



I'm still me

THE LIVED EXPERIENCES
OF RESIDENTS
IN DESIGNATED
SUPPORTIVE LIVING



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THE STORY OF A DESIGNATED SUPPORTIVE LIVING RESIDENT

Meet Elsie

This report has been crafted to acquire and convey a deeper understanding of resident experiences in designated supportive living facilities in Alberta, based on what 32 residents told us in interviews. Their contributions are shared in detail in the following pages, and in many cases, we illustrate what we heard by sharing direct quotes from residents.

We believe it is helpful to first share resident experiences through the lens of Elsie. Elsie is a fictional character. However, her story represents what many residents typically encounter, providing a valuable perspective into what's truly important and meaningful to those in designated supportive living here in Alberta. From Elsie, we can learn what's been working well and what can be improved to provide the best experiences for residents.

Let's begin Elsie's story with her move into designated supportive living.

An uncomfortable transition

Elsie had been living independently in her home in Red Deer for many years, eventually with increasing support from her family. One day, she fell and broke a bone and was taken by ambulance to the local emergency. She was admitted to hospital. After being treated and then assessed by her healthcare team, Elsie and her family decided together that she needed a higher level of care and should no longer live alone. While Elsie waited in hospital, her family did a lot of research to find a care facility that suited her needs. This could take months, she was told, but only a few weeks later the hospital informed her and her family about an open bed in a local facility that had the right level of care. Elsie was upset by how fast everything was going, because in no time at all she was moving, unable to return home.

"All of a sudden, there's a room empty.
I was so upset that it went so fast."

- RESIDENT QUOTE

A few weeks after she arrived at the facility, her frustrations lessened. She liked how clean, bright and open the building was. She was pleased her room was private, with a living area, bedroom, and bathroom. Though not as big as her house, her new space accommodated some of her belongings, including her bed, an armchair and some plants. Her room also came with storage cupboards, a kettle for tea and a small fridge for her favourite snacks. She was especially happy when she found out she could hang as many pictures as she liked, just like in her house.

Even so, Elsie had difficulty adjusting to her new life. Although grateful for round-the-clock help from the staff, she wanted to retain some independence in caring for herself. The staff respected Elsie's ability to dress and bathe herself, while maintaining her need for supervision. Elsie was thankful that she was being cared for by such friendly and accommodating staff, receiving enough help to live as she wanted.

Trust through relationships

Elsie's relationship with the staff continued to grow as she got to know them, and as they learned about and endeavored to meet her needs. Elsie liked being cared for by the same staff because she trusted them. Elsie appreciated the way staff treated her, with their hugs, nonjudgmental attitude, and genuine interest in how her day was going. She was being treated as a person, the person she had always been.

"I've always been independent. It is hard to depend on anybody else."

"They accommodate as much as they can. They're very helpful."

- RESIDENT QUOTES

Understanding through communication

Elsie felt heard and valued by being kept informed about her care. Staff discussed the care with her in advance, and answered her questions and concerns. Elsie liked it when staff communicated with her after she rung her call bell to acknowledge her need for help, and gave her an estimated wait time. Elsie was patient knowing staff would arrive after they finished helping other residents.

Maintaining meal expectations

One new reality was the change in style of meals. After a lifelong routine of cooking for her family and then just for herself, Elsie now had meals prepared for her. These meals weren't always reflective of what she liked or what she was used to eating. She'd been used to meat, potatoes and garden vegetables, a menu option that now was

only available a handful of times. Elsie wanted the meals to better meet her expectations, and was pleased to learn she could take part in a resident food council at the facility.

Sustaining interests in activities

Elsie had mixed experiences with the activities available to her, which, again, didn't always match her lifelong interests. She enjoyed playing card games or trivia, but saw they were difficult for some others to participate in. She tried exercise classes, but she did not find them challenging, in some cases it was merely a lot of rubber band stretching or throwing a ball in the air. To socialize with others, she began playing the many varieties of bingo available. Elsie wanted more meaningful activities that better reflected her interests and abilities, but she persisted in this opportunity to socialize.

"You ring the bell and they answer on the telephone."

"I used to live to eat and now I eat to live."

- RESIDENT QUOTES

"Because all they have is bingo and you know I mean bingo is all right, but I mean."
"I really love it very much. And I can't see living anywhere else."

- RESIDENT QUOTES

Elsie's home

Time has turned out to be Elsie's friend. Now age 80, she has lived in the facility for 18 months. While some things could be better, she considers them small concerns. Her experiences so far in designated supportive living have been quite positive. Elsie is happy at the facility and says she could not ask for anything better. "Home" at last, Elsie looks forward to many years in these surroundings that provide professional care, friendship, and leisure.

