ideas Worth Sharing*, the first of these bookettes, there are significant differences in funding among countries. For instance, Canada comes second to Sweden in terms of the number of available places for long-term care — calculated as the number of beds per 1,000 people age 65 and over. However, in 2013, Sweden spent 3.6% of its Gross Domestic Product (GDP) (the total value of all goods and services produced by a country over a particular period of time) on long-term care while Canada spent only 1.3% of its GDP.<sup>30</sup> The higher funding levels in Sweden are reflected in higher staffing levels and may help explain why Swedish staff are much less likely than Canadian staff to say they face violence on a more or less daily basis.<sup>31</sup> More staff means more time to know and to accommodate resident preferences, reducing the potential for residents to become violent created by lack of knowledge of the resident and lack of time to respond appropriately based on that knowledge.

### **Factors inside homes that affect choice**

Multiple factors within homes also structure the opportunities for exercising choice. In her speech to the Ontario Health Coalition Conference, Margaret McGregor used her experience in a Swedish home we studied to identify many of the critical factors that shape options for those who live, work and visit in long-term residential care.

It was quite large but each unit only had 11 residents and 3 care aides — that's a ratio of one care aide to four residents on days and

evenings. Each unit also had its own dining room and kitchen area and each care aide provided total care to one or two residents — they brought them coffee in bed in the morning, helped them get dressed and take a shower or bath. They administered their medications, did their laundry, and cleaned their rooms. Staff decided each day how to organize the routine and recreational activities depending on the rhythm of the day. In fact they said one of the reasons they enjoyed working there were the surprises that any given day would bring.

What struck me was the tremendous pride they took in the care they provided and the fun they had doing it. I would often observe peals of laughter as staff joked with residents and chatted with family — and this was on a dementia unit. On the day we visited, the weather was fine so we did an outing in the park outside the facility — watching the residents soak up the sun, I reflected on how many of our residents with dementia in facilities barely see natural light. Besides the time spent socializing with residents and engaging them in activities as part of their everyday work, each staff spent a dedicated ½ hour per week socializing with their primary resident. It was also striking how the staff would spend time outside of work hours on their own time, thinking about the residents because they were passionate about the work.

Two of the caregivers were best friends and would frequently call each other to discuss issues like how to help calm a resident who was crying out a lot or the ethical dilemma of keeping a budgie on the unit when one resident loved to visit it, but the budgie chirping made another resident really agitated.

There was also a big focus on the well-being of the families of residents. In one of my interviews with a care aide she said, “In Sweden we have children and early on take them to daycare.... When I drop my kids off I hope they will make some friends and I hope the staff is good to them... the staff can do anything to them so I need to trust them.... It’s the same for the families here. They put a big trust in us.... They need to be able to live their lives and trust us with caring.... Many are burned out taking care of their loved one by the time they get here.”<sup>32</sup>

In her description, and in those presented here, the most obvious factor shaping choice is the **high staffing level**. The staff have time to know their residents because they have the time to spend with the residents and with the families.

While the number of staff in the Swedish case is important, so too is continuity among paid staff. They get to know the residents over time, which not only means they can build relationships but that they can understand the changes over time in any individual resident. Such an understanding is essential to making decisions about a resident's capacities and choices as they change over the day, weeks and months in non-routine ways. Equally important, continuity allows staff to get to know other staff and to build relationships with them, providing the basis for the kinds of consultation on choices and problem-solving evident in this report. In Germany, we observed staff aided by a large number of apprentices. While many places we studied had students doing practicums, what was unusual about the German apprentices was the duration of their stay in the home and the long time they spent with residents each day, allowing them to develop relationships as the basis of their care practices.

A less obvious factor is the managerial approach that supports continuity by providing decent working conditions and that allows considerable discretion to the staff. This discretion, as well as the time they have, allows staff members to figure out together what to do about the budget. It is also what allows them to plan the day in response to variable conditions such as the weather, a death, or an upset family member. The limited division of labour, with staff doing a range of tasks, and staff having the time to provide relational care contribute to the flexibility in responses to non-routine incidents and preferences. Instead of a rigid hierarchy, there is more distributed power and more time is spent caring for residents than in filling out forms reporting on the care. This distributed power is based on an assumption that, as a team, the staff have the skills required to provide the care. Some of this is based on formal learning but some is based on knowledge acquired on the job from the work, from residents, from families and from other staff.<sup>33</sup>

It is also important to note that **families are included** in the approach to care in the Swedish home. They do not expect the families to provide care. Instead they understand their job as relieving families of the work and the pressures, while taking their interests into account. There are enough staff to give families confidence that the care will be there. This contrasts with many homes in North America, where families privately pay for companions to supplement the care provided by the paid staff because paid workers have too little time to provide relational care.<sup>34</sup> Other families, and especially daughters, provide the extra care themselves. For example, in a BC home several daughters brought in Asian food for their parent because the care home did not provide the culturally appropriate food.

The Swedish example contrasts with the managerial approaches and staffing levels we saw in much of North America. Staffing levels are lower in North America, with care aides responsible for as many as 15 residents. There is often a detailed division of labour, with relatively rigid lines of authority. There are often clear restrictions on who can do what. The care aides, who provide most of the direct care, have the least discretion in adjusting their time and responses to non-routine incidents, based on the assumption that they do not have the necessary skills. The hierarchy is reinforced by regulations and by managerial efforts to standardize care as a means of maintaining control and ensuring quality care. The higher turnover characteristic of some homes means staff do not have time to understand the needs and wants of each resident. High turnover also means there are fewer staff with the experience that comes with long tenure and who are able to teach newer recruits how to adjust to constantly changing issues and opportunities.<sup>35</sup> In contrast, flexible positions supported shared knowledge of residents, enabling the exercise of choice.

As part of managerial strategies to have just-enough staff, there is often a heavy reliance in some places on part-time, casual and agency staff. There are some good reasons to hire part-time staff. They can fill in for staff on vacation or sick leave or when there are surges in admissions. However, agency staff are unable to really get to know residents and the facility. In contrast, permanent-part time staff are familiar with the place, the staff and its residents. We saw, for example, care homes in

Manitoba and Nova Scotia that kept their own list of people willing to work part-time and thus had a roster of workers who could fill in the gaps with less disruption than agency staff. They also used the part-time list as a way to fill full-time jobs. However, those hired through agency services in other homes are unlikely to know the home or those who live and work in it.

The pressure to standardize routines and increase reporting may be one strategy used to combat the consequences of staff who do not know those who live and work in the care home. But the result is fewer options for everyone. Of course, replacing vacations and sick time with agency staff is better than leaving the positions unfilled. In our survey, nearly half of the Canadian workers said they worked short-staffed nearly every day, compared to 12% in Sweden.<sup>36</sup> Given that many homes regularly operate with the minimum number of staff needed to provide adequate care, the failure to replace staff who are absent due to illness, injury or other factors means less care for residents and more work for workers. At the same time, however, the failure to provide the minimum number of staff usually does not show up in the reporting data record, which records who is paid rather than who is actually at work.

### **Facing violence, sexual harassment and racism**

Managerial strategies, regulations and staffing all play a role in the extent to which staff can exercise choices in facing violence, sexual harassment and racism. Violence against health care workers is increasing and with more workers in the predominantly Caucasian countries coming from racialized and/or immigrant communities, racism is more frequently an issue. That staff in the Scandinavian countries report facing less regular violence than staff in Canada suggests that having more staff overall, more staff who know the residents, and more room for staff discretion all help reduce many forms of violence.

Whether or not workers can exercise choices when facing racism depends to a large extent both on regulatory protections and managerial support. In a United Kingdom home, for example, the

manager told us that when families or residents make racist comments, she meets with them. She tells them that such behaviour is not tolerated and repeated racism means they will be asked to leave the care home. In some other places, staff told us that when they reported incidents such as residents grabbing breasts or uttering racist slurs, they were told to “suck it up” and forget it because it is the illness that causes the behaviour. As Chapter 5 illustrates, in one Norwegian care home, aggressive sexual behaviours were addressed by listening to and responding to a resident’s needs in ways that protected everyone’s dignity.

### **Wages, benefits and job security**

Pay, benefits and job security also influence whether or not staff can exercise choice and respond to residents and families. The mainly female staff are not highly paid, in part based on the assumption that this is low-skilled work any woman can do. The staff in the Scandinavian countries and in Germany are better paid than staff in Canada and especially in the US and the UK, in large measure as a result of union efforts. However, the pay still does not match the skill, effort, responsibility and often very difficult working conditions in long-term residential care. When we asked a Human Resources Director in a large Norwegian home what she would change if she were in charge, she said she would pay the women employed in the nursing home what they pay the men employed in the oil fields — because these women work harder.

Part-time and casual staff earn even lower pay and have few or no benefits, which often means they hold multiple jobs in different workplaces, leaving them little choice about how long or where to work and little opportunity to know residents or become friendly with other staff. It is easier to have smooth operations in the face of disruption and changes if staff know each other and the residents.

### **Location and the physical environment**

The physical environment also has an impact on working conditions and shapes the possibilities for exercising choice. As we explain in

*Physical Environments for Long-Term Care: Ideas Worth Sharing*,<sup>37</sup> where homes are located, for example, structures who can visit and how easily, who can work there and what options residents have in terms of access to gardens, shopping and seeing others going about their lives. In Canada, we studied a home located in the middle of a busy market that meant residents could leave the home to enjoy common routines of life and be part of a larger community.

There are no easy or right ways to address the tensions of the changing populations in long-term residential care. Dementia takes multiple forms and behaviours change over time as well as with circumstances. However, it is clear from our research that working conditions matter in the extent to which residents, families and staff can exercise choices based on relational care. When staff know the residents and have some discretion in providing care, they are better able to respond to resident choices. Complex health issues, especially when combined with dementia, require skilled care. When not all those involved in care have the formal credentials determined to be necessary to providing care, teamwork can help ensure both a response that builds on collective knowledge and some accountability for care. In this book, we identify some ideas worth sharing about the conditions that allow those who live, work and visit long-term residential care to exercise choices.

## **The evidence**

This book is based on evidence gathered in a project called “Reimagining Long-Term Residential Care: An International Study of Promising Practices,” funded for seven years by the Social Sciences and Humanities Research Council of Canada and in a shorter project on “Healthy Aging in Residential Places,” funded by the Canadian Institutes of Health Research and the European Research Area on Ageing 2 Project. It is the third in a series that began with *Promising Practices in Long-Term Care: Ideas Worth Sharing* and continued with *Physical Environments in Long-Term Care: Ideas Worth Sharing*. Researchers from six countries are involved in the projects: Norway, Sweden, Germany, the UK, the US, and Canada. The five major unions in the Canadian health care sector are partners, along with an employer association and a senior’s organization.<sup>38</sup> These partners keep us connected to those who work and live in residential

care, provide advice on where we should look for ideas worth sharing, and help keep our publications grounded in their experience.

We are looking for conditions in long-term residential care that support active, healthy aging for residents and staff, taking gender, racialization, contexts and individual capacities into account. They are conditions that allow residents, staff, volunteers and families to flourish or at least enjoy as much as possible their time in long-term care. This means allowing choices and allowing staff the capacity to respond to the non-routine, non-standard incidents that characterize daily life in a care home.

In conducting this research, we have used two basic strategies. The first, ongoing approach involves producing analyses of funding, payment and ownership; staffing and work organization; approaches to care; and means of ensuring accountability, such as reporting on injuries. Our scholarly and popular work on these areas can be found on our website at <http://reltc.apps01.yorku.ca/>.

This research provides the background for our second strategy, the one that is the primary basis for this small book. Called rapid, site-switching ethnography, our method involves taking a team of 12 to 14 researchers into a long-term care home to observe and interview. We have conducted ethnographic research in 27 different sites, with at least two studies in each jurisdiction involved in the project. The homes ranged significantly in size, location, age and ownership, although most were non-profit. They also varied in terms of the models of care, with The Eden Alternative, Dementia Care Matters, and the Gentle Persuasive Approach just some of the examples of models we saw in practice.

To identify homes to study, we interviewed union representatives, community groups and government officials to ask where they would go to find promising practices and why they would select that particular home. While issues such as ownership, staffing and overall approaches to care were high on the list of factors contributing to the suggestions for homes to visit, most of those interviewed also identified physical environment issues such as location in relation to

the community, floor plans, outside spaces, home-like atmosphere, and staff input on design as the basis for selecting these homes for promising practices. And they also talked about the importance of choices.

Based on these recommendations, we approached homes to ask if they were willing to have us look for promising practices in their places. This most commonly involved providing us with background information on such matters as floor plans, staffing, and ownership and allowing us to observe and interview over a week. We also conducted shorter “flash” ethnographies at another home in the same jurisdictions.

The teams that went in to study these long-term residential care homes were both interdisciplinary and international. Although each team was different, they all involved researchers from multiple countries and multiple educational backgrounds. They worked in pairs over three shifts, with the first shift starting at 7 a.m. and the last ending at midnight or later. We also made sure we included weekdays and weekends in our stay, based on the assumption that the involvement of families and volunteers would vary over this time period.

This approach allowed researchers from different countries and different perspectives to observe and talk with the same people in the long-term care home and to constantly compare how they understood what they saw and heard. So, for example, in one site Bob James, who is a Canadian physician and former medical director of a nursing home, was paired with Anneli Stranz, a Swedish woman just finishing her doctorate in social work. The physician was much more likely than the social worker to notice how medications were stored and delivered while the social worker paid particular attention to the places where staff could rest and have quiet time away from residents.

Each night, team members who were not on shift met to discuss the day and the entire team met midweek and at the end of the week to discuss what we saw. These meetings allowed us all to reflect on what we thought we saw and heard and to compare what we learned, adding more voices and more perspectives to the research. It also allowed us to identify discrepancies, issues worth pursuing further, and

missing information we needed to seek out. For example, during one study, a researcher reported to the group that they were told that the blue section on the linoleum floor confused a resident who thought it was water and tried to dive into it. We followed up on the story to ensure it was not simply apocryphal. This led us to ask questions in each site not only about dementia and floor coverings but about colours.

These reflections taught us how much we have been trained to look for negative practices rather than for good ideas worth sharing. It is often much easier to notice a resident yelling than it is to recognize the calm that results from a worker handling a situation effectively. It is easier to see a worker sitting recording liquid intake in a dining room than to see the absence of recording and a worker offering a resident a drink as she walks down the hall. To counter this tendency, we daily reminded ourselves to look for ideas worth sharing and at the end of the week we together worked to identify both what we saw as promising practices in that place and what conditions made them promising for whom.

Comparisons and reflections went further than one site. Carrying out the same kind of research in all six countries allowed us to compare across countries as well as within them. Witnessing staff having a meeting where they discussed how to deal with issues like feeding budgies or how to get a woman to agree to have her hair washed allowed us to ask how decisions about such issues would be made in other jurisdictions. This is also an example of another important contribution of the comparisons and reflections. They allowed us to see what was missing. We started to notice, for example, when staff could see and respond to incidents in the dining room or that in some care homes the RNs never helped with the meals.

Seeing what had negative consequences allowed us to appreciate what did seem promising, for whom it worked and why. These comparisons and reflections allowed us to consider options and their consequences, asking questions and rethinking old assumptions. A Swedish colleague, for instance, started to wonder if their notion that organizing long-term care homes into home areas for 9 to 11 residents created social spaces that were too small, after she saw larger units in other homes that

allowed residents to socialize with a more varied population.

We now have well over 500 interviews conducted with the entire range of people involved in long-term residential care. We have hundreds of documents about the places we studied and a thousand pages of fieldnotes. And we have the notes on our many reflections and our lists of promising practices. Together they provide a rich source of evidence on ideas worth sharing and worth trying. Here we focus on those that relate to exercising choice, reclaiming the word “choice” in order to improve the quality of care. Instead of focusing on individuals, we are looking at the extent to which conditions make it possible for workers, residents, managers, family/friends, and volunteers to exercise meaningful choices based on care relationships.

### **Our goals**

A senior manager we interviewed in Ontario explained to us that the

average length of stay or living in the home is 18 months and every day I say, “If you had only 18 months to 24 months of life left what do you want it to be?” And it’s our job to make that the best it can be and so it’s a very empowering and enriching thing to do. (Interview with Senior Manager, Ontario)

We seek to contribute to that work. This book is one of several publications we have written as part of our project to make nursing homes places where residents, workers, families, volunteers and managers are treated with dignity and respect and where joy, as well as appropriate care, is a goal.

Working conditions, as well as the context set by ownership, regulation and funding, are critical factors in achieving that goal.

---

## NOTES

1. All the names of residents, care workers and family in this book are pseudonyms.
2. T. Daly and P. Armstrong. (2016). Liminal and Invisible Long-term Care: Precarity in the Face of Austerity. *Journal of Industrial Relations, Special Issue on Care Work*, 58(4), 473-490. DOI: 10.1177/0022185616643496.
3. F. Colombo, A. Hena-Nozal, J. Mercier and F. Tjadens. (2011). *Help Wanted? 4. Providing and Paying for Long-term Care*. Available at: <http://www.oecd.org/els/health-systems/47884930.pdf>; Organization for Economic Cooperation and Development. (2015). Health at a Glance 2015. Available at: [http://www.keepeek.com/Digital-Asset-Management/oecd/social-issues-migration-health/health-at-a-glance-2015\\_health\\_glance-2015-en#](http://www.keepeek.com/Digital-Asset-Management/oecd/social-issues-migration-health/health-at-a-glance-2015_health_glance-2015-en#)
4. J. L. Wiles, A. Leibing, N. Guberman, J. Reeves, and R.E.S. Allen. (2012). The Meaning of "Aging in Place" to Older People. *Gerontologist*, 52(3):357-366, p. 357.
5. Canadian Health Services Research Foundation. (2002 and 2011). Myth: The Aging Population Will Overwhelm the Healthcare System. Myth: The Aging Population is to Blame for Uncontrollable Healthcare Costs. *Mythbusters*. Available at: <http://www.cfhi-fcass.ca/SearchResultsNews/2011/02/22/f20f6cb8-bfd0-453e-b470-6fb63c93a629.aspx>
6. World Health Organization. (2002). *Ethical Choices in Long-Term Care: What Does Justice Require?* Geneva: WHO, p. 5.
7. Community Care Access Centre, Toronto Central CCAC. Available at: <http://healthcareathome.ca/torontocentral/en/care/Documents/DEC-EN2016.pdf>
8. L. Lloyd, A. Banerjee, C. Harrington, F. F. Jacobsen and M. Szebehely. (2014). It is a Scandal!: Comparing the Causes and Consequences of Nursing Home Media Scandals in Five Countries. *International Journal of Sociology and Social Policy*, 34(1/2):2-18.
9. F. Colombo, A. Hena-Nozal, J. Mercier and F. Tjadens. (2011). *Help Wanted? Providing and Paying for Long-Term Care*. OECD Health Policy Studies. Available at: [http://www.keepeek.com/Digital-Asset-Management/oecd/social-issues-migration-health/help-wanted\\_9789264097759-en#.WKbKJLe-iw#](http://www.keepeek.com/Digital-Asset-Management/oecd/social-issues-migration-health/help-wanted_9789264097759-en#.WKbKJLe-iw#) K. Laxer. (2014). Mapping the Division of Labour in Long-Term Residential Care across Jurisdictions. Doctoral Dissertation, Department of Sociology, York University, Toronto.
10. P. Armstrong, A. Banerjee, M. Szebehely, H. Armstrong, T. Daly and S. Lafrance. (2009). *They Deserve Better: The Long-Term Care Experience in Canada and Scandinavia*. Ottawa: Canadian Centre for Policy Alternatives, p.135.
11. M. McGregor. (2016). Presentation to the Ontario Health Coalition Conference, Toronto, Ontario.
12. Canadian Aboriginal Aids Network. (2008). Relational Care: A Guide to Health Care and Support for Aboriginal People Living with HIV/AIDS, p. 8. Available at: <http://caan.ca/wpcontent/uploads/2012/05/Relational-Care-20081.pdf>
13. L. A. Ronald, M. McGregor, C. Harrington, A. Pollock and J. Lexchin. (2016). Observational Evidence of For-Profit Delivery and Inferior Nursing Home Care: When Is There Enough Evidence for Policy Change? *PLOS Medicine*, 13(4), e1001995. DOI:10.1371/journal.pmed.1001995.

14. M. McGregor, R. B. Abu-Laban, L. A. Ronald, K. M. McGrail, D. Andrusiek, J. Baumbusch, M. B. Cox, K. Salomons, M. Schulzer and L. Kuramoto. (2014). Nursing Home Characteristics Associated with Resident Transfers to Emergency Departments. *Canadian Journal on Aging*, 33, 1–11.
15. M. McGregor, C.-R. Stocks-Rankin, et al. (2011). Complaints in For-Profit, Non-Profit and Public Nursing Homes in Two Canadian Provinces. *Open Medicine*, 5(4).
16. D. Mukamel, D. Weirner, C. Harrington, W. D. Spencer, H. Ladd and Y. Li (2012). The Effect of State Regulatory Stringency on Nursing Home Quality. *Health Services Research*, 47(5):1791-1813.
17. A. Banerjee and P. Armstrong. (2015). Centring Care: Explaining Regulatory Tensions in Residential Care for Older Persons. *Studies in Political Economy* 95. Regulating Care, 7-28.
18. J. Choiniere, M. Doupe, M. Goldmann, F. Jacobsen, L. Lloyd, M. Roothan and M. Szebehely. (2016). Mapping Nursing Home Inspections and Audits in Six Countries. *Ageing International*, 41(1): 40-61.
19. M. McGregor, J. M. Murphy, J. W. Poss, K. M. McGrail, L. Kuramoto, H-C. Huang and S. Bryan. (2015). 24/7 Registered Nurse Staffing Coverage in Saskatchewan Nursing Homes and Acute Hospital Use. *Canadian Journal on Aging / La Revue canadienne du vieillissement*, 34(4):1-14.
20. J. F. Schnelle et al. (2004). Relationship of Nursing Staffing to Quality of Care. *Health Services Research*, 39(2):225-250.
21. T. Daly, J. Struthers, B. Müller, D. Taylor, G. M. Goldmann, M. Doupe and F. Jacobsen. (2016). Prescriptive or Interpretive Regulation at the Frontlines of Care Work in the “Three Worlds” of Canada, Germany, and Norway. *Labour/Le Travail*, 77, 37-71.
22. Ibid.
23. Ibid.
24. I. Carpenter and J. P. Hirdes. (2013). Using InterRAI Assessment Systems to Measure and Maintain Quality of Long-Term Care. Chapter 3 in *A Good Life in Old Age? Monitoring and Improving Quality in Long-Term Care*. Paris: OECD/European Commission.
25. P. C. Kontos, K.-L. Miller and G. J. Mitchell. (2010). Neglecting the Importance of the Decision Making and Care Regimes of Personal Support Workers: A Critique of Standardization of Care Planning Through RAI/MDS. *The Gerontologist* 50(3):352-362, pp. 359-360.
26. T. Daly and M. Szebehely. (2012). Unheard Voices, Unmapped Terrain: Care Work in Long-Term Residential Care for Older People in Canada and Sweden. *International Journal of Social Welfare* 21(2):139-148.
27. K. Laxer. (2014). *Mapping the Division of Labour in Long-Term Residential Care across Jurisdictions*. Doctoral Dissertation, Department of Sociology, York University, Toronto.
28. T. Daly and P. Armstrong. (2016). Liminal and Invisible Long-Term Care: Precarity in the Face of Austerity. *Journal of Industrial Relations*, Special Issue on Care Work, 58(4), 473-490. DOI: 10.1177/0022185616643496.
29. M. MacDonald. (2015). Regulating Individual Charges for Long-Term Residential Care in Canada. *Studies in Political Economy* 95. Regulating Care, 83-114.

30. D. Baines and P. Armstrong, eds. (2015/16), *Promising Practices in Long Term Care: Ideas Worth Sharing*. Canadian Centre for Policy Alternatives, pp. 23, 25.
31. P. Armstrong, A. Banerjee, M. Szebehely, H. Armstrong, T. Daly and S. Lafrance. (2009). *They Deserve Better: The Long-Term Care Experience in Canada and Scandinavia*. Ottawa: Canadian Centre for Policy Alternatives, p. 135.
32. M. McGregor. (2016). Presentation to the Ontario Health Coalition Conference, Toronto, Ontario.
33. P. Armstrong. (2013). Puzzling Skills: Feminist Political Economy Approaches. *Canadian Review of Sociology*, 50th Anniversary Special Issue (3):256-283.
34. T. Daly, P. Armstrong and R. Lowndes. Liminality in Ontario's Long-Term Care Facilities: Private Companions' Care Work in the Space "Betwixt and Between." *Competition & Change*, 19(3):246–263.
35. N. Castle and J. Engberg. (2007). The Influence of Staffing Characteristics on Quality of Care in Nursing Homes. *Health Services Research*, 42(5):1822-1847.
36. P. Armstrong, A. Banerjee, M. Szebehely, H. Armstrong, T. Daly and S. Lafrance. (2009). *They Deserve Better: The Long-Term Care Experience in Canada and Scandinavia*. Ottawa: Canadian Centre for Policy Alternatives, p.59.
37. P. Armstrong and S. Braedley, eds. (2016). *Physical Environments in Long-Term Care: Ideas Worth Sharing*. Canadian Centre for Policy Alternatives.
38. Partners include the Canadian Federation of Nurses Unions, Canadian Union of Public Employees, the National Union of Public and Government Employees, the Service Employees International Union, Unifor, the Ontario Association of Non-Profit Homes, Services for Seniors and the Council on Aging, Ottawa.



## Chapter 1

# YOU'VE GOT TO GET UP IN THE MORNING!... OR DO YOU?

*Ruth Lowndes and Tamara Daly*

*Everyone should have the right to sleep in. (Manager, Fieldnote, Manitoba)*

The morning is usually the busiest time in long-term residential care (LTRC). In many cases, workers are waking residents to wash and dress them, brushing their hair and teeth, transferring them from bed to the dining room, setting them up, serving food, and assisting those who need help eating. Depending on the care home, this may all need to be done within a short period of time.

In Canada, it is not uncommon for care aides to be individually responsible for nine to 12 residents, and to face time restrictions on when residents must be up, dressed and at the table. Fifty to 75% of their residents need to be transferred from beds to wheelchairs, and safety regulations require workers to seek help from another worker to do this task. This excerpt from a fieldnote illustrates how busy the morning can be:

7:35 a.m. [C]all bells are ringing consistently and do not stop. It is loud and irritating to listen to....The RN [registered nurse] takes the medication cart out... and begins to do her medication round.... All [four care aides] are working in the bedrooms.... They go in and out of bedrooms, getting supplies and bringing out dirty laundry, diapers, etc.... [Care aides] appear to be very busy. Much time is spent in the rooms because they are getting up four people [in each room].... I hear a female resident screaming from a bedroom down the hall, "Oh

stop it!"... Bells continue to ring.... A [care aide] comes out of the one room [and asks another care aide], "Can you give me a hand with Sue? She's hitting." She tells her to be careful as they enter the room.

8:32 a.m. Meanwhile, another [care aide] brings a... female resident out of the bedroom on a commode chair, naked, wrapped in a sheet, and heads towards the shower/tub room down the central hall.

8:42 a.m. The [care aide] now wheels the resident, who is still in a sheet, from the tub room, back to her bedroom. She has dripping-wet hair. One [care aide] sees that the other has used the commode chair... and says, "You took my chair." She tells her a resident was using hers, and she goes to retrieve it from a bedroom down the hall. She has a little chat with the resident, tells her she's fine, "you look beautiful." She then tells her, "I'm really busy right now" as she brings out the other commode and heads for the next room.

9 a.m. ...a [care aide] comes out of a bedroom rushing, saying, "There are too many people!" [as she] goes into one room, then into another... then back to the room she came out of first.

9:03 a.m. The two RNs are now finished giving medications. [One] is sitting at the desk in the nursing station.

9:10 a.m. The [care aides] are still working in the [bed]rooms as breakfast is being served in the dining room. (Fieldnote, British Columbia)

The possibilities for either residents or workers to exercise choice during this morning routine are limited. Too often strict regulations or efforts to contain staffing costs lead to standardized routines, with little or no input sought from residents or frontline workers. For instance, in BC residents need to have breakfast served between 7 a.m. and 9 a.m., and meals must be provided in a dining room.<sup>1</sup> The regulations include specific restrictions limiting tray service to resident bedrooms and mandate that "meals are not provided by ongoing room tray service for the convenience of employees."<sup>2</sup>

In order to align with the regulations, residents need to be up by 9 a.m. at the latest to have breakfast in the dining room. Although these morning routines are often justified as a way of ensuring that care is provided efficiently and that residents are not left in bed too long, they limit the choices of both residents and workers. However, some of the homes we studied used alternative methods to help ensure good care while allowing residents and staff to exercise choice. Here are some examples of conditions that support calm, relaxed morning routines.

### **Philosophy of care**

Exercising choice was embedded in one Canadian care home's care philosophy and prioritized in its practices. This encouraged a peaceful morning-time experience for residents and staff. The manager began our visit by explaining: "This is the residents' home. Everything we do is for the residents... [Residents] can stay in bed as late as they like and get fed accordingly, getting less the closer to lunch that they eat" (Fieldnote, Manitoba).

This philosophy directed work organization and set conditions that allowed residents and staff to develop care relationships that took resident preferences and capacities into account. In practice, this meant recognizing that at home, residents would not necessarily get up early. Those who slept in at home could continue to do so at this site without fear of missing their breakfast or bath. Breakfast-time options were possible because food was available in open, accessible unit kitchens, and food services were located in the home. This contrasted sharply with other Canadian homes that contracted out food services and restricted food preparation to a narrow range of times.

#### *Morning wake-up*

A staff member said the conditions of care were "excellent" in this home, and described how staff wake up residents in the morning:

First thing you're going to make sure you knock on the door to make sure to protect their privacy. Most of them cannot answer anyway or maybe they are sleeping sometimes or sometimes just don't answer.

We make sure we knock. You talk to them like “Good morning” and call their names and introduce yourself to them. Sometimes it depends, you let them know what day it is today. Then you tell them what you’re going to do, like you’re going to get them up for breakfast and [ask] if they would like to get up. Some of them could refuse. If they do refuse you leave them and come back. Give them a chance to... you come back and it’s changed, yes they want to get up or sometimes they start getting up themselves so they are ready. You give them that opportunity to choose. (Interview with Care Aide, Manitoba)

One researcher noted: “I observed a [care aide] knocking on [a] resident’s door and singing, as he entered, “Good morning. Good morning” (Fieldnote, Manitoba). Bedrooms in this home were all single rooms, and the doors were often closed or slightly ajar, facilitating privacy. Staff knocked on residents’ bedroom doors, introducing themselves upon entry, and giving residents a choice about when to get up. In order to further enhance the feeling of privacy, staff did not walk through resident living areas to access stairs; instead, they used elevators located outside the resident “houses.” Phones were located at the ends of hallways and residents could use them to call nurses if they desired, instead of using the call bells. No pagers were used by staff in order to keep the resident living areas quiet.

### *Bathing and hygiene*

Staff in Canadian homes frequently talked about bathing times as challenges, though flexible approaches mitigated difficulties, especially in the morning. “Most [residents] sleep in on bath days” (Manager, Fieldnote, Manitoba), a promising practice that eased the work for care staff because they weren’t racing around before breakfast trying to get residents bathed and into the dining room. This rushing does not allow much time for resident choices, as a BC resident noted:

I had a care aide who tried to rush me through my bath...she did it three times...I timed it from the time I left my room until I went to the bathtub, had my bath, and was back in the room. It was 16 minutes altogether...I wanted to have a little bit of soak time and she wasn’t willing to give it. (Interview with Resident, BC)

Staff in the Manitoba care home were also given some decision-making capacity. They could, for example, carry out hygiene processes in a manner that fit particular needs, based on their knowledge of the resident and of necessary care. One resident had not had a typical bath since her admission in 2007 because she didn't want one: "It has too many traumatic issues.... We just wash her in her sink in her bathroom" (Interview with RN, Manitoba). There have been no obvious health consequences and the resident is not upset by bath trauma. According to a researcher, "[The RN] tells me there are no baths done on weekends, that they are all done on days and evenings from Monday to Friday and the requirement is one bath per resident per week. The residents are allowed to refuse their bath" (Fieldnote, Manitoba). The conditions also allow residents to get extra baths if they wish, another example of exercising choice. This combination of encouraging staff to make autonomous care decisions and pushing back on regulations that mandate strict mealtime and bathing routines supported comfortable, easy-going morning awakening experiences.

### **High staff ratios, flexibility and teamwork**

Higher staffing ratios reflected the philosophy of care and enabled numerous choices. In this home, the care aide-to-resident ratio was 1: 8 on the day shift, and the registered nursing staff (RNs and licensed practical nurses [LPNs]) were each responsible for 20 residents, alternating with administrative duties. Staff provided input on who to hire based on applicants' fit, their ability to work well in the teams, and their desire to make the care home a real home for residents. To promote continuity of care, the home hired full-time and regular part-time employees, had only a few casual staff, and tried to maintain minimal use of agency workers. The result of such staffing policies and the approach to care was that staff turnover was low.

The continuity of staff supported teamwork, as did other managerial practices emphasizing staff autonomy. Indeed, teamwork was a priority at the home, and this allowed flexibility in morning care. Staff worked together and became very familiar with residents and their particularities, as the following vignette illustrates.

7:30 a.m. The dietary aide enters the unit and starts setting up the tables for breakfast.... The RN comes into the dining room area with the medication cart. She starts to set residents up at the table. [The RN] asks a woman resident, addressing her by her first name, if she would like her usual peach juice. She asks another woman, "Do you want your favourite tomato or something different? We have peach, apple, orange, prune, cranberry." The resident, looking undecided, says, "Cranberry!" The RN replies, "Ohh, you're going to try something different today!" as she pours her a cup of water from the jug. She sits beside the woman and says, "Did you figure out what juice you would like? The resident replies, "Tomato." The RN smiles and says, "Nine times out of 10 you pick tomato. I was surprised that you picked cranberry at first." She gets her a cup of tomato juice.... [She] continues to pour water and asks each of the residents what juice they want. She knows everyone's favourite.... [At] 8:30 a.m. breakfast is served.... [At] 9 a.m. [the RN] sits with one woman who sometimes needs help. She asks her, "May I sit with you?"... It's a very relaxed environment.

9:30 a.m. Breakfast is over but there are still some residents at the tables drinking their juice and water. It is not rushed as residents are allowed to stay in the dining room as long as they wish. (Fieldnote, Manitoba)

Regulations intended to provide accountability often mean that RNs are responsible for more paperwork than care work and that there is a hierarchical division of labour. In this home, however, the RN was personally familiar with all of the residents and their preferences, in part because she was involved directly in providing at least some of the daily care.

A flexible division of labour, along with staff continuity and the teamwork they facilitated were encouraged by management. The fieldnotes describing how the RN set residents up in the dining room, served, and then assisted those who needed help — orchestrating morning mealtimes and even sitting down to chat with residents — was not an isolated occurrence but something we saw frequently throughout our stay. This kind of involvement meant the RN as well as

the care aides had considerable knowledge about resident preferences and dislikes. The managerial practices encouraged care relationships which in turn allowed both staff and residents to exercise choice.

### **Physical structure and non-profit status**

Other conditions, including the building's physical structure and non-profit status, contributed to the sense of "team" and "community" found in this care home. This was a small facility of 80 residents, which made it easier to get to know everyone. There were no locked doors inside, so residents could go anywhere in the care home. This made for easy movement between the central common area, the outdoor enclosed garden, and resident living areas. All services, including food, housekeeping, and laundry were in-house. This meant that all those involved in services were employees and therefore had a continuing interest in the home. In keeping with the home's philosophy, work was organized to ensure that all staff made daily contact with the residents. Everyone knew each other, and many reiterated they were like family, a close-knit community.

"Everybody is friendly in here" (Interview with Laundry Worker, Manitoba). This was echoed by another staff member: "Like we work well together like a team so that's what I like most about [my job] ... whoever needs help, you know, so if I need help with something I just say 'Can you help me with this?' So it's that kind of teamwork" (Interview with Receptionist, Manitoba). The maintenance person also confirmed that the best part of the job is "just being able to work with everybody as a team like that. Everybody is so close, you know?" (Interview with Maintenance Worker, Manitoba).

At this home, residents had morning-time choices — such as sleeping in, having different breakfast times, and bath-time flexibility — as a result of some key conditions. Together, these conditions facilitated a sense of community. Staff members knew each other and worked well together, and they knew the residents well enough to know their preferences and dislikes. All of these conditions allowed for exercising the right to choose in a meaningful sense, which is imperative to quality care and resident quality of life.

## PROMISING PRACTICES FOR EXERCISING CHOICE

- A philosophy of care that structures a home's policies and work organization to prioritize relational care rather than medical interventions and tasks.
- Decision-making capacity for both residents and workers that allows for pushback on regulations so that residents can choose when, if and how to take a bath.
- Single rooms that allow residents and staff to make decisions about privacy. Doors can be closed. Staff knock prior to entering bedrooms. Residents can call nurses by phone. Staff do not use pagers. There is a conscious effort to keep resident living areas calm and quiet.
- The teamwork that is integral to relational care is made possible because of work conditions, including: no contracting out; a shared division of labour; management support for teamwork; higher staffing ratios; staffing with full-time and regular part-time positions; minimal reliance on casual agency staff; and staff input about new hires.

---

## NOTES

1. BC Residential Care Regulations, 2009, 64(1a), 63(3a). Available at: [http://www.bclaws.ca/Recon/document/ID/freeside/96\\_2009](http://www.bclaws.ca/Recon/document/ID/freeside/96_2009).

2. BC Residential Care Regulations, 2009, 63(4). Available at: [http://www.bclaws.ca/Recon/document/ID/freeside/96\\_2009](http://www.bclaws.ca/Recon/document/ID/freeside/96_2009).

## *Chapter 2*

### **SMALL BITES AND FOOD IN SIGHT**

*Susan Braedley and Pat Armstrong*

Food is central to health, well-being, and social relationships for us all, but food takes on a particular significance in long-term residential care. Mealtimes are the main activities for residents in a long-term care home. They can offer opportunities for engaging with others, enjoying and savouring tastes, and experiencing a sense of control that can come from exercising choices. Various health conditions and frailties associated with aging often mean residents have little appetite and are frequently at risk of malnutrition or dehydration, making attractive food options especially important to this population. At the same time, many need assistance with eating and may have difficulty chewing and swallowing, complicating food presentation, preparation, and assistance.

Because our research team understood food as central to health, to social care, and to the work involved in these homes, we paid particular attention to how meals were prepared, presented, and consumed. We tasted what residents were served, noted how much they ate, observed how residents and staff interacted (or didn't interact), documented the work of both paid and unpaid care providers, and asked about food in interviews with residents, families, staff, and managers.

#### **No choices, poor choices**

Searching for promising practices, we were often disappointed in food service, to say the least. Indeed, throughout the project, we saw

multiple examples of practices that prevented choices and that failed to make food an enjoyable experience.

Too often our research team saw residents served meals heaped on trays, with unappetizing-looking food crowded on unattractive plastic dishes. There were no pleasant cooking smells to tempt the palate because food was prepared far from the residents, sometimes even off-site. An entire meal, including the main course, side dishes, bread, dessert, and beverages were placed in front of each resident all at once. Residents in these homes told us they were turned off by the sheer volume of food, by the presence of food they hated and too little of the food they liked, and by having to choose between having their cold food warm or their hot food cold — if indeed the food came hot and cold rather than all lukewarm.

We saw lots of food left on trays. Although it was common to provide residents a choice between two main courses, these choices often had to be made a week in advance. The choices bore no relation to how a resident felt the day the meal was served and many forgot what they had chosen the week before. Moreover, the options were often the same, week after week, as we learned in an interview with a resident and his wife in a BC home.

You can state likes and dislikes but it's really limited what you can do with that. So yes, it's difficult. You have choices, limited choices. For example, in terms of the meat... we didn't like the pork. (Interview with Resident, BC)

Because roast pork was thinly sliced I guess it was dry and hard.... So we told the dietician that no pork.... There were other times where there are dishes with ground pork in them so that's out too. So he's been getting too many chicken legs.... Chicken legs, chicken legs. You get sick of chicken legs. How do you explain the hard, dry roast [pork] stuff? Whether it's a patty or something else or it's pasta or what have you, well, that would be alright. Well we did manage [chicken] with rice. Sam doesn't like white rice. I don't either. There's not much food value in white rice is there? For some people here that seems to be the main dish. So we said no white rice but fried rice has vegetables

and eggs and stuff and so it's quite nice. So we did manage to get them to give Sam fried rice but not white rice [laughter]. (Interview with Wife of Resident, BC)

The dietician in this BC home told us more about food choices in practice. When we asked how the food service catered to the majority of residents who have an Asian heritage, she explained that, as a result of advocacy work from families, “We have a western menu and also we have an Asian menu. When they come in I will ask the residents and family which menu they want.” It is possible to change from one to the other “halfway through if they’ve been here for two weeks and say ‘I don’t think that this is really Chinese food. I’d rather go on western food.’ And then we can switch over. That’s no problem.” However, that meant the resident was stuck with western food at every meal, every day. And those who chose the Asian menu could not have soya sauce because it was considered a risk due to its high salt content, although families did bring some in for residents. Alcohol was seldom allowed either, as it was also considered a risk. For those who required a diet of pureed food, the options were even more limited and less appealing. In more than one case, pureed foods were mystery foods, their origins impossible to detect. Their colour, texture, and taste provided no clue.

Lack of choice was also a factor that limited health and wellness. In a Maritime home, a family member told us she became very worried about the high carbohydrate meals served to her mother. Her mother kept gaining weight, regularly required new clothes to accommodate this weight gain, and even a new wheelchair. The staff in the home told her the only option was a diabetic diet, which her mother refused to eat. These conditions were no doubt shaped by the fact that food in this home was pre-prepared and brought in from a distant production facility.

In many of the North American homes we visited, choices were limited not only in terms of what residents could eat but in terms of when they could eat and for how long, as well as how they should be dressed, and with whom they should eat. At least four structural factors shaped these choices: regulations, the ownership and location of food services, accountability processes, and staffing levels.

Especially in North America, there are lots of regulations covering mealtimes. In BC and Ontario, for example, regulations require as many residents as possible to eat in the dining room at set mealtimes. Intended to encourage social interaction and ensure nutrition, this regulation may be interpreted to mean always eating at the same table and with others. And the residents have to be dressed in appropriate clothing. To protect that clothing, we often saw residents wearing giant bibs or what one home calls clothing protectors. A UK home used light blue plastic ones.

In homes where the food services were contracted out and meals prepared at another location, all the food arrived at the same time on large, cafeteria-style carts. Dietary staff were employed by the contracted company. A large sign warned others not to talk to the food service staff, effectively preventing any care relationship. The arrival of the cart meant staff had to have every resident seated at the table by a specific time. Given that so many residents need assistance, staff had to start bringing them to the table long before mealtimes.

In a BC home, we saw a man who was the first to be brought to the dining room for breakfast, sitting alone and placed in front of a television show on cooking while he waited more than a half hour before the rest of the residents and food arrived. With only an hour scheduled in an Ontario home to serve and feed all residents between the time when the food was delivered and when the carts were taken away, the limited number of staff rushed from resident to resident to assist the many who needed help eating. Some residents didn't get enough time to eat properly, never mind to enjoy their meal. Moreover, in homes that used the standardized RAI-MDS documentation system intended to ensure accountability, we saw staff take time during the meal to write down how much residents ate and drank, consuming precious staff time while also undermining residents' dining as a shared, pleasant experience.

All this made it very difficult for staff, residents, or families to exercise choice in eating times.

## Choices that made a difference

Although we documented many structures and practices that prevented choices, we also documented promising practices that allowed residents, staff, and families to exercise choices in food and in the mealtime experience.

Offering the most choices were homes in which the staff prepared the food on the premises, and especially where some of the food was prepared in residents' living areas. In one Nova Scotia home, a kitchen tour, led by the cook, allowed us to learn how their food service worked:

[The cook] was pleased about their capacity to influence what was cooked and how it is cooked. They prepare the food for the hot carts that they then take to the floors and serve the food according to residents' choices as to how much and what they want. It is complicated to plan because a resident may initially want fish but then see the chicken served to someone else and change their minds. They take this into account in planning but, because they have the just-prepared food in hot carts, they can use the leftovers. This also allows them some creativity as they figure out how to use these leftovers. Experience has also taught them about who is likely to change their minds, who likes only some fish, etc., experience made possible by their contact with residents. (Fieldnote, Nova Scotia)

The kitchen staff took the hot food carts to the residents, allowing each resident to choose how much they wanted of anything on the cart or to reject it all in favour of an alternative such as sandwiches. From what we saw, this meant that most residents ate what was on their plates.

When the home was being designed, the kitchen staff in the old residence were involved in designing the new one. The main kitchen was located directly off the entrance foyer. Distributing food allowed the kitchen staff to see, greet and get to know all the residents, with whom they took time to chat. These interactions built social relationships and allowed food planning based on residents' eating practices. In addition, the small cafeteria supplied by the kitchen

allowed staff, families, and residents to buy food at very reasonable prices and, not incidentally, sit around and chat while checking out the quality of the food.

In addition to the main kitchen, there were kitchens located in each living area of nine residents. These kitchens were controlled by Food/Cleaning Aides (F/C Aides)<sup>1</sup> whose primary food responsibilities were to provide breakfast and snacks. F/C Aides also ordered supplies based on their understanding of resident needs. Our fieldnotes demonstrate the choices exercised by both residents and staff in this home:

Other residents wandered or wheeled in and the F/C Aide seemed to know what each wanted in terms of coffee and/or juice, whether they wanted eggs and how they wanted them done. One resident sat down for breakfast in her housecoat and slippers. Another had curlers in her hair. When the hot food arrived, the F/C Aide explained to the dietary worker that a particular resident required the bright blue plate because she had sight issues. The television was not on and people could sit where they wanted (including alone)... Later in the day I smell banana bread cooking and see the F/C Aide take her banana bread out of the oven, before slicing it for the residents who are around. (Fieldnote, Nova Scotia)

Some of the residents wore bibs but these had been purchased by staff in local shops and were made of a popular tartan.

We saw other promising practices. In some homes, smells and sights of favourite foods not included in dietary rules and restrictions were facilitated via, for example, a large popcorn machine in the main living room of a US home and an ice cream parlour in another US home. In Sweden, Germany and the US, we saw food available 24 hours a day, made possible by kitchens on site and flexible management. In a German home, residents had the option of participating in regular food preparation. This was the case even for those who had dementia.

We saw that even pureed food could be made more palatable under such conditions. In one Ontario home the food manager decided to take the time to show residents the food before she pureed it, allowing

residents some choice about what went into the blender as well as an opportunity to enjoy the shapes and smells of the food. In the Maritimes, the on-site kitchen staff avoided the pre-prepared pureed food and pureed all food on site.

### **Food challenges mean changing the rules**

Offering choices for residents means that managers must be willing to allow both residents and staff some autonomy. This can mean resisting regulations and even families. We saw many examples of this resistance and a resulting rule change in the UK.

When a woman with long-term anorexia entered a UK home we studied, the family wanted the manager to cure the anorexia. The manager explained that the home does not fix people. Nevertheless, when she and the staff noticed that the woman became upset on entering the dining room, they did not make her sit there. Instead, they placed small bits of food in various spots that made it possible for her to nibble. The resident gained weight. Leaving the food around and allowing her to avoid the dining room were not in keeping with regulations or the family's wishes, but it respected resident preferences and well-being. Accountability structures that emphasized documenting exceptions rather than every practice, and that recognized staff's ability to judge problems, facilitated these responses.

In this same home, the chef noticed that residents were not finishing their meals. His investigation suggested that the presentation of full plates of food dampened their appetites. So he offered residents colourful, attractive food in bite-size portions, arranged on trays, much as what you would see at a cocktail party. Eating was no longer a problem as residents kept coming back for more of the appetizer-sized food. This strategy was possible due to the autonomy granted to the staff, the staff's and manager's knowledge of the individual residents, and the manager's willingness to go beyond the strict confines of regulations. The staff were trusted to ensure proper hydration and nutrition rather than spending precious time on documenting consumption.

Choice extended to alcohol consumption. This same home had a fridge with beer and wine. Residents could have a drink when they chose. When we returned to this home a year after our initial study, there was a drumming party for staff, residents and family in the garden. Staff and family members were serving trays of beer.

As Sally Chivers explains in Chapter 3, we saw a more relaxed approach to alcohol in Sweden and Germany than we did in Canada. What we did not see was anyone under the influence of an excessive amount of alcohol. The staff knew their residents and the managers trusted the staff to exercise their knowledge to ensure that no one drank too much. Moreover, the division of labour was flexible in ways that both allowed staff to know residents and supported team decision-making around the safety of resident choices.

Meals are critical to care and choices are central to the pleasure as well as to the nutrition provided by meals. In order for there to be choices for residents, there also must be choices for staff and we saw many examples that allowed meaningful choices to be made.

## **PROMISING PRACTICES FOR EXERCISING CHOICES**

- Food prepared and cooked on the premises; food that is both available and accessible 24/7 in the living area and in the residence and that can be prepared there; healthy, colourful food that is familiar, appealing, and easy to consume in small portions.
- Regulations that allow flexibility in mealtimes.
- The promotion of care relationships, including time for kitchen staff to “get to know” residents and families in ways that allow them to take food preferences and histories into account.
- Managers who support staff autonomy, innovation, flexibility, and teamwork and who are willing to challenge regulations that inappropriately limit the exercise of choices.

- Ensuring staff have knowledge not only about health but also about food appropriate to late life and pleasure; ensuring that staff have skills in food safety and eating and how to support the exercise of choice; and ensuring that staff be allowed to apply these skills.
- 

## **NOTES**

1. We refer to this worker as a Food and Care Aide although this was not the actual title used in this work setting.



## *Chapter 3*

### **MAKE MINE A DOUBLE**

*Sally Chivers*

We should expect that people living in long-term residential care who drank alcohol before moving in would want to continue to do so in their new home. But given the predominance of medicalized routines, to the extent of measuring and recording input and output, even having a little nightcap can complicate care in some care contexts. In this chapter, I explore how allowing residents to choose when and whether to consume alcohol, within reason, transforms experiences of living in long-term residential care.

Although people sometimes drink for the physical effects of relaxation, drinking alcohol is also deeply social. It offers a form of altered consciousness that many people are accustomed to from their social lives outside long-term care, so it has the potential to be less alarming to them than the sedating effect of medication prescribed within long-term residential care. Since drinking alcohol has often been part of how people interact in life outside long-term care, continuing to be able to indulge within an institutional space can help to ease the transition and mark the new space as homelike.

Not only did we learn about the social and physical function of liquor during our visits, we also learned about each place according to how they approached the provision of alcohol to residents, particularly whether it was a matter of choice or not.

One UK long-term care residence handled the consumption of alcohol

in a smooth transaction that was facilitated by working conditions framed by a perspective on care that welcomed and encouraged flexibility. In this home, breakfast time was staggered over a few hours, as residents awoke and could choose whether to eat in a small hybrid dining-living room or in their bedrooms. A cheerful care aide offered up her name to each resident and made sure they demonstrated that they understood who she was as she attended to their requests one by one.

One resident chose to eat in the living room area and worked her way through a Weetabix with a sprinkle of sugar, then a piece of toast, then a whole banana, not cut up. The care aide took time to let the resident know when she was leaving the resident's side to fill part of the order and when she returned. She also made clear where she placed the food. As she helped the resident eat, she chatted amiably about the resident's children, whom she knew by name. When the care aide asked the resident what she would like to drink, the resident ordered, quite straightforwardly, a gin and tonic. Unfazed, the aide gently suggested that perhaps the resident would prefer to have a cranberry juice first. When the resident made it clear that her choice was to have a gin and tonic, it was served in the same manner as the Weetabix and toast. What to many people might be an unexpected event, ordering a stiff cocktail for breakfast, was handled smoothly by a worker who had the latitude, materials, and time to meet the request.

An open and accepting attitude towards alcohol consumption in the home was the primary condition that allowed a seamless response to the beverage portion of the resident's breakfast order. While not typical at breakfast, the consumption of alcohol was an expected part of day-to-day life for the residents. When residents wobbled on their feet, carers joked about whether they might have had too much to drink.

Just down the hall from the living-dining area was a small lounge with plush recliners complete with pillows and throws, a television, a sound system, and a small bar, the type one might have in a den or basement at home. There were sherry glasses on a decorative platter, cold beer, assorted liquor bottles, and a dartboard. Volunteers were quite proud of the bar, which they helped to stock from their own supplies. As a volunteer told us in an interview:

I mean if you say to somebody, "Have you seen the bar?" and they look at you a little bit condescending and a little bit "Yeah, right." But it is. There is a bar. There is alcohol here. They can have a drink if they want one.

[Janet] does love her wine. I mean obviously we don't let them get drunk but if they want a drink they can have a drink. As I say, obviously we wouldn't let them get blind roaring drunk but I think this is lovely really. Nice isn't it?...

And somebody shouted out to one of the residents "Do you want a gin and tonic?" And I said, "Yes please." Didn't get one. [laughter] In the afternoon if somebody is a bit down, "Do you want a gin and tonic?" Or [the manager] will come round with the Bailey's and tubs of crisps and popcorn and that sort of thing very often on an afternoon. (Fieldnote, UK)

This bar is for the residents, and a log is kept of what residents drink but it does not strictly measure input-output as at other sites we visited. A sign states that only staff should be dispensing drinks. But there were bottles of wine scattered in different kitchens throughout the home, for residents who were able to help themselves. And we observed a maintenance worker getting a beer for a resident who had just returned from an outing. There was latitude in the ability to retrieve drinks from the bar upon request in that it wasn't restricted to the workers who normally served meals.

Broader conditions in the home allowed for the possibility for alcohol to flow relatively freely.

In this space, drinks and meals were served individually, and there was a relaxed feeling of going with the flow, a phrase we heard often from the manager and various staff. Staff were not obsessed with nor overly regulated by risk prevention or health and safety concerns, though they met the minimum guidelines for the area. Meals were treated as social occasions rather than tasks. Each resident's care plan included the responses to questions about relaxation and habits, which were then taken seriously in how they chose to live in the home.

In different settings, for example, when all residents were fed in a defined seating plan in a dining hall by a few frazzled staff, or when the intake of alcohol was permitted only by doctor's prescription, offered in plastic cups in the evening rather than in glasses with a meal, residents' desires to drink alcohol outside of prescriptive times and places and amounts led to difficult encounters for staff and visitors. In some sites we visited, alcohol was allowed only with a doctor's prescription and stored in a locked medications room. Those sites also had strict dining-room hours and much less flexibility in their daily routines. While we were encouraged by the open approach to alcohol at one Norwegian site, it was treated as a very special nighttime occurrence rather than reflecting a response to a request from residents.

The promising practice of flexibly accommodating the consumption of alcohol, according to the expressed desires of residents, benefits the residents in clear ways. But it also makes for a smoother working experience for staff. Further, it creates possibilities for a convivial form of social interaction between visitors and residents. This should perhaps be expected because if long-term residential care is meant to be homelike or even hotel-like, such social drinking could be the norm. But based on observations at other locations where alcohol was treated as parallel to medication, our team was struck by the amount of alcohol consumed at the UK site and by the greater latitude and approach to aging in long-term residential care it represented. By contrast, the strict regulation of alcohol that we saw at other sites reinforced the hospital-like aspect of some long-term care residences and a power dynamic whereby staff appear to have power over residents while also having little or no leeway to choose whether to serve liquor.

### **PROMISING PRACTICES FOR EXERCISING CHOICES**

- Alcoholic beverages that are available in ways that provide pleasure for individuals and for groups.
- Staff with the capacity to respond to resident choices about alcohol, based on their knowledge of residents and of their medical conditions.

## Chapter 4

### SPONTANEOUS ACTIVITIES

*Christine Øye, Gudmund Ågotnes, James Struthers and Frode F. Jacobsen*

In recent years there has been a growing demand in the Western world that persons living in care homes enjoy more active lives based on their own needs and interests, regardless of their degree of cognitive impairment.<sup>1</sup> Many older people living with dementia in these homes lack meaningful activities. Care is often routinized and scheduled like clockwork rather than being spontaneous or adjusted to individual needs. Activities, spontaneous or not, are widely recognized as important for living a meaningful care home life and preserving a sense of self.<sup>2</sup>

Care homes can more or less be understood as “total institutions” in which residents live together with few possibilities of escaping their premises.<sup>3</sup> Social life for most residents is limited to the social and physical boundaries of the home and visitors from the outside world can be few and far between. Boundaries within the homes can either limit or promote spontaneous activities with and among residents.

Care homes differ significantly, across and within jurisdictions, with regards to whether they focus on formal and strictly organized or spontaneous activities. The need for and advantages of spontaneous activities, which are often difficult to maintain during a home’s hectic everyday life, are too often underappreciated. This chapter explores examples from our site visits in Norway, Sweden and Ontario that show how spontaneous activities can both enrich the quality of resident lives and reduce anxiety and agitation.

### **Yahtzee. Late afternoon in a memory unit of a Norwegian care home**

A spacious common room is the physical and social centre of the unit. It has four tables: a big one primarily used for dining, and three smaller coffee tables. At one end of the room there is a television constantly playing in front of a sitting area.

The unit is quiet. Supper is finished, many residents are napping in their rooms, and no visitors are present. Two care staff are tidying up in the kitchen area, while the others are in residents' rooms. In the common room an aide is clearing up from a coffee table. She departs, leaving the room empty except for five residents. Two are dozing in front of the television while another is fast asleep at a coffee table. The other two are sitting far apart at the large dining table, awake but not communicating.

A student enters the room, sits down between the two residents at the dining table and tries to get a conversation started. The residents, Kevin and Chloe, both suffer from Alzheimer's and struggle to follow the conversation. Kevin, in particular, likes to talk, but mumbles and does not appear to understand what the student is saying. She is frustrated with her attempts to provide the residents with some company. After ten minutes she walks over to a small basket beside the table where she finds a game of Yahtzee. She returns and asks Kevin if he wants to play. Kevin looks at the game and asks, "What's that?" The student explains. "All right, then," he says. The student invites Chloe to play too. She nods, moves closer to the other two and joins them. Chloe gives the impression she knows the rules.

They play for 20 minutes. The student enthusiastically assists Kevin and Chloe, creating a sense of excitement. She helps Kevin with the dice, since his fingers are clumsy, and reads the numbers aloud, since his eyesight is poor. She also helps Chloe, who can roll and read the dice but struggles with the numbers. She seems frustrated but smiles when the student helps her out. After a while, Chloe takes over the job of filling in the numbers on the small notepad, something she does with a little help from the student, while Kevin awaits his turn. On two occasions Chloe fills in the wrong number. The student notices her

error but does not point it out. The game ends with a victory for Kevin, who seems happy. Chloe is grinning despite coming in second.

During the game several staff enter the common room. One approaches the student and asks what they are doing. She explains. The nurse praises her initiative. She also whispers quietly that she is amazed Kevin is able to play at all. Another nurse joins them and asks where they found the game. The student explains that it was right beside the table in the basket. The nurse, apparently unaware of the small batch of games sitting adjacent to the residents, is surprised.

Activities usually happen at regularly scheduled times. Four days a week residents can join in at the care home's main activity centre while other activities are brought to their unit one day per week. They are mostly limited to one and a half hours per day. Only on rare occasions such as holidays are other events planned. Playing games or making puzzles rarely occur. Care staff do not see this as part of their job description but rather the responsibility of specialized personnel. Significantly, this home does not have a group of volunteers to lead either scheduled or unplanned activities. Students are clearly a valuable resource for sparking such initiatives. Having not yet internalized the routines of the unit and the care home, their fresh eyes and open minds may result in spontaneous and meaningful social interactions (Fieldnotes, Norway).

### **Bike tour. A memory unit in a different Norwegian care home**

A resident approaches a researcher and asks if she would like to be shown around, since the researcher has a "visitor" nametag on her chest. First, the resident shows her a forested area outside by pointing through the window and tells her that she used to go for walks in these woods. She says that it is a shame they are locked up in here because there are so many nice places to go for a walk outside. Another resident approaches and says this is like being in a prison and asks a care aide, "Why can't we go out as we want?" The staff member, somewhat embarrassed, replies, "What if you get lost?" The resident answers, "But, see (pointing out the window), where can we get lost? It's just going around here." She continues, "Well, even though we are a bit 'nutty'"

(pointing at her head). “Yes, a bit ‘nutty,’ I don’t know the word but ...” The other resident laughs and also points at her head, repeating the word “nutty.” Then the first becomes serious again and says, “I really want to go outside for a walk. Look at the nice weather, we are locked up here.”

After a brief conversation about the outside area, the “tour” continues up the corridor. When they arrive at a stationary exercise bike, one of the residents climbs on it and starts cycling. After a few minutes, five other residents show up and begin mingling around the bike. Two male residents form a line waiting to get on it. When the first male in the line starts to cycle, the other man takes his walker and begins pushing it into the bike. The resident who is trying to cycle tells him to stop because he is disturbing him: “I can’t cycle when you push that thing on my bike,” he says, pointing at the walker. The man keeps on pushing his walker until the other man gets off the bike. The man with the walker then tries to get on the bike but without success. He loses interest when the “tour guide” continues down the other corridor. The five residents follow her on the rest of her “guided tour” until it ends (Fieldnotes, Norway).

As these two Norwegian vignettes illustrate, “objects” can spark possibilities for spontaneous activities. A Yahtzee game, a nametag on a visitor, or an ergonomic bike can create an opportunity for a “show and tell” activity. Based on present experiences as a resident (being in a locked-up institution) or memories from earlier lives (showing a visitor an activity or skill from well-known surroundings or recalling a familiar game), spontaneous activities can reinforce residents’ continuity of identity. Small events, such as a visitor entering a hallway, can also provoke spontaneous activities by encouraging residents to flock towards and interact with each other and so create meaningfulness in each other’s company. This can emerge from sudden conversations over what it is like to be a resident with impaired cognitive functioning (“we are a bit ‘nutty’”) as well as from quarrels around whose turn it is to ride a bike.

Spontaneous activities like showing a visitor around create a space for residents to be helpful as well as to be a part of something outside themselves, instead of always being the ones who seek help.

## **The right to vote. Election day in the dementia unit of a Swedish care home**

In this new home, located in the downtown area of a large city, a conscious effort is made to encourage staff and residents to engage in regular conversations with each other about events both inside and outside of the home, and to encourage residents to spend time together. The building is continually supplied with newspapers, films, print and audio books in a variety of languages through a program run two and a half days a week by a staff member from the municipal library. Residents read newspapers quietly by themselves, or occasionally out loud to others sitting nearby. The most cognitively aware residents, staff explain, were “deliberately placed together when they moved into the new building” so they “would have a lot to talk about,” a recognition that speaking and listening to others is one of the most important of all human activities.

A European Union election is taking place during our visit and it is a lively topic of discussion at one dinner table, both among residents and among the culturally diverse staff. Staff are encouraged to eat small meals with residents to promote sociability and are also regularly coached by a dementia care nurse specially trained in strategies for sparking conversation and activities among the home’s inhabitants and visiting family members. Staff are reminded by this nurse that when pressed by family members to provide more formally organized activities, they need to “find a balance. There are all those demands on activation from the facility.... It is important to inform family that [residents] need both activity and rest.”

One of the most articulate residents, who speaks forcefully about “who she voted for and why,” has returned from a voting station in the main lobby where her daughter took her to cast a ballot. Earlier in the day, staff vigorously debated whether or not another resident on the unit with severe dementia, who also wanted to vote, should be allowed or aided to do so. His wife was insistent that he should be helped to participate in the election since casting a ballot for the same party had been an important part of his former life and political identity.

The head nurse sought out the advice of her staff. "It is an ethical dilemma. On the one hand, it can be seen as maintaining him as he always was. On other hand he does not know what he is doing and he can't decide what to do and not to do." The position of senior management was that helping him vote was a family rather than a staff responsibility. The assisting nurse had doubts but said she had promised his wife that she would help him go downstairs in his wheelchair to cast a ballot. The issue was resolved with the assisting nurse taking him to the voting station in the lobby. In the end, due to the degree of his cognitive impairment, he was unable to vote successfully, but the decision to reinforce his citizenship identity was thoroughly discussed, respected, and acted upon by the staff (Fieldnotes, Sweden).

### **Let's dance. A memory unit in a new suburban Ontario care home**

There are 23 residents finishing breakfast. Four care aides and one Licensed Practical Nurse (LPN) are on staff, along with a dietary services person. After breakfast, the residents are wheeled out into the lounge area in front of the nurses' station so that the LPN can start her round of medications. One of the most aggressive residents, a woman who is restlessly pacing the room, mutters loudly to a care aide, "I'll give you a whack. You said you'd whack me," and "I'd like to get out. What can you do about it? It's not fair. I'll never get out."

The LPN, noticing her agitation, stops her work and walks the woman over to a piano, where a male care aide is playing "Hey Jude." The resident continues to complain loudly that she is "not getting out." The LPN calmly replies, "I'm not speaking to you right now... I'll put some music on and you can sing along. I just want to hear your voice nice and loud." She puts a CD on the player and starts singing along with the resident, while holding her hand and dancing to "Love is a Many Splendored Thing." The resident "starts singing softly" and the LPN says to her, "it's beautiful.... Look at your audience. They're enjoying it. You're a great singer." The resident is now "whistling to the song and spinning around." The LPN asks, "Why don't you go for a nice walk by yourself," takes her by the hand and leads her off down the corridor. The care aide tells the LPN as she passes by, "You're Jesus today" (Fieldnotes, Ontario).

By interrupting her busy round of medications, and choosing to engage with this resident in song, dance, and a walk, the LPN demonstrated the power of spontaneous activity and relational care for defusing anger and restoring calm to one of the unit's most aggressive and anxious residents.

### **“Oh Canada.” An evening shift on the same Ontario memory unit**

It is an hour past dinner time. Five residents, accompanied by a volunteer, are returning from a church service elsewhere in the building. Their entry unexpectedly sets off a loud door alarm. There are a dozen or more residents lined up in the lounge area. A woman in a wheelchair is startled and tries to stand up, setting off her wheelchair alarm. Another woman resident, also startled, begins to yell loudly. The space, which had been calm, is now a cacophony of noise from suddenly agitated residents.

The daughter of one of the residents seizes the moment by moving into the middle of the lounge to begin an impromptu “singalong” of Canadian folk songs and children’s songs. Six of the other female residents start to sing along with her, while a male resident stomps his feet to the rhythm. One of the Scandinavian student members of our research team then asks if they would sing Canada’s national anthem for him. The resident’s daughter announces formally to the group that “we have a request,” and starts singing “Oh Canada. Our home and native land.” Some of the other residents join in. The others listen quietly. Calm is restored. The student who asked to hear the national anthem afterwards notes that the daughter, who started the impromptu singalong, “is the first relative that I see really trying to involve other residents than just their own relatives.” This family member had also previously been “very critical of the lack of suitable activities for the residents” (Fieldnotes, Ontario). By imaginatively taking matters into her own hands, she transformed an unexpected outburst of agitation into a joyful event.

### **Opportunities for spontaneity**

Within this memory unit, understaffing, overcrowded common areas (due to poor design), insufficient activities, and noisy alarms created

challenging conditions of care during our site visit. Despite these obstacles, on these two occasions we observed staff, visitors and family members taking the initiative to use music, song and dance to calm the anxiety and agitation of residents and create pleasurable outcomes. Both examples occurred within a home that did not have a formal program of training around music therapy or daily musical events beyond twice weekly singalongs and hymn sings, making the spontaneous interventions of the LPN, the visiting student researcher and the family member all the more significant.

The vignettes in this chapter, across a spectrum of four residences in three countries, illustrate how spontaneous activities and choices can open up care homes to the outside world by:

- mobilizing fresh student eyes;
- creating spaces for residents, staff members, relatives and visitors to exercise choice and agency and experience unplanned encounters as well as the pleasure of being heard;
- reaffirming continuities and meaningfulness in residents' personal identity;
- defusing anxiety and aggression through the power of music, dance, touch and song; and
- responsibly negotiating the ethical dilemmas of citizenship for those with advanced dementia.

In some of these cases spontaneous activities occurred against a backdrop of unpromising conditions of care. In others, they flowed out of the tacit and often underappreciated knowledge of staff, visitors and family members or, as in the Swedish example, they were fostered by a workplace culture that promotes resident, staff and family conversations; practices collaborative decision-making; and maximizes opportunities for residents to spend time together. These stories underscore how spontaneous social interactions emerge from and enhance opportunities for exercising choice by residents, staff, family members and volunteers in care homes.

## PROMISING PRACTICES FOR EXERCISING CHOICES

- Recognizing the importance of allowing spontaneous activities.
- Allowing staff to create spontaneous activities, to respond creatively to unplanned events, and to consult together on strategies to address new situations.
- Encouraging visitors and volunteers in ways that create unplanned events.

---

## NOTES

1. K. Ervin and A. Koschel. (2012). Dementia Care Mapping as a Tool for Person-Centred Care. *Australian Nursing Journal*, 12(110):32-35.
2. B. Harmer and M. Orrell. (2008). What is Meaningful Activity for People with Dementia Living in Care Homes? A Comparison of the Views of Older People with Dementia, Staff, and Family Carers. *Aging & Mental Health*, 12(5):548-558.
3. E. Goffman. (1961). *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates*. New York: Anchor Books, 1-124.



## Chapter 5

### LET'S TALK ABOUT SEX... IN LONG-TERM CARE

*Tamara Daly and Susan Braedley*

*We treat them as asexual and it's a tough area.... I sense there's a lot of discomfort and it's somehow not okay here. Surprisingly. They're human beings. [laughing] So it's an area I guess I haven't even... that's one of those mountains... just by you talking to me about it I'm thinking well, if we don't ask the question, if we don't open up that conversation, they are not going to tell us. (Interview with Social Worker, Ontario)*

*We get to know mothers and fathers as very different people from how their children know them. It is easier for us to handle the fact that residents have sexual needs than it is for sons and daughters. (Interview with Unit Nurse Manager, Norway, Translation)*

These quotes are taken from interviews with front-line care workers in Ontario and Norway. The conditions that they represent are very different, leading us to ask: what conditions enable residents to exercise choice about sex and sexuality in long-term care? How are residents enabled to maintain or develop intimacies? In what way are families involved? What is the role of staff and what are the options available to them? How is choice protected?

Sex, sexuality and feelings of intimacy are intensely private matters for most people, for most of their lives. In long-term care, these topics have often been treated with discomfort or even as taboo — an effect of ageist, ableist notions that seniors and those with disabilities are, or should be, sexless. After moving to a facility setting, people's privacy

about sex and sexuality, and opportunities for intimacy and closeness, are often lost.

In our site visit interviews and observations, we encountered many dilemmas related to intimacy, sex and sexuality. These dilemmas were shaped by collective living and residents' differing vulnerabilities, as well as by moral judgements and social stigmas. In observing staff discussions, we noted that residents' needs for intimacy and privacy were often forgotten. Instead, the focus was usually on the who, where, what and when of having intercourse, moral issues such as infidelity to a non-resident spouse, and health issues such as sexually transmitted diseases or infections. Concerns about sexual preference, or people's different needs depending on age or stage of disease, were less often discussed. Yet we also observed more promising approaches to intimacy, sex and sexuality that promoted respect and dignity.

In the following, we highlight conditions related to exercising choice for residents and for workers related to three different issues regarding sex, sexuality and intimacy for residents and for workers, drawing on three examples from our research. First, we discuss dilemmas linked to privacy and dignity that were problematic due to shared rooms; second, dilemmas linked to intimacy that remained unresolved; and finally, dilemmas of sexual aggression from a resident towards staff that were effectively handled in ways that respected the dignity of residents, staff and family members.

### **Dilemmas of privacy and dignity**

It is often difficult to find privacy in communal living settings, but this is especially the case when rooms are shared or when there are no locks on doors. The following fieldnote excerpt highlights some of the tensions.

In an Ontario residence, a 48-year-old woman resident shared a room with two much older women. The younger woman watched pornography on television every evening, leaving the television on until four in the morning. The other residents complained that they were disturbed by the light from her television and by her

masturbating. The younger resident had taken over a larger portion of the shared room and the staff re-arranged the beds to try to minimize disturbance. It didn't work. The issue was a regular source of complaints and quickly deteriorating relationships. (Fieldnote, Ontario)

The conditions of care in this facility have created this challenge. In Ontario, double/shared rooms are the standard, while single rooms are both in short supply and involve extra resident fees. In this case, all three residents relied on government pensions and subsidies so fees for private rooms were impossible for everyone. In addition, resident in-take processes do not include a requirement to consider or discuss intimacy, sex and sexuality needs. Further, despite being trained and knowledgeable of the Patients' Bill of Rights, workers told us that there was no institutional flexibility to accommodate the rights to privacy.

An interview with a social worker at the facility explained some of the issues:

We have these modules that we had today. One of the modules was, you know, the Patients' Bill of Rights... specifically about being able to create a private space for people to enjoy intimate relationships. We're not even there, you know... it's challenging what's become acceptable... this young woman who watches a lot of porn on her thing and it also says they should be allowed to go to bed when they want and get up when they want. Well if she wants to go to bed at four o'clock in the morning well that's just not acceptable. And I can understand why it doesn't work, you know. (Interview with Social Worker, Ontario)

These conditions put workers and residents in contradictory, often no-win situations. While workers were required to respect residents' needs and preferences, the means for problem-solving were not available to them. Residents were left coping with a lack of privacy that required them to either give up intimacy and sex or to become a "challenge" for staff and other residents. In this case, follow-up research revealed that the younger resident had been given her own room. We did not discover how the cost for a private room was covered. We wondered

if the resident's late-night activities were a form of resistance to the institutional failure to address and support her needs and desires for intimacy, sex and sexuality. And what are the options for residents who do not or cannot resist in this way?

### **Dilemmas of intimacy**

A resident in her 70s is seeing an unemployed man in his 40s who hangs out in the neighbourhood. He had become friendly with another resident and then this woman. According to a staff member, the resident has "really perked up" since this involvement. However, she and the other staff are worried about the relationship. "We worry about economic exploitation." They have no indications of exploitation, other than that the resident has purchased some cigarettes and coffee to share with him. (Fieldnote, Ontario)

Staff often said that they felt protective of residents whom they believed to be vulnerable, lonely and longing for intimacy. In this case, staff were worried about economic exploitation, but had not spoken to the resident or their family about their worries.

In contrast to staff concerns, residents spoke to us about their desire for intimacy. Intimate, even romantic feelings, relationships and fantasies are sources of pleasure. In some instances, the need for intimacy resulted in awkwardness or shame. One Ontario resident told us: "You see, I'm not supposed to have these feelings or if I do, it's ridiculous. But I want them, I like them, I wasn't expecting anything, you know, just to have that feeling and feel something."

Issues related to intimacy, sex and sexuality are part of everyday/every night problems in long-term care, but how these issues are addressed in favour of choice is directly related to conditions that enable staff, residents and their families to have frank and open conversations about positive, intimate relationships. In this example, what is the staff responsibility, and what are residents' rights to pursue intimacy, even if it involves gifts such as coffees or cigarettes? How can staff support residents to seek and maintain intimate relationships?

## Dilemmas of sexual aggression

Care workers often talk about being grabbed, pinched and touched in a sexual manner during the course of care work, and especially during intimate body work, such as baths and changing of incontinence products. This aggression can come from men or women, and is often attributed to dementia or other conditions.

In our research, we noted that sexual aggression may be critically affected by the conditions of care. During a series of interviews at a Norwegian nursing home, an assistant nurse described a resident who “was very interested in women” and proceeded to make grabbing motions in the air to mimic how he grabbed at the female staff.

The workers took the opportunity to address the problem. The assistant nurse, a male, had gained the resident's trust. The resident confided his desire, prompting the nurse to discuss it with staff and accede to the resident's request. The assistant nurse (A) explained his thinking in an interview with one of the authors (I):

- A: I think sexuality is going to be a theme...
- I: Is that an important question in elderly care?
- A: I think so. That was a surprise for me when I started here that the elders showed so much of their own sexuality in a way maybe because of the sickness also because you never look at your grandmothers or grandfathers like sexual human beings in a way.
- I: That's true.
- I: Was it a new way of thinking for you?
- A: Mhmm. Yeah, absolutely.
- I: So is this the sort of place where residents can be sexual beings?
- A: Yeah, I think so.
- I: How do the staff make sure that it's available to people?
- A: For example, I have this guy on the other side and he's very interested in women. He doesn't like men that much. But I was going to buy some porn magazines for him in 7-11 and I got quite friendly.... I did agree [with his request for porn]. Yeah, I did buy it for him and he got a magazine every month. So I guess

we try to meet them. There were some discussions around this because some women said porn is not something we want to support and we had to talk about it. But we ended up it's he that wants it. (Interview with Assistant Nurse, Norway)

Following the conversations among staff, the assistant nurse followed up with the family.

I talked to this man. I made the phone to his sister and told her before we are going to do this and she absolutely supported it. But I think it's important to have that talk before. (Interview with Assistant Nurse, Norway)

In order to accommodate the request, the assistant nurse was allowed to use work time to go to a convenience store to purchase the magazines. Staff members agreed that once the resident was receiving the magazines the sexual aggression stopped. Later, another challenge was presented when the assistant nurse decided he no longer wanted to make these purchases; colleagues raised the issue and its resolution in interviews with us.

I: So you bought a magazine for him?

A: Yeah... I don't buy them anymore because we had this argument.

I: So he subscribed?

A: Yeah, so he got it in the mail so I didn't have to go. It was stressful for me. I was feeling like a teenager again. [laughs] (Interview with Assistant Nurse, Norway)

A subscription meant that the magazines were delivered to the office and distributed directly to the resident, allowing dignity for both staff and workers. Importantly, the problem of the resident's sexual aggression was resolved. This Norwegian nursing home displayed a particularly open and amenable atmosphere and conditions of work and care that made discussions of sexuality and the positive resolution of intimacy issues more likely.

## **Concluding thoughts**

Sex, sexuality and intimacy can trigger dilemmas for residents, families and staff in long-term care settings. In our research, we heard from staff and families who expressed concern about whether a resident experiencing cognitive disability was capable of informed consent for sexual intimacy, and about the realities of transmission of sexually transmitted diseases. There were cases of residents romantically pursuing other residents who did not want this attention; residents whose sexual activity was considered inappropriate or problematic; residents who experienced discrimination due to their sexuality; and residents who sexually harassed staff. These situations, and many others we encountered in our research, forced us to consider the conditions of work and care that could anticipate, respond to and support residents' varied needs and desires for intimacy and sex while ensuring conditions of dignity and respect for both workers and residents.

Creating these conditions is neither easy nor straightforward. For both staff and residents, discussing and addressing issues of intimacy, sex and sexuality can be uncomfortable. Staff may have concerns that raising sex and sexuality is an invasion of a resident's privacy, especially when family are involved. Staff may also lack the skills or training to discuss intimate life in ways that maintain residents' dignity and personal boundaries. Residents may have concerns about whether their information might be shared with family or others without their consent, and may not want to share this kind of information at all. Yet when there is a failure to address these issues, it means that residents' sexual and intimate needs, desires and relationships go unacknowledged, unaccommodated or denied.

## **Factors that limit resident choices**

Our findings suggest that the following conditions serve to limit residents' opportunities to exercise choice regarding intimacy, sexuality and sex:

- An institutional culture that treats residents as asexual and reinforces ageist and ableist attitudes.

- An absence of protocols that require staff to learn about residents' preferences regarding intimacy and sexuality.
- An absence of staff training to build skills and comfort for thinking through and addressing issues of intimacy and sexuality.
- An absence of institutional supports for residents or workers to problem-solve effectively.
- The high cost of private rooms.

In contrast, several conditions in the Norwegian example enabled choice for both residents and workers in ways that addressed sexual aggression beyond normalizing it as part of "the disease"; identified and supported the need for sex, sexuality and intimacy; and retained the resident's, workers' and family's sense of dignity and respect.

### **PROMISING PRACTICES FOR EXERCISING CHOICE**

- Working conditions, such as time, autonomy and the ability to make decisions that enable personalized care, along with the time to talk with the resident, staff and the family about how to resolve the issue.
- Flexible working conditions that enable staff, family and residents to redress an issue and confront sources of discomfort affecting both residents and workers.
- Staff time to use interpersonal, social and problem-solving skills.
- A social, rather than a strictly medical, response.

## Chapter 6

# OPPORTUNITIES TO PROBLEM-SOLVE: CONDITIONS FOR DEMENTIA CARE

*Susan Braedley and Marta Szebehely*

*It is lunchtime. Yelling interrupts the tranquil atmosphere in a bright, comfortable dining area in a dementia care unit in a US nursing home. A privately paid companion is trying to persuade the resident she cares for to eat. She [the paid companion] is aggressive and loud, interrupting the pleasant atmosphere for the other eight residents who are eating while also failing in her objective to get the resident to eat. Although there are three staff in the dining area, no one intervenes.*

*At other times, the paid companion's yelling and screaming streams through the closed door of the resident's room and can be heard clearly throughout the hallways. (Fieldnotes, US)*

Opportunities to problem-solve are central to attentive, responsive and respectful care. In the situation observed and recorded in this fieldnote from our team research at a US nursing home, a resident was regularly subjected to verbal abuse, while her reluctance to eat or to cooperate with other daily routines was not understood or addressed. Moreover, this situation was tolerated, sending an unintended but disturbing message to other residents, staff and visitors.

In interviews and chats with staff, we learn that they were very concerned about the yelling, but had not acted to deal with it. Further, care aides didn't know if the family had been informed about this situation. (Fieldnotes, US)

Care aides told us they felt powerless to do more than merely report the issue to the nurses who supervised them. The paid companion worked for the resident and her family, but not for the residence. She was not part of the staff team. Yet care aides and nurses were responsible for this resident's care when the paid companion was not around, and at those times, they experienced some of the same struggles in caring for this resident. While managers met regularly at this nursing home to address care issues, there were no meetings or mechanisms for care aides to sort out how to provide care when there were challenges. They had few choices in how or when to offer care.

In comparison, we observed workers solving all kinds of typical dementia care problems in a Swedish nursing home, where those providing residents' daily care are called assistant nurses. Here is one example:

I am told that the workers used to approach Margareta (a former diplomat or diplomat's wife) as if she would stay in a hotel. Margareta doesn't get up for breakfast and as the workers want her to have something to eat so that her nightly fast would not be too long, they have started to call her mobile or knock on her door and wait for her to open (to get her up from bed). Then they say "you ordered breakfast," which works well for her. She still doesn't come out of her room until maybe 11, but she gets something to eat. (One assistant nurse says when I interview her that they do the same with showers for her — she doesn't want to have a shower, and the solution they have found that works for her is that a worker who normally does not work on the floor knocks on her door and say[s] "you have booked a bath, I am here to help you with that." (Fieldnotes, Sweden)

The difference in dementia care between these two homes is striking. But what accounts for the difference? Our research shows that working conditions that offer opportunities for staff to engage in problem-solving can support promising dementia care. These conditions offer workers the time, skills, autonomy and relationships to make good choices in resident care.

Opportunities to problem-solve are important for all nursing home workers, but particularly for those involved in dementia care. Working

with residents living with dementia means continually adjusting to residents' perceptions of their environments and relationships as they struggle to make sense of living with the limitations of memory loss. This means what "worked" to help someone take a shower today might not work tomorrow. It also means that what worked with one resident won't necessarily work with others, and that figuring out how to assist each resident to dress, toilet, eat, bathe, rest, relate to others and engage in activity requires many attempts, strategies and flexibility regarding time and timing. Workers must sort out what is best for each resident and for each activity, right now and again later. Everyone benefits when workers (and families) can share how best to approach and work with residents to meet their needs and support their enjoyment of life.

#### **Four conditions that support problem-solving**

In the US home, care aides had few choices in how they provided care. They did not have time to problem-solve as they were busy with their individual, heavy workloads of assigned tasks. They had little training to support them in addressing the specific challenges of dementia care; they lacked sufficient autonomy or authority to make decisions about care; and a hierarchical division of labour seemed to prevent frequent consultation. These circumstances positioned these US care aides to report problems to nurses or managers, but did not give them opportunities to solve them.

In the Swedish nursing home, we observed dementia care organized to offer workers opportunities to problem-solve and exercise choice in how they provided care. These opportunities involved:

- small unit size and consistent staff assignments that allowed workers, families and residents to get to know each other;
- sufficient time for workers to do collective problem-solving;
- specialized training in dementia care; and
- sufficient autonomy and authority to try out potential solutions to care dilemmas.

Each of these four conditions was important in providing individualized, respectful care in the context of a collective living and caring arrangement.

### *Unit size and consistent staff arrangements*

While keeping units small is not an all-encompassing answer to support problem-solving, problem-solving is blocked or prevented when a unit size and/or approach to staffing mean that staff are not able to get to know each other and residents' preferences, habits and families. This happens from a combination of factors, including large unit size and situations in which many staff do not work consistently with the same residents or with each other. In the Swedish home, nine residents lived in each unit (ward), and the workers normally worked regular shifts in one unit only. Assistant nurses were assigned the job of being the primary contact person for two residents. They were expected to get to know these residents and their families, including their histories, habits and preferences, by spending time with them. Swedish workers also got to know each other, creating relationships and trust that supported problem-solving choices.

In the US home, 16 residents lived in the dementia unit, with rooms along two hallways, and many staff worked part-time and casual shifts. The US home assigned managerial staff as resident "angels" to know and respond to the needs of residents, but this left out the staff who had most responsibility for residents' daily care and reinforced the hierarchical divisions among workers.

To provide some Canadian comparators, in Ontario, we conducted observations at nursing homes with 36 residents per unit, and Nova Scotia homes where there were nine to 11 residents per unit. We found that fewer residents makes it easier to learn what is important for each resident, and working with a stable, consistent team makes it easier to dare to be creative when problem-solving.

### *Time to problem-solve*

The care staff-to-resident ratio was very important in supporting time to problem-solve, with a peak daytime care staff-to-resident ratio of

1:3 at the Swedish nursing home. In the US home, the ratio during the day was 1:7. In Ontario, we saw a peak daytime ratio of 1:8, and in Nova Scotia, we noted a 1:3 ratio in a non-profit residence and a 1:4 ratio in a for-profit residence.

While the staff mix and responsibilities varied among jurisdictions, we noted that opportunities to problem-solve were more frequent when workers who provided daily assistance with dressing, toileting, bathing and eating also had responsibility to spend time getting to know and to do social activities with the residents.

Meetings to problem-solve were also important. Care aides and nurses at the Swedish home had begun to meet regularly to problem-solve in what were called “reflection meetings,” led by workers with specialized training in dementia care. The explicit aims of the reflection group meetings are to improve staff knowledge, become even better at understanding and handling difficult situations in order to improve the care, and make the environment more stimulating for both residents and workers. Fieldnotes from one such meeting show how this problem-solving can support residents, workers and families, including developing creative approaches to improve care:

The [staff team]... talked about Agnes and her declining eyesight, which makes her increasingly anxious. Raimond, [the meeting leader] summarises [from their last meeting]: “We talked about how we could facilitate for her, e.g. to have her soap on a red plate, and to have brightly coloured towels. I helped her with her shower today and it was fantastic to see that it had actually happened.”

The RN says that they have... changed her medication so she is much less hyperactive now. “She is more ‘present’ now, with less wandering and other signs of anxiety.” An assistant nurse, Nanci, says, “Her emotions are changing quickly — when she is calm, her face gets smoothed out — she turns into a totally different person and it is so easy to help her.” The RN says that she has Lewy Body Dementia so sometimes she is totally clear and sometimes she has hallucinations. Nanci responds: “Sometimes you just want to cry — you can’t reach her.” The RN: “What do you do then?” “I tell her that I will leave you for

a while and come back later." Another assistant nurse says that Agnes was very tired yesterday. Raimond: "We must find a balance. There are all those demands on activation from the facility... and also from family members. It is important to inform family that they need both activity and rest. They come and find their mom in bed and wonder if they don't have any activities." Judith: "Just to get up from bed can be an activity — they need to rest."

The discussion on Agnes continues. Nanci: "Maybe she thinks that we [the ordinary staff] are nagging — maybe it is better if someone else goes to her." An experienced assistant nurse responds: "Maybe one person can take her questions for one hour and then another person takes them the next hour, so not everybody becomes totally worn out... Nanci: "[Agnes' contact person] sometimes asks for help." Raimond: "That's good. You can be so frustrated — sometimes it is enough just to open the window and take a deep breath. Then you can put on your air hostess smile." (Fieldnotes, Sweden)

These workers had time to think through and choose how to problem-solve, taking residents', families' and their own needs, abilities and perspectives into account.

### *Training in dementia care*

An important factor that supported problem-solving was the Swedish nursing home care staff's advanced level of knowledge about dementia, supported by assistant nurses with specialized training in dementia care. Raimond, an assistant nurse with this specialized training who is mentioned in the fieldnotes, acted as a resource and facilitator to support dementia care.

In Sweden, the specialized training in dementia care is a national training program called Silviahemmet certification (for more information, see <https://sci.se/certifications/silviahemmet/>). There are specialized training programs in dementia care available in other countries, but the Swedish national program and its provisions offer a model to support nursing home dementia care by certifying not just individual workers, but nursing home units.

The dementia care training is in addition to the programs workers have completed to become assistant nurses. These workers, who provide most of the care in Sweden, have either a three-year course that they have taken as part of their high school program, or a shorter course combined with on-the-job training. In the US state where we conducted our research, many care aides had limited training (as little as 75 hours), but some were working on upgrading their skills through diploma programs, paid in part by their employer. In Canada, care aides (also called personal support workers) complete programs that vary in length and intensity, from about 24 weeks to a year of training.

Training for family members was also offered in the Swedish nursing home. Raimond was responsible for educating family members about dementia care, which he often provided informally.

#### *Worker autonomy and authority to try ideas*

As the reflection meeting fieldnotes show, the workers in the Swedish nursing home not only had opportunities to report and discuss dementia care challenges, but they were supported to create and implement solutions to care challenges. Workers had sufficient autonomy and authority to try ideas and make choices about how to provide care. These included sufficient autonomy to change routines, and to involve different workers or use different tools or supplies, such as different towels or dishes. In the US home, supervisors and managers seemed to hold these capacities. While workers were expected to report problems, they did not have the time, training or autonomy to address them.

The evidence from the Swedish nursing home suggests the following promising practices that support opportunities to problem-solve in dementia care and allow workers to exercise choice in how care is provided.

## **PROMISING PRACTICES THAT SUPPORT OPPORTUNITIES TO PROBLEM-SOLVE**

- A sufficient staff/resident ratio to allow time to problem-solve.
- A limited number of residents per resident grouping or unit, with a consistent staff team.
- Deep knowledge of the individual residents' situations, histories and preferences.
- Deep knowledge of the families' situations and preferences.
- Opportunities to discuss and collaborate on addressing challenges and opportunities with colleagues and families.
- At least some workers with specialized and/or advanced training in dementia care.
- Worker/team autonomy to decide how and when care tasks are accomplished, taking resident preferences into account.

## *Chapter 7*

# **A FLEXIBLE DIVISION OF LABOUR: POTENTIAL FOR CHOICE**

*Jacqueline Choiniere*

This chapter explores how under certain conditions, residents and workers in long-term care settings benefit from more flexible divisions of labour. Specifically, we offer examples where flexibility increases the opportunities for residents and workers to exercise choice, which in turn can enhance their quality of life and quality of work, respectively. Our analysis explores ways in which the benefits of choice, not unlike those of freedom, rely on context. By this we mean that neither choice nor freedom is absolute or consistent in its implications. Janis Joplin suggested this when she sang, “Freedom’s just another word for nothin’ left to lose.”<sup>1</sup> Similarly, the choices people are able to make should be significant, and should make a difference in their lives.

We present two examples where we observed enhanced levels of choice for residents and workers in long-term residences. Our analysis explores the conditions that have contributed to these successful choices, making a positive difference for both residents and staff in long-term residential care.

### **Eastern Canada — Food/Cleaning Aide (F/C Aide)**

In one Eastern Canadian nursing home, several team members commented in their fieldnotes on one category of worker whose job combined what in some places are classified as health care aide duties with some housekeeping duties.<sup>2</sup> The nursing home was divided into “houses,” each containing a common living area and separate

bedrooms for 10 residents. The common living areas contained a kitchen with stove, fridge, and sink, a dining area with a series of small dining tables (to accommodate one, two or four residents each), a lounge area with television, comfy chairs and couches, and a section of cupboards and counters that housed resident charts and care information, and was also used to prepare medications and document residents' care.

During the day shift, the F/C Aide was responsible for preparing and serving breakfast for residents as they awakened, tidying up residents' rooms after everyone had eaten, washing occasional individual items of clothing, and overseeing residents' lunches. Those classified as health care aides would wash and/or bathe residents in the morning, while the F/C Aide concentrated on breakfast. While hot breakfast arrived by trolley from the main kitchen every day, the F/C aide also had bread, eggs, fruit, yogurt, coffee, tea and other breakfast food available on the unit to give to residents prior to the arrival of the main breakfast, or afterwards, if they wished. The majority of residents in each unit came to the common dining area for their morning meal, with only one or two taking breakfast in their bedrooms on the days we were there.

Several members of our team noted how well these workers knew the 10 residents for whom they cared, and the positive implications of this familiarity for both the resident and the worker. As one team member wrote:

Juanita used to be a housekeeper in the old... home (before the new building). She has worked here for 36 years. She likes things to be well-organized, clean and proper.... She tells me that she knows all the residents, and knows what they like for breakfast. I found that she was interacting with them in a respectful manner — providing them with whatever she knows they like, but still asking them, "would you like some pineapple juice this morning, Joe?" "Would you like some more tea?" constantly small talking while she prepared breakfast in an appealing way — peeling oranges, serving small cups of yoghurt, etc. (Fieldnote, Eastern Canada)

Later, this team member noted:

Juanita told me there was an idea behind the way people were seated ... [at] the table. For instance the 102-year-old Violet, "who had a sharp tongue," should be kept at a distance from one particular woman. The man sitting alone and the woman sitting alone do so because they are severely demented and keep grabbing others' food. (Fieldnote, Eastern Canada)

Another colleague wrote:

Freda can start with her breakfast right away and does not have to wait until the hot breakfast, which gets prepared in the central kitchen, arrives. She gets asked if she likes a banana and if she'd like to have toast. When the (F/C Aide) brings the toast she says: "you like a plain toast don't you?" It was more a reassuring rhetorical question, she seemed to know what Freda likes. She eats on her own — alone at the table. The F/C Aide talks to her sometimes while she is going on with breakfast preparations and tells Freda about the upcoming music event at 2 o'clock on the same day. (Fieldnote, Eastern Canada)

The housekeeping duties performed by F/C Aides were also more targeted to individual resident needs. As fieldnotes describe, "small pieces of laundry are done on the floor... whereas larger elements are done centrally." The F/C Aides often washed a sweater or blouse that a resident was particularly interested in wearing. The tasks in this case served to further strengthen the relations of care between residents and workers.

It was clear from these and other observations that having a unit of approximately 10 residents was an important factor in the F/C Aide getting to know each resident well, including her or his likes, dislikes, and special needs.

Other necessary conditions are having adequate staff, with a majority working in full-time or permanent part-time positions, and having consistent assignments. This continuity enables workers to get to know residents, including who could — or should not — sit together during

meals, who likes fruit or yogurt, who likes to chat in the morning, who would rather be left alone, who is likely to have a visit from family, and who needed more social engagement opportunities on a particular day.

There were several indications that workers in these positions enjoyed their work. The familiarity and intimacy with which the F/C Aide greeted the residents each morning, knowing what each resident usually likes to eat, yet respecting residents' autonomy by not assuming what they wanted, all suggest workers who are engaged with the residents. In short, having continuity in care assignments facilitates a worker's ability to anticipate residents' needs and preferences, contributing greater autonomy and choice for the worker, and in turn contributing to more enjoyable working conditions.

Our observations indicate that residents also enjoyed the continuity of care provider, having the same person greeting them each day, offering them what they usually like to eat, reminding them of activities they would likely enjoy, knowing whether or not they have regular visits from friends or family. Also, residents were able to take their time getting to the dining area each morning, since there was always some food available on the unit.

Their autonomy, in terms of opportunities to choose the elements of their day, was also enhanced. In order to achieve this level of quality and continuity of care, it is important for the care home to place a priority on relational care,<sup>3</sup> or care informed by knowing the resident and her or his contexts very well, and incorporating this into all aspects of care. The care home also needs to ensure that workers have the time to utilize this critical skill.

Another condition necessary for this position to provide autonomy and choice for both residents and workers is for the nursing home to keep its food preparation in-house, rather than contracting it to outside agencies. In-house food preparation makes it possible for each unit to have — and maintain — a supply of fresh food items so that residents can have breakfast or snacks when they wish to have them. It also means workers are not pressured to awaken residents early just to avoid missing breakfast, and are able to facilitate residents who decide

they are hungry outside of meal times. It also offers some flexibility to how the long-term-care home organizes the preparation and delivery of food by staff to residents.

An important element contributing to the success of more flexible job descriptions is access to adequate training for all aspects of the positions. Researchers' fieldnotes from this Eastern Canadian home question whether comprehensive training was provided or if these skills were viewed as "natural," and thus, not requiring training. One researcher quotes one of the F/C Aides, who compares her work to "something that any mother would do." Another F/C Aide, when asked whether she had training in food handling, said no. "I don't handle food. I only make toast, eggs and coffee in the morning and put out the cereal." Another researcher included a similar observation:

(T)here is no extra training for this position... which makes it again seem like a natural skill of a woman, not a learned task. So it stays hidden... (Fieldnote, Eastern Canada)

Adequate training in the various components of the F/C Aide job category would reaffirm the value of this work, and increase resident safety and worker satisfaction even further.

Researchers also noted how the more flexible divisions of labour served to improve relations between different categories of workers. For example, individuals who were tasked with getting residents up, washed and into the dining room (Care Aides) were observed engaging and often collaborating with the F/C Aide over shared responsibilities. This level of cooperation, given the context of having deep knowledge of residents' likes and dislikes, also served to increase resident well-being.

When [a resident came to the dining area]... twenty minutes later, she was dressed and the [Care Aide] was helping her walk to her place at the breakfast table. The [F/C Aide] moved to help.... This woman had great difficulty walking and yet they took the time to help her walk rather than putting her in a wheelchair as we have seen in far too many places. When they had her seated at the table, the two workers had a discussion about her sweater. One thought the green did not

match the blue blouse, while the other thought the colours were attractive together.... Again I was impressed by the consideration and time given to making sure this woman was dressed with dignity. Both workers chatted to the resident the whole time even though the resident had great difficulty speaking. (Fieldnote, Eastern Canada)

Yet another example of cooperation (and perhaps a bit of shared training) occurs between a dietary worker and an F/C Aide in the following:

One resident sat down for breakfast in her housecoat and slippers. Another had curlers in her hair. When the hot food arrived, the [F/C Aide] explained to the dietary worker that a particular resident required the bright blue plate because she had sight issues. (Fieldnote, Eastern Canada)

A union contract that is open to job descriptions containing both a broader variety of activities and a greater overlap of activities than the norm is also key to achieving successful flexible divisions of labour. It would be important for the union to be part of negotiations when these positions are created, providing oversight to ensure adequate training is offered to workers, and guaranteeing that increased flexibility does not mean an increased workload.

### **Germany — Qualified Elder Care Provider**

A second successful example of a flexible division of labour was observed in a German long-term care residence, or nursing home. This home was also structured around common living units for approximately 10 to 12 residents. Each resident had a separate bedroom and most often joined others in the common unit for all meals and various activities. The large common room was equipped with a full kitchen, and contained a stove, refrigerator, dishwasher and other appliances. There were three large tables where residents would take their meals, have refreshments, or engage in various activities, including crafts. A couch and large chairs were clustered in another section of this large room.

In this setting, workers included: Qualified Elder Care Providers, Health Care Aides, and Apprentices. The focus of this discussion is particularly on the Qualified Elder Care Provider (QECP), a staff member who can be compared to a position between a licensed practical nurse (LPN) and a registered nurse (RN) in Canadian contexts. In spite of this comparison the QECPs were observed as having a much broader cross-section of work responsibilities than their Canadian counterparts.

The following observations are from fieldnotes about staff members in the German nursing home. The first observation notes a lack of differentiation in how various categories of workers are dressed, observing they all wear “street clothes” rather than uniforms. Unconstrained by uniform clothing expectations, staff members are able to choose the clothing they wish to wear.

There are five staff members coming in and out of the room — is difficult to see their designations (who is a qualified provider, who is a qualified provider apprentice, and who is a care aide). They are all quite casually dressed — wearing jeans, t-shirts, etc. Residents are coming into the room for “coffee” time (around 2:30). Two residents sit at a dining table and one begins chatting to the other — seems to be sharing a long and complex story (not in English). One resident seems quite concerned about the lack of fresh-air... but another resident doesn't want the window open (she is cold)... Staff members seem to work through the “disagreement.” (Fieldnote, Germany)

Other fieldnotes capture the many concurrent activities taking place, including several performed by residents. This activity level, including an obvious familiarity between staff and residents, lends a sense of warmth and intimacy to the room. While there are demands on staff to keep track of the residents in the common room, there is adequate staff to do so.

The following fieldnote demonstrates how resident choice is encouraged. Walter decides when to unload and then reload the dishes. And, in spite of the proximity to dinner, James isn't discouraged from having an apple. The approach seems to be that if he wants an apple, he should have an apple. The staff members are observed facilitating this level of choice.

Back in the common room at 4:30 and pizza preparation (for dinner) is underway. One of the residents (Walter) is unloading clean dishes from the dishwasher and re-loading dirty dishes... some things he puts away in the cupboard, other items he leaves on the counter and one of the assistants puts them away later. (I later learn he is one of the residents receiving a stipend for performing certain duties in the unit.) He also cleaned the counters.... Another resident (James) walks from the table where he is sitting to the island where there is a bowl of fruit — and he takes an apple. One of the apprentices asks him if he wants it peeled. The apprentice then brings him a peeler — encouraging him to move to one of the tables to work on his apple. He proceeds to peel the apple, cut it into pieces and eat it. (Fieldnote, Germany)

The fieldnotes capture that the provider in charge is directly involved in food preparation and in watching for residents who may wander; and she often intercedes to redirect their activities. They also illustrate that residents are encouraged to engage in meal-related activities. The residents appear to enjoy their participation in preparing the evening meal.

Agnes (the QECP) is the responsible or reference provider for the unit. She is working on the pizza dough — but at the same time, very aware of what each resident is doing.... There are two or three apprentices in the room as well. James seems to be a potential wanderer. He starts for the door a few times and each time Agnes or one of the apprentices stops him by distracting him — drawing his attention to something else in the room. Agnes is rolling out the pizza dough — using a large water bottle covered in plastic wrap. Meanwhile, another resident (Olive) is starting to cut peppers and onions for the pizza, using a sharp paring knife. Another resident is adding parchment paper to the baking tray — in preparation to bake the pizza. Agnes helps him cut the paper. There is considerable chatter in the room and a very active, warm, intimate feeling.... Agnes also helps serve the residents once the pizza is ready. (Fieldnote, Germany)

A flexible division of labour is one condition for implementing work organization where staff members have broad responsibilities. As

the fieldnotes illustrate, the QECP engages in activities that in other jurisdictions would be considered well outside of her job description. These include food preparation, assisting residents to participate in food preparation, monitoring residents who may wander, distracting residents who are wandering, and serving food and wine to residents at dinner. Comparatively, in several North American jurisdictions, the RNs are not involved in any of these activities and the LPN is only peripherally engaged in them. In the North American homes, these activities of daily living are the responsibilities of health care aides, dietary aides or even volunteers.

In the German nursing home, there was no suggestion from the QECP that these responsibilities were outside of her responsibilities or skill set. While this staff member is the most senior worker in the room, she is observed engaging in many and varied aspects of work, ensuring residents enjoy not only quality care, but a high quality of life, which includes increasing residents' choices regarding their activities, the food they eat and when they want to eat it. In addition to the different types of staff performing many of the same kinds of care work, the eschewing of uniforms, particularly those that are colour-coded according to type of position (which we witnessed in agencies in other jurisdictions), also seemed to reduce boundaries and increase cooperation between different workers. The following fieldnotes illustrate this:

In the common unit two care workers are preparing for breakfast... One carer passes by a cleaner, says hello and asks how she is. The cleaner says, very good her vacation is coming soon. The cleaner seems to be relaxed, not in a too bad rush. (Fieldnote, Germany)

A qualified care worker sits with the resident who likes to hold hands. She holds her hand, the woman kisses her hand and touches her. The interaction is very much like in one's own family (or better put: it is like in an idealistic construction of a family)... Many care workers with different qualification levels (Qualified Care Worker, interns, apprentices) and the residents sit at the table. They sing spontaneously. (Fieldnote, Germany)

Having a union agreement that values job flexibility and an overlap of work tasks, rather than one that pursues a strict itemization and division of tasks, would effectively support even more flexibility. Of course, it would require other approaches to protecting workers rather than the traditional approach of sharply differentiating between different categories or workers. The majority of North American nursing homes we visited employed a rigid division of labour, and it was rare to see a high level of cooperation among the different worker categories.

The German care home's emphasis on all staff members engaging in the full breadth of resident activities and care reflects a relational care focus. Even staff members with the highest level of clinical expertise were focused on the activities that underlie residents' quality of life, meaning more than the clinical aspects of care. We did not witness staff members telling residents that certain activities were outside of their responsibilities. Instead there was a strong sense of need and desire to care for the whole person.

Of course, another condition facilitating a relational care approach is having adequate numbers of staff. The German nursing home managed this by having a large apprenticeship program. Several individuals learning to become a QECP were caring for residents on each shift. If this program was discontinued or reduced, it would make a significant difference to the ability of workers to exercise choices in ensuring residents enjoy quality of care and life (which in turn would impact residents' ability to choose).

The fieldnotes illustrate other ways that staff members enjoyed elements of autonomy and flexibility (and consequently choice) in their work. They could spend time sitting with the residents during activities, or chatting with them while meals were prepared or consumed (which we observed). The physical structure of the unit (common living units for 10 to 12 residents), the organization of space, and the activities that were carried out (from preparing and consuming meals to enjoying craft activities) all contributed to resident and staff autonomy and flexibility.

Another element contributing to enhanced choice among both residents and staff was a more relaxed approach to avoiding risk.

Residents were encouraged to participate in all aspects of meal preparation and were observed cutting vegetables for pizza (using sharp knives), and serving and drinking alcoholic beverages. Workers rolled out pizza dough using a water bottle covered in plastic wrap. They also varied the mealtimes, depending on the circumstances of the day. This contrasts with the lack of choices we witnessed in nursing homes where outside contractors delivered meals and retrieved trays at specific times, or where regulations were in place that severely curtailed the timing and approach to mealtimes. This included jurisdictions where regulations specify residents must be in the dining room for breakfast by a specific time every day.

Yet another condition supporting an environment that enhances autonomy and choice among both residents and staff in long-term residential care is the approach to training and education. The apprenticeship program in the German nursing home meant that those soon-to-be Qualified Elder Care Providers were learning in an environment that reflected a relational approach to care, and one that valued autonomy and choice among both residents and providers. Arguably these workers would carry these particular approaches to care and work to any future positions.

Finally, it is important to reflect on the ways in which increased autonomy and choice for workers can result in the same for residents. Critical to whether the exercise of autonomy and choice is beneficial to both residents and workers are the conditions in which they occur. The examples of the F/C Aide in Eastern Canada and the QECP in Germany illustrate some of the conditions that contribute to residents' and workers' abilities to exercise autonomy and choice, improve collaboration between and among different types of staff, and achieve improved quality of life and work in long-term residential care.

## **PROMISING PRACTICES FOR EXERCISING CHOICE THROUGH A FLEXIBLE DIVISION OF LABOUR**

- Long-term Residential Care Facilities (LTRCFs) organized in common living units for 10 to 12 residents, cared for by adequate numbers of full-time or permanent part-time staff

who are familiar with the needs, wants and histories of each resident.

- Food prepared in the home — with some items always available on each unit — in response to the differing likes and dislikes of each resident and increasing the likelihood of resident participation whenever possible.
- Administration support for ongoing education and training for workers in all positions, recognizing that knowledge and skill underlie the successful performance of all work within the facility.
- Union support for jobs containing a wider variety of activities, including overlapping components of work, and for adequate and ongoing training for all aspects of each job.

---

## NOTES

1. Me and Bobby McGee. Songwriters: Fred Foster / Kris Kristofferson, 1969.

2. We refer to this worker as a Food and Care Aide although this was not the actual title used in this work setting.

3. See for example, P. Armstrong, H. Armstrong and J. Choiniere. (2015). *Before It's Too Late: A National Plan for Safe Seniors' Care*. Report prepared for the Canadian Federation of Nurses' Unions (CFNU). Ottawa: CFNU.

## Chapter 8

# APPRENTICES: MORE HANDS ARE NECESSARY BUT NOT SUFFICIENT

*Beatrice Müller, Monika Goldmann and Hildegard Theobald*

This chapter discusses an innovative approach in a German residential care facility in the federal state of North Rhine-Westphalia. The care facility attempts to supplement a low staff-resident ratio by employing a large number of apprentices who are attending a three-year vocational elder care training program.

This chapter raises the following questions: can apprentices who are still being trained to be care workers improve the life and working conditions in long-term residential care and accordingly support the exercise of choice in LTRC? Does the employment of many apprentices allow more time for staff to provide more high-quality care? Or does the large number of staff in training create more work for qualified staff responsible for much of the training, thereby limiting their options for exercising choice? We explore both the positive and the more problematic sides of the apprentice model and ask for whom, under what conditions, the program is useful or can cause problems.

### **Background**

At the time of our research, the German residential care facility was home to 90 residents. It employed 30 qualified care workers (Elder Carers and Nurses, equivalent to Licenced Practical Nurses in North America), 36 care assistants (some similar to Licenced Practical Nursing Assistants and some to Personal Support Workers) and 110 apprentices

(who will become Elder Carers). In other words, there were significantly more apprentices than there were trained staff or residents.

The massive employment of apprentices at this site is a response to the restricted public financing of the German long-term care system. The facility employs apprentices as a means of compensating for a very low staff-resident ratio, which is a common problem in Germany. Recently, the federal state of North Rhine-Westphalia introduced a funding system that covers the costs for apprentices. This was designed to encourage employers in the elder care sector to offer more training possibilities as a way to counteract the shortage of care workers in the sector.

Usually, the elder care training program in Germany requires at least a 10-year school certificate compared to the 12 to 13 years required to enrol at a university. Apprentices earn a monthly salary of about 1,000 Euros (about C\$ 1,460). The education program is based on a combination of on-the-job training at the workplace, with general education and occupational theoretical training provided by vocational colleges at the upper secondary level, where final exams are also taken. The mix of training by vocational colleges and training on the job is the core of the German apprenticeship system and is regulated by national standards. Apprentices at our research site completed a care aide course where they learned the basics of nursing in the first six weeks.

Almost all German site fieldnotes describe the commitment, relationships, and interaction between apprentices and residents in a very positive way and illustrate that the more people who have the ability to relate to the residents, the calmer the atmosphere. However, fieldnote descriptions and interview segments also demonstrate some more problematic aspects of the apprentice program.

### **More time, more energy, more heterogeneity**

In general, the large number of apprentices on the site means that residents get more care worker time, more liveliness and more heterogeneity in responses. A few representative examples from fieldnotes taken at this German site illustrate these benefits:

There are at least two apprentices during the entire meal. Family atmosphere — do not get the impression that apprentices are working (even if they are); they are part of the meal and place. Apprentices are dressed in street gear, some have many earrings, some tattoos.

11:45 a.m. The apprentice is combing one resident's hair. The male resident is now setting the table for lunch. He is in and out of the kitchen and getting things from the dishwasher. The radio is still playing songs in the English language. The apprentice stops and massages the male resident's lower back (he walks with a bit of a limp and slouched over) and he appears to have a sore back.

12 p.m. The young girl with the head scarf from Harmony Unit comes in with a cake and cupcakes to bake in the oven. They smell great! The apprentice reads the lunch menu to the residents and says a blessing. The residents repeat with her...

There is banter. The apprentice asks, "Was the soup good?" He replies, "*Wunderbar*" (wonderful). She says, "I am glad to hear it is wonderful." (Fieldnotes, Germany)

The researchers describe the apprentices as authentic, diverse people who make the work not seem like work and create a family-like atmosphere. In most cases, the apprentice-resident relationships are positively portrayed, because "there are enough hands and hearts." This is also the case for nursing care; apprentices provide nursing care in the morning for at most three residents, allowing them time to attend to individual preferences. The atmosphere at the facility is calm and pleasant, and not at all boring or desolate.

Not only do the apprentices have more time than other staff; they also generate a lively atmosphere and heterogeneity. Apprentices offer emotional support and body work: they talk to, touch, or massage residents but also do light kitchen work. Some have tattoos and come from different faith communities, which is somewhat unusual in Catholic facilities in Germany. The diversity of individual apprentices suggests that they too are allowed to make choices.

The apprenticeship program also serves as a form of community service as staff feel responsible for the apprentices. For example, the apprentice trainer accompanied an apprentice to the youth welfare office to support her in getting childcare assistance in order to continue her apprenticeship.

These positive aspects of the apprenticeship program and especially the resident-apprentice interaction demonstrate that many apprentices or more staff in general can mean more time for interaction, a more relaxed atmosphere and more choices. However, there is also evidence of a downside to the apprentice program.

### **Many not-yet-trained workers**

Here's a rather more complicated aspect of the apprenticeship program. It took place during a shift handover:

All the staff of two shifts and two units ...enter the [very small] room, they talk to each other, it's loud in the room, they are making jokes, laugh a lot. The atmosphere seems very relaxed and friendly. Some people try to change their shifts. [A care worker] asks, "Which one of you is Melanie?... Handover starts.... The qualified care worker goes on to report the condition of every resident.... Suddenly a mobile rings, and the care worker to whom it belongs excuses herself. The atmosphere gets a little intense.... A little later people start to talk to each other. The qualified care worker tells everybody to be more quiet. (Fieldnote, Germany)

The handover illustrates the very relaxed situation we observed at the whole facility. People talk to each other; it is lively and pleasant. However, the high turnover of apprentices represented in the question, "Which one of you is Melanie?" limits continuity in care, and the large number of people who have to be trained and organized represents significant work for the permanent staff.

The next situation appears to be even more problematic. It raises concerns about the high number of staff in training, the prevention of risks, and the question of skills. Here, an apprentice in her first year

hands out medication and does not make sure that the pills are taken. One pill ends up on the floor and the staff members don't notice it for a long time.

10:21 a.m. The pill is still on the floor as I watch the residents gather for the game at the other table. There are three males and two females. The [care assistant] is in and out of the fridge, getting glasses for water (bottles always on the table), gets out the bingo machine. She goes out of the room and the young apprentice enters, then the [care assistant] comes back with paper bingo sheets and pens. She sets each person up with a sheet and pen then sits down herself at the end of the table.

10:35 a.m. Two more residents enter the room and the worker stops the bingo game, gets up and moves the other table (where the pill sits on the floor). I now think she will *have* to see the pill, but she doesn't right away. Once she finally moves a chair the pill is shuffled and she sees it, picks it up off the floor and walks over to the garbage and throws it out. I question myself, thinking, no she didn't just do that, so I wash my hands at the sink, take a piece of paper towel, throw it away and double check looking into the garbage as I dispose of the paper towel, and there is the pill sitting right at the top of the garbage sitting on some plastic that had been thrown out. (Fieldnote, Germany)

Besides the risk for the resident who did not take his or her medication, the considerable responsibility given to the first-year apprentice also means more responsibility for the permanent care workers who are in charge of apprentice training and supervision. Without enough qualified staff to ensure supervision, trainees may have too much room to exercise choices and not enough time to learn from the experienced staff about how to make choices.

The handover and medication examples illustrate underlying tensions and structural problems that several interviewees addressed.

## **Structural problems addressed by care workers**

Apprentices work for a six-week or three-month period at the facility, depending on their school schedule, and then leave for six weeks/three months to attend classes at school. In addition, they have to rotate to home care and day care.

Some care workers consider this discontinuity to be problematic, both for themselves and for the residents. The following comments from qualified care workers and a care assistant illustrate some of their concerns:

I wouldn't have quite as many apprentices. I work in a dementia unit and it's a known fact that dementia patients orientate themselves very much to faces and then when there is a regular change of people coming that's not such a good thing. My ideal would be that we would have less fluctuation in apprentices in the dementia department so that the people can identify more closely with the apprentices. (Interview with Qualified Care Worker, Germany)

At the moment the biggest challenge is the apprentices. Because of the fact that I work 50% of the time I'm frequently away from here and every time I come back I have different apprentices, different people but also different situations, different problems.... So you sometimes have the impression after you've been away for one or two weeks when you left they were all very fit and now you come back and you feel as if you're starting all over again. (Interview with Care Assistant, Germany)

If a lady with dementia no longer wants to eat... if a colleague, male, female qualified, apprentice has to deal with this person... and this person, the employee doesn't have a sense of fine judgement, then they might for example try to force their mouth open and force a spoon into their mouth. It shows no respect. It shows no respect or dignity and it demonstrates a complete lack of knowledge of the illness. That brings us back to the subject of whether you have good apprentices, not so good, and that's the reason why if I had for example five apprentices in my group I'd like to be present when meals are served. Then these things just don't happen. (Interview with Care Assistant, Germany)

So it's got two sides. It's nice that there are so many students here who want to get into the job and are interested but on the other hand, um, they have to be introduced into the work, into the task and that takes a lot of time....You have to explain what you are doing, why you are doing it, and how to do it.... And then you have to let them do it by themselves... and delegate and tell them what he's done wrong or she has done wrong and what could be done better. That shortens the time that you have with the resident itself. And there is a lot of paperwork also because you have to um... you have to give a report. How they did. (Interview with Qualified Care Worker, Germany)

These examples illustrate the problematic aspects of the apprentice program. The difficulties are related to the turnover of apprentices, which is challenging for their relationships with residents who have dementia and for the work organization as a whole. The permanent staff identified apprentices' lack of training and skills in the context of dementia care and in relation to working conditions as problems.

Time is also an ambivalent issue. More hands imply more time with residents but more untrained apprentices also consume more of the time of the qualified care worker and the care assistants who provide their training. Under these conditions, apprentices may exercise choices without sufficient knowledge while qualified staff have more limited choices in terms of supervision and training.

On the one hand the high number of apprentices acting as extra staff are a relief for the permanent care workers because the apprentices spend time with residents, provide nursing care and engage in social and relational interactions. On the other hand, it takes a lot of time to provide high-quality training, and to organize and supervise the apprentices to make sure that they provide good and safe care. This also implies that the permanent staff need to receive additional training in order to be able to train the apprentices and deal with occurring problems.

The apprenticeship program demonstrates that more staff in a long-term care facility are needed and more staff have a positive effect on residents, workers and the overall atmosphere. However, the results

also show that training takes time and that staff need both time and training in order to provide the training.

More hands and more time are a necessary but not sufficient condition for appropriate care and working conditions. Staff continuity, along with sufficient training and experience, are critical for caring conditions. They provide the conditions for the exercise of appropriate choices in LTRC.

### **PROMISING PRACTICES FOR EXERCISING CHOICE**

- More apprentices mean more time, more activity and more heterogeneity — in other words, more choices.
- Many apprentices provide extra hands but they also require additional training work from the trained staff.
- The extensive use of apprentices and the problematic aspects of the apprenticeship program illustrate the need for acquired skills and formal education as well as for continuity in staff as a condition for exercising choice.

## Chapter 9

# FAMILIES AND CHOICES

*Pat Armstrong*

The move to residential care can open up choices for families, especially if family members have been providing considerable unpaid care. Those most likely to provide direct personal care at home are women. Thus the move may be particularly important in opening up choices for them. As a granddaughter in the UK explained to us:

My mom is a lot happier now because she works full time as well so she can go working now knowing granddad is being well looked after and fed. It's peace of mind. That's the biggest thing isn't it?... She knows that you're okay, that grandpa is okay so she can go do her work and not worry basically. If there's any problems, they phone up straight away and say. (Interview with Family Member, UK)

With choices about which home to go to, families can remain connected and provide social support. Asked if he visits his mother regularly, an Ontario son replied:

[We go] between three and five times a week. So depends how you define regular but that's what I can make regular. I live around the corner so I can walk here in like 10 to 15 minutes. So we live in the neighbourhood.

There's four siblings...and my dad lives five minutes away in the condo that they lived in together. So we get good coverage. All the kids are making at least between one and five trips in a week.

My siblings travel mostly from downtown. (Interview with Family Member, Ontario)

Because he is close, he is “the frequency guy, shorter visits, kind of an hour, an hour and a quarter, an hour and a half.” Proximity also means that his father “gets here a lot. He supports at least two meals, two dinners a week, and then other social visits, right?”

Care plans too provide opportunities for choices. In the Canadian homes, policy provides for the family and the resident to be directly involved in developing the care plan at the beginning of the move. This meeting offers an opportunity to indicate resident preferences and history as well as information on the state of the resident’s health. This care plan is expected to be revisited with the family on a regular basis to allow for changes in the resident’s health or preferences.

There are other ways families can mean more choices for residents. In a BC home for example:

One of the ladies, a Vietnamese lady, she doesn’t eat very well. The family bring all kinds of Vietnamese sauces and we have a fridge for the family so they can put it there if it needs to be refrigerated or leave it in the room so they can bring it out with them when they want. (Interview with Family Member, BC)

Families can also help ensure clothing choices for residents. In Canada and the UK, women told us they regularly do personal laundry for their families in order to protect precious garments. With family support, residents can wear what they did at home and women in particular can feel they are contributing to care.

Families even report providing personal care. One BC daughter offering such care helps her mother hold on to the privacy she values:

I’ve been basically helping my mom bathe. Like she’s a very private person. This whole idea that some stranger is going to be bathing her is sort of it’s just really, really upsetting, you know, to begin with

anyway. I said, "Hey, I'm happy." It's a mother/daughter bonding experience. (Interview with Family Member, BC )

Family councils, a requirement in several Canadian provinces, can allow families to participate in decisions about the home as a whole. A son-in-law in Manitoba described how he sees the contribution of such councils:

We want to establish ourselves as a body that is there to help, which doesn't mean to say we can't criticize, but we want to do it in not a confrontational but in a more productive way so that there can be some improvements in that. So this way we're not breathing over anyone's shoulder. We just feel that the suggestions that we're making are for the benefit of the residents and ultimately for the benefit of the institution in improving the quality and safety of the residents. (Interview with Family Member, Manitoba)

However, conditions can severely limit choices in all these areas.

We heard repeatedly that when there are long wait lists for care homes, residents often end up far from where their families live. When there is limited public transit and long distances to travel, families have much less choice about how often and for how long they visit. Providing food, laundry and personal care is more difficult when there are long distances involved, whatever the means of transport. And we heard from many family members that providing such support was frequently not an option. As the daughter who began by bathing her mother explained, "the problem is if I'm not there it doesn't get done." Similarly, a Canadian daughter of a resident reported that she has:

been doing her laundry since day one because in the beginning she was in a shared room and the daughter of the woman next to her said, "If you don't want your mother's clothes ruined take them home," because they tend to throw everything here in hot water and sometimes, you know, it may bleach some things. So I've been doing it since day one. (Interview with Family Member, Canada)

One reason families see little alternative to doing the work is that "there are not enough hands," as we were told in Ontario. Instead, families

are expected to fill the gaps or to hire someone privately to do so. In a Swedish home, by contrast, where staff levels were significantly higher than in Canada, the staff told us they saw their job as doing the work on behalf of families. They even shopped for residents and were able to include this shopping as part of their workday.

A second reason that families often have little choice about doing the work is the lack of continuity in staff. A BC daughter described the problem as follows:

One of the family members was saying that she's had to introduce herself to different people almost every day kind of thing and right now there's a lot of temps in, there's a lot of rotation because of people trying to use up the holidays for this year, you know, because you can't carry them over. And she was frustrated with that because of course there's no continuity of care. And I think that would help a lot if I knew that there were certain people always looking after her that know her. (Interview with Family Member, BC)

This daughter raised the issue at a family council meeting but nothing changed. This is not surprising, given that more than one family council meeting we attended primarily involved the director providing information, with little opportunity for frank exchange or recommendations that might lead to implementation.

According to another BC daughter, a third problem is the rigid division of labour she experienced in trying to deal with laundry:

Today actually I came in and I had dropped [off] four new undershirts for my mom to be labelled ... with a pink label because I do my mom's laundry at home versus having it done through laundry facilities. So I went up to the nursing station and asked to speak to the nurse that's looking after my mom's area and I said "I dropped off some shirts for my mom on Thursday." I said, "I'm just following up to see where they are." "I can't help you. That's not our..." How did she put it? I don't know quote/unquote but we don't do the housekeeping or the laundry. And I said "I realize that. I'm just asking when I can expect my mom's clothes to be back" because some of

her clothes have already gone missing. And clothes are expensive to replace. (Interview with Family Member, BC)

While care plans are intended to allow input from families and residents and to identify preferences, lack of staff, lack of continuity and a rigid division of labour can undermine these plans. A Canadian resident gave the example of a care plan that said he could stay up to watch the hockey game but the staff put him to bed long before the game. He fought for a compromise, which allowed him to watch only part of the game, in spite of what it said on his care plan.

It should also be noted that family choices may conflict with other policies. One example is family objections to men providing care to female residents. We heard from staff and residents that there was resistance to male care providers, resistance that may be further complicated by racism, given that most of the male staff are from racialized communities.

“Even the men don’t want a man,” according to one nursing assistant. A husband told us, “I will not have a man look after my wife.” While one manager reported that “I have to politely explain to them [the family] that you can’t discriminate when you hire based on gender, sex, religion, whatever,” our research<sup>1</sup> indicates that a flexible division of labour, combined with structures that allow workers to decide how to deal with the objections to male caregivers, led to some creative solutions. In one case, for instance, the staff decided to start by working in a male-female team to help the family and residents become comfortable.

## **PROMISING PRACTICES FOR EXERCISING CHOICES**

- Care homes located near families, with easy access by public transit.
- Family Councils with the ability to provide meaningful input into decision- making.
- Enough staff and continuity in staff to ensure families are not

required to fill the care gap and enough flexibility to promote staff choices in care.

- Care plans that are followed.

---

## NOTES

1. P. Storm, S. Braedley and S. Chivers. (2017). Gender Regimes in Ontario Nursing Homes: Organization, Daily Work, and Bodies. *Canadian Journal on Aging*, 36(2):196-208.

## *Chapter 10*

# **DEATH WITH DIGNITY IN LONG-TERM RESIDENTIAL CARE**

*Shauna Zinnick, James Struthers and Malcolm Doupe*

One of the challenges in work activity in long-term care is the death of a resident, especially a death that does not fit a usual pattern. In this chapter, we explore how a personal care home in Manitoba coped with an unanticipated death. We also highlight the necessary conditions that allowed for the transition to be dealt with collaboratively and respectfully.

A resident at the Manitoba home had taken an unexpected turn for the worse at eight o'clock the evening prior to her death. At six-thirty the following morning, she passed away. She had lived in the home for almost three years. At the time of her admission, she had been given only two weeks to two months to live by three independent physicians who recommended that she remain in acute care. However, the family made the decision to transfer her to long-term care instead. Prior to her death, personal care home staff did not consider the resident to be at risk. Indeed, she was scheduled to participate in a group outing to a local historical site the day she died and her family was out of town at their cottage for the weekend.

### **Dealing with death in a positive way**

According to its Director of Care, the home always tries to make the experience of death as respectful and caring as possible. "We really don't want them to leave, to go anywhere to die. They should die at home with the people that love them and care for them."

The family of residents in end-of-life care are encouraged to stay at the home and a bed, food, and beverages are provided for them in the resident's room. Staff, including someone who provides spiritual care, also spend time visiting the resident. "They'll pop in and just talk to the resident because no one should be alone when they die" (Interview with Manager, Manitoba).

However, as this death was unexpected, the staff on duty did not have time to do this. The family was away for the weekend. The RN in charge knew their weekend schedule and how to reach them quickly at their cottage.

The Spiritual Care Advisor was not on duty at the time, but was called in on her day off to help support the family. She drove in early in the morning, from over an hour away, to be there (Fieldnotes, Manitoba). In order to ensure that the family could return from their cottage and have ample time to spend with their deceased family member and with the Spiritual Care Advisor, the RN used her discretion and waited to report the death to the coroner, even though regulations require that coroners be informed quickly.

During the stressful period created by a death, staff continuity is important, not only for residents but for families. Following this unexpected death, the charge nurse who had gone through the resident's admission with the family had the responsibility for counselling them through the grieving process. She contacted spiritual care and made all the necessary phone calls and arrangements. This nurse was able to use her skills, discretion and her knowledge of the family. The family, in turn, was able to deal with one main person throughout the entire process (Interview with RN, Manitoba).

Later in the morning of her death, the resident's body was draped with a red velvet cover and escorted by family members and the charge nurse to the funeral vehicle, via the entrance to the home. "They go out the front door the same way as they came in... and the nurse always escorts them to the funeral vehicle because basically we escort them from the front door when they come in" (Interview with Manager). One staff member reflected on her grief:

It happens that you get really close. This one I was really close to the resident and very close to the family so it was very hard for me this morning. Even when she was going out I had to hide in there because I just didn't want to see her going. So you get really attached. (Interview with Receptionist, Manitoba)

In order to allow time to reflect and say a prayer for the resident who passed away, staff and residents are permitted to enter the resident's room once the body has been removed.

Other residents were informed of the death, depending on their cognitive ability. Here, too, continuity was important in establishing the knowledge necessary to make such a decision. In this instance, one of the deceased's table mates, a close friend who was cognitively aware, was told about her death immediately (Fieldnotes, Manitoba).

The home holds a memorial service for residents who pass away. Memorial brochures are made for the families, which include personal pictures of the residents and their families (Interview with Receptionist, Manitoba).

During site visits in Nova Scotia and in Germany, team members observed other deaths in care homes that allowed residents and staff members the time and space to grieve, a promising practice. In the German home the resident's body was left in her room, and "marked by a special 'candle' for a few hours to allow residents and staff to visit." As in the Manitoba care home, her body was then "removed by the front door, acknowledging death as part of life." A large book was left near the home's entrance "with one page on the right with a colour photo for each resident at entry and another on the left at death, with lots of room for messages of condolence" (Fieldnotes, Germany).

In a Nova Scotia care home, hearts were placed on the doors and at the table place settings of residents who had recently died, providing memorials and acting to "allow the grieving process" (Fieldnotes, Nova Scotia). Team members observed the departure ritual performed for a deceased resident who was leaving the home:

We saw staff walking slowly in a line behind the bier of the deceased person. The bier was covered with a beautiful patchwork coating. The ritual seemed to be spontaneously organized and lasted only a few minutes — the few minutes it takes to walk from the room of the deceased to the door where the hearse was waiting. This small ritual was a very moving moment. Actually, I had problems holding back my tears. We later saw that the nursing home had a memorial book — with photos and obituary notices of deceased residents. (Fieldnotes, Nova Scotia)

### **Tacit knowledge**

Several factors present in the Manitoba care home helped ensure that the unexpected death was a skillfully handled and collaborative transition. First are the expectations that staff use their “tacit” or un-codified knowledge on the job. As a care support worker told us:

If you feel competent in what you’re doing then go for it and do it. That way someone is always calling for you. “Go do this. Go do that.” If they can see that you’re confident enough to do what you’re doing and you know what you’re doing then it just flows that way. (Interview with Care Aide, Manitoba)

Other staff agreed:

Like even the kitchen, the housekeeping, we all... if they see something we all talk about it. We talk to the nurses. Flexibility. I think we take in a lot of what our residents want to do. What they have to say about our programming. (Interview with Recreation Facilitator, Manitoba)

Staff also recognize the importance of collaborating with each other and getting to know the residents. According to the Director of Care, “one of the deals is that everyone in the building has to know the residents and so everybody’s job incorporates at some point in that day that they have to spend some time doing something with residents” (Interview with Manager, Manitoba).

This shared knowledge was powerfully evident, as several staff came over to offer heartfelt consolations to members of the deceased's family. The charge nurse was observed "talking in the hall to family members of the person who died and explaining things to them. They hug" (Fieldnotes, Manitoba). At her first opportunity the LPN "walks over to the two sons... and says, 'I'm sorry for your loss. She passed peacefully and quickly.'" The recreation facilitator, who was busy organizing a group outing that morning, took time to speak with the woman's sons. "[She] didn't want to go. I'm going to miss her so much. She was one young lady. Don't be strangers." They laughed and one quipped that the next time she saw them, his brother would most likely be a resident of the home. She replied, "I already have my own room booked." Throughout the entire process the RN on duty was calm and efficient as she discussed with other staff (and students) the tasks that needed to be completed to prepare for the removal of the body (Fieldnotes, Manitoba).

Finally, the importance of "just being there" for the residents near an end-of-life transition was evident in how staff described their approach to such care. "You need to use your common sense.... Don't wait for the doctor.... The resident is part of my... it's just a family for us.... If we know there's something wrong or they passed away it's like we're always there for them" (Interview with Care Aide, Manitoba).

Employees from different areas within the home also come to visit the resident or simply just hold their hand. They were described as being "very connected in that way" (Interview with Educator, Manitoba).

### **Teamwork, lack of hierarchy and distribution of leadership**

During difficult or irregular situations, factors such as teamwork, an absence of managerialism or standardization, a lack of hierarchy, and distributed leadership all help ensure that smooth transitions occur. Within this Manitoba care home, all staff work together to ensure residents receive the best possible care. Nurses are expected to use maximum discretionary initiative as there are no other managers on the units. All the nurses are trained to handle the paperwork related to a death, including who needs to be notified (e.g., coroner, funeral home) (Interview with Manager, Manitoba)

As one staff member described their teamwork approach,

If everybody is busy there's no reason why a nurse can't start clearing tables.... We want to get things moving, I'll grab the mop and do the floor. You know, it's just everybody pitches in to keep the whole place running. (Interview with Educator, Manitoba)

A lack of hierarchy means that all staff members appreciate the role each one plays and all are willing and able to exercise autonomy in order to help out when needed:

Yes, the environment, everyone around here. Like we work well together like a team so that's most what I like about it. Everyone is, like I said, whoever needs help. You know, so if I need help with something I just say, "Can you help me with this?" So it's that kind of teamwork. (Interview with Receptionist, Manitoba)

Maintenance staff agreed:

That's what I found even just coming to this place six years ago. Everybody just seemed to help each other out and there wasn't "This is my job. This is your job." Everybody just kind of helps and when I need help I just ask people for help too. (Interview with Maintenance Staff, Manitoba)

According to the home's physician, this collaborative approach is key to its successful model of resident-centred care:

I'll see custodians holding hands and walking someone back to their room because they're on the wrong side and things like that or because they've soiled themselves and they need to get back to the side where the health care aide can help them.... And so I think there's a sense of everyone is caring for this community and that reflects because the person who is working on the frontline is treated equally to everyone else or is valued for their contribution. I think that comes across in this home for sure. (Interview with Physician, Manitoba)

### **Low staff turnover and continuity**

Low staff turnover and continuity of care mean that residents (and their family members) get to know their care providers very well. This personal care home employs only full-time and 0.4 full-time employee (FTE) relief staff. Approximately 65% of the staff working at the care home in 2015 had been employed there since the home opened in 2007 (Interview with manager, Manitoba).

The home has a list of individuals waiting for full-time employment.

To get an interview you really have to be referred by a staff person, so a lot of the students are referred because what they want are people that will work the same way that they do and treat the residents the same way.... So you know, that's sort of a good thing. (Interview with Manager, Manitoba).

According to the home's physician,

We haven't had much change over the years.... I've worked in a lot of homes so I've seen what the problems are in other homes and one of the things is nurses take a lot of ownership over the care here so it's pretty keen. (Interview with Physician, Manitoba)

The conditions of work at this home support continuity of care.

### **Modelling from the top**

The model of resident-centred care began when the care home first opened. All residents are treated with dignity and given choices regarding what they would like to do (Interview with Manager, Manitoba). And staff are consulted frequently. The manager explains:

My role is to ensure that everyone in here has what they require to do their role. When we're talking about the residents everyone is included. So the housekeepers are included, the health care aides are included, physicians, because you need more than one opinion when

you're discussing many things. And so the staff are very used to being asked their opinion because their opinion is valuable. And sometimes you don't have to ask, and they'll come and sort of give you their opinions. (Interview with Manager, Manitoba)

This approach can pay huge dividends in rallying staff support during times of emergency, such as when a resident choked and died in the dining room. The charge nurse not on duty received a call and text. The director of care and spiritual care advisor both came in on their day off. Although this care home was located a large city rather than a rural area, the RN told us "there was probably an extra 20 staff here all unpaid because we wanted to be, support the family, support the residents. We treat everyone like it's our own... well they do become part of our family" (Interview with RN, Manitoba).

The end result is ongoing support from the relatives and friends of residents even after the residents have died. Families of residents said that continuing to come in as volunteers meant a lot to them and helped ease the transition to accepting these deaths:

It's definitely something that people want to still be a part of and we treat it like a family. You know, this is still the family. The resident that just passed this morning they said, "What can we do to come back? How can we volunteer?" You know, they're walking out the door escorting their mom and saying, "She's supposed to be at the... outing today but she's passed suddenly. When can we come in and start helping?" So we give to them but they also want to give back. I think they just feel good. (Interview with RN, Manitoba)

This is an exceptionally promising practice and a key non-medical indicator of the quality of care this home provides.

## **PROMISING PRACTICES FOR EXERCISING CHOICE**

- Allow staff to use their “tacit” or un-codified knowledge on the job.
- Practice distributive leadership, reduce hierarchy and promote teamwork.
- Create conditions for low staff turnover and continuity.
- Model from the top.



## *Chapter 11*

# **EXERCISING CHOICES: IDEAS WORTH SHARING**

*Pat Armstrong and Tamara Daly*

How can we put long-term care residents first and provide them with choices, as many governments seek but fail to do?

Our research indicates that strategies intended to support choices for long-term care residents must be based on the understanding that care is a relationship involving residents, their families and workers. It also means understanding that appropriate conditions of work are central to care as a relationship that allows residents and their families to exercise choices. Included in those conditions are provisions that allow staff to know residents and families, that give them the time they need to devote to resident care and that encourage staff to use their judgement in responding to the preferences of residents and families. Although what makes up appropriate conditions varies from place to place, we have identified some that are essential to supporting choices.

**1. Conditions that make long-term residential care a positive choice.** There must be enough spaces in long-term residential care to provide those needing care with actual choices in terms of when they move to a care home and where they move. The latest available comparable data indicate that Sweden has close to 80 beds per 1,000 people over age 65<sup>1</sup> compared to 46 per 1,000 people over age 65 in Canada.<sup>2</sup> When only half of those assessed with high or very high needs can count on getting into a nursing home within a year, as is the case in Canada, choices are severely limited.<sup>3</sup> Clearly, those needing care in Sweden have more choices available.

It is important to have eligibility criteria that include factors such as the burden on unpaid care providers, cultural accommodation and keeping partners together, as is the case in Ontario. But such criteria have little impact when there are too few beds available and when priority is given to those in acute care who are assessed as very high need.<sup>4</sup> Care homes should be known not only for the quality of nursing care but for the care that allows residents and families to have choices.

**2. Conditions that locate long-term residential care homes near where residents' families live, near where activities happen and near public transit.**

A Norwegian home we studied was physically part of a structure that housed the town cinema and swimming pool, a cafeteria and day care, a spa and a climbing wall. The services made it both attractive and easy for families and friends to visit while also providing ways for residents to get out "without putting their shoes on." Such integrated services may not be feasible in all jurisdictions, but it is possible to locate homes in communities accessible by public transit and close to activities that afford residents, staff and families some options. An Ontario home located amidst a busy market meant families could combine shopping and visiting, staff had easy transit and residents had someplace to go that offered stimulating variation.

**3. Conditions that promote regulatory systems based on a balance between risk and safety, accountability and autonomy, and medical and social care.**

An emphasis on safety and accountability too often leads to the standardization reflected in rigid schedules, limited activities and few options for either residents or staff. When fear of falls and the consequent negative mark on quality indicators lead to putting everyone in wheelchairs for safety's sake, neither staff nor residents have much choice in terms of activities. When staff are so busy writing down everything they do, they do not have time to chat during meals or even assist residents who need help to eat. The result is limited choices for both staff and residents. When medical services are what count the most, then many of the activities that make life worth living are eliminated. It becomes more important to take the pills than to enjoy the meals, and time pressures often mean one must be sacrificed for the other.

Allowing residents to get up and have breakfast when they feel like it or to sleep in when they need to, as in the Manitoba and Swedish examples, requires flexible dining hours and food prepared in the residence by the home's staff. Allowing alcohol for those who were accustomed to a drink or two before they moved to long-term care can make a place feel more like home and relax residents, as in the UK example. But this is only appropriate if staff know their residents well and if managers and doctors are willing to take the risk of allowing residents to make choices.

Allowing staff teams to deal with potentially disruptive issues and to respond creatively to requests such as a resident's desire to vote, in spite of a medical diagnosis of dementia, can help satisfy residents and promote a more serene living and working environment. Allowing staff to decide about such things as whether or not residents are getting enough liquids means staff can chat during mealtimes instead of checking off the sections on their accountability documents, but it also means that managers and policy-makers must trust staff to know what is appropriate.

#### **4. Conditions that create physical spaces designed to allow choices.**

Private rooms that are financially accessible can provide spaces for privacy, as the example of the Ontario woman who, despite having roommates, wanted to watch pornography late at night demonstrated. Accessible outdoor spaces, as we saw in BC and Norway, can mean residents enjoy the garden or even do gardening when they choose. Kitchens in the unit, as in Germany, encourage residents to participate in food preparation and clean-up.

#### **5. Conditions that provide enough staff to allow variation from rigid routines and time to take individual differences into account.**

The example of apprentices in Germany shows the extent to which social care can be provided when there are enough staff. It also demonstrates that violence is less likely when neither workers nor residents are stressed because there is time to care. With ample staff the whole care home becomes livelier and there is much more variation in resident activities, variation that results from responses to individual choices of residents. Trainees also require mentoring work, especially because some may

lack the skills that come with completing formal education. In Sweden, small units with adequate staffing demonstrated that staff knew the individual residents well and had both the time and knowledge to support residents' choices. When there are not enough staff, the focus is on completing essential tasks as quickly as possible, following standard routines that offer little choice to either staff or residents.

**6. Conditions for a flexible division of labour based on teamwork.**

The teamwork and flexible positions in the Manitoba home allow workers to support each other in making appropriate decisions as well as in sharing the workload, thus allowing them to respond to resident choices. In Sweden, the flexible division of labour and teamwork create the conditions for problem-solving based on the staff's shared knowledge of residents and their complementary skills. The result is staff capacity to respond to the regular irregularity of resident behaviours in ways that permit individual choices and encourage a calm environment while allowing staff to support each other and the residents. Such flexibility is more likely to benefit staff if they are protected by unions.

**7. Conditions that support continuity, combined with shared decision-making among staff.**

Responding to resident choices appropriately is based on staff knowing each other and their residents. Staff who know the residents also know what choices are safe for them or at least can consult with others when they are unsure. Staff who know each other can build trust and recognize each other's skills and needs.

The kind of shared problem-solving described in Sweden (getting a mother to have her hair done in time for her daughters' visits) and in Norway (accommodating a resident's requests for sexual material) would be difficult in situations with high staff turnover and multiple casual employees, because staff would neither know each other nor the family well enough to negotiate such difficult conversations or approaches. A Manitoba home's practice of keeping its own list of people to work part-time and to base new hires on this list provides just one example of ensuring continuity. The distributive leadership, combined with allowing staff to make decisions, contributed to the lower turnover rates and elevated the ability of staff to exercise choice.

**8. Conditions that ensure all services are provided in-house by employees engaged as part of the team. Food, laundry and cleaning are all central to care.** In the UK, the chef employed by the home who prepared food in-house and who participated in the team was able to create “small bite” options for residents that enhanced both their joy and their health. In the Maritimes, the women working in unit kitchens could decide what food needed to be ordered, based on their knowledge of who wanted to eat what and when in the morning. They could provide breakfast when a resident woke up, could vary how the egg was cooked or the juice provided and could chat while doing it. They could also respond to individual preferences about where to sit, even if a resident changed their preference every morning. In addition, the staff in the main kitchen could vary the food with the seasons as well as with local flavours and delights, based on residents’ tastes — which they had worked to understand during the two meals the kitchen staff served directly to residents.

**9. Conditions that acknowledge and address taboo topics and ageist, sexist, racist, homophobic or ableist attitudes where and when they exist.** Too often there are topics that are off-limits in long-term care. Whether or not the dilemmas presented by complex issues can be openly addressed shapes whether or not long-term care is a place of choice for residents, staff and their families. These include the fine lines drawn by libido and consent, dementia and infidelity, drinking and alcoholism, intimacy and abuse, loneliness and lack of privacy, sexuality and perversion. When families oppose care for women from male staff, racism often plays a role because virtually all male staff are from racialized communities. As we saw in Sweden, supporting staff in making decisions that allow them to navigate these complex issues also supports residents’ choices. Communal living presents unique challenges that can rob people of their dignity and humanity. Addressing these dilemmas makes it more likely that choice is of paramount concern.

**10. Conditions that allow families and friends the option of participating or not in care.** If the other nine conditions listed here are met, then families may well have more choices about how, when and in what ways to participate in care. In considering these and other

conditions, gender, racialization and culture are all factors to take into account.

We have stressed conditions because these set the context for making choices possible. While we are convinced that there is no single, right model for long-term residential care, our research has convinced us that these ten conditions are necessary but not sufficient for exercising choice and for providing the kind of options that make life and work rewarding in nursing homes today.

---

## NOTES

1. Organization for Economic Cooperation and Development. (2012). *Long-Term Care Data: Progress and Next Steps*. Paris: OECD. Available at: [http://www.oecd.org/els/health-systems/Item%204\\_0\\_LTC.pdf](http://www.oecd.org/els/health-systems/Item%204_0_LTC.pdf), p.6.
2. Canadian Institute for Health Information. (2011). *Health Care in Canada 2011: A Focus on Seniors*. Ottawa: CIHI. Available at: [https://secure.cihi.ca/free\\_products/HCIC\\_2011\\_seniors\\_report\\_en.pdf](https://secure.cihi.ca/free_products/HCIC_2011_seniors_report_en.pdf), p. 90.
3. Canadian Institute for Health Information. (2011). *Health Care in Canada 2011: A Focus on Seniors*. Ottawa: CIHI. Available at: [https://secure.cihi.ca/free\\_products/HCIC\\_2011\\_seniors\\_report\\_en.pdf](https://secure.cihi.ca/free_products/HCIC_2011_seniors_report_en.pdf), p.93.
4. CCAC Client Services Policy Manual. (2006, September). Chapter 12. Management of Long-Term Care Home Waiting Lists by CCACs. Available at: [http://www.health.gov.on.ca/english/providers/pub/manuals/ccac/ccac\\_12.pdf](http://www.health.gov.on.ca/english/providers/pub/manuals/ccac/ccac_12.pdf).

Expanding choice has long been a central feature of health care reforms, with a focus on choices for individual patients and residents. However, choices are structured by factors often beyond the control of individuals or even particular care homes and by the extent to which staff or unpaid providers can build relationships that provide the basis for appropriate decision-making. Moreover, there is a fundamental tension between the need for routine, for evidence-informed decision-making and for safety on the one hand and on the other, responding to individual choices and events that disrupt routines on a regular basis.

Based on our team research on long-term residential care in six high-income countries, *Exercising Choice in Long-Term Residential Care* identifies conditions that set the context for exercising meaningful choices for residents, staff, families and managers in long-term residential care. We start from the assumption that there will be events and choices that do not conform to routine patterns. And we assume that the conditions of work are the conditions of care.

**PAT ARMSTRONG** is a Distinguished Research Professor in Sociology and Fellow of the Royal Society of Canada. She teaches Sociology at York University, Toronto, Canada and publishes in the area of long-term care, women's health, social policy and social services. She is the Principal Investigator on Reimagining Long-Term Residential Care: An International Study of Promising Practices, the project that provides the basis for this book.

**TAMARA DALY** is an Associate Professor, CIHR Research Chair in Gender, Care Work and Health as well as the Director of the York University Centre on Aging Research and Education. She teaches Health Policy and Equity at York University. Her publications are in the areas of long-term care, access to health and social care, women's health as well as non-profit health services. She is a co-investigator and work organization theme leader on Reimagining Long-Term Residential Care: An International Study of Promising Practices.



CCPA

CANADIAN CENTRE  
for POLICY ALTERNATIVES  
CENTRE CANADIEN  
de POLITIQUES ALTERNATIVES