INTRODUCTION

From January to May 2017, the Health Quality Council of Alberta (HQCA) interviewed 32 residents across ten designated supportive living facilities in Alberta to gain a deeper understanding of their experiences. Participating facilities were large and small in terms of number of residents, located in both rural and urban communities. Specifically, the HQCA engaged residents to gather first-hand views of what was working well and what could be improved at their facility, and understand why these things are meaningful to them. The HQCA then analyzed what we heard to look for themes. For more information about our methodology for this work, please refer to the appendix.

The results are not HQCA opinions. Simply put, we heard from residents – about what is important to them, and how things can be changed to improve residents' experiences in designated supportive living. Learning what's working well first-hand from residents is valuable information that can be used for quality improvement.

For ease of reading, throughout this report we will refer to designated supportive living as simply supportive living. Resident experiences are illustrated through direct quotes from interviews, and are shown in italics.

WHAT WE LEARNED - THE BIG PICTURE

Transitioning to supportive living can be challenging because it involves adjusting to a different living environment that may be inconsistent with how residents have previously lived their lives. Based on the stories residents told, it is important that they be able to preserve or maintain their personal interests, lifestyles, and expectations as much as possible to better support them in this transition and beyond. This will be apparent in the findings throughout this report.

What is working well?

Most residents described supportive living positively. Regardless of their particular facility, residents consistently cited two key elements that worked well. These elements were prevalent in all areas of resident experience, and are evident in most sections of the findings.

These were:

- Resident relationships with staff.
 - Staff and management who took the time to talk with residents and personally demonstrated caring and kindness.
- Communication with staff.

Staff who acknowledged and communicated with residents promptly. Residents said they were usually willing to wait for help if staff communicated with them.

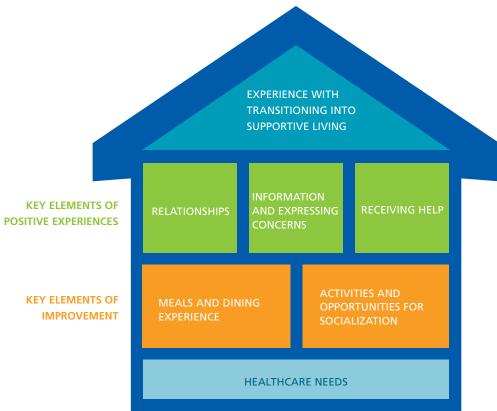
What can be improved?

Similarly, regardless of the facility, residents discussed common key elements for improvement. These included:

- Meals and dining experience.
 - Residents consistently felt food was an area for improvement specifically, the quality, taste, nutritional value, variety, temperature, presentation, and transport of food.
- Activities and opportunities for socialization.
 - Most residents said the variety and number of activities available at their facilities didn't always fit their personal interests, and did not take into account varying cognitive and physical capabilities. Activities often viewed as a way to get out of their room and socialize with others should still be meaningful and engaging.

Resident input about what was working well and what could be improved was captured in seven themes that are outlined in Figure 1 opposite.

FIGURE 1: Themes in findings



WHAT WE LEARNED - THE DETAILS

The following section summarizes eight themes that reflect what we heard from residents about their experiences, and what is most important and meaningful to them.

Experience with transitioning into supportive living

Residents reflected on their experiences in leaving their previous home to move into supportive living. They discussed adjusting to communal living when fellow residents have varying mental and physical capacities; maintaining their privacy; making their room their home; and fitting in with other residents in their building. Most residents said they had made the move because they needed additional care or support that was not otherwise available. Many said a family member chose the facility, while others recounted touring facilities themselves before making a decision. Contributing factors to their choice of facility included where the facility was located in relation to a family member, the level of available care needed, and the facility's affordability.

When recalling first impressions, residents gave positive descriptions of factors such as cleanliness, room size and staff.

Experience with transitioning into supportive living - continued

"Everything is clean and all of that sort of thing. And everything where you go to eat is a nice area and you can go downstairs and there's big rooms down there to go and do things and stuff. So yeah, at least I thought this is a really good place; I think this will be good... I looked at others up in this area, but I didn't like them. I wanted to come here."

"Well, it was not all set up and it looked so small to me you know. And then when everything was set up here, I thought it was nice and cozy here."

Residents' impressions also varied according to where they previously resided – whether in communal living or independent in their own home.

"It's different living than I've ever had before, because you know you don't have to do anything. You're waited on for everything, so that was new to me."

"It took a while to get used to it, because being independent, and then being here where everybody just waits hand and foot on you... it's quite a shock."

"You're as independent in here as you want to be, sort of thing."

"I think [supportive living is] good because as you age, no matter how much your family is going to give you, you still are independent.

You know you've lived your life and you're

independent and for me, it bothers me less to ask an aide to help me than my [family member]... Like I'm not missing anything, but it's just the idea that it's to lose your independence. It's hard."

The appearance and design of the building and private room were especially important in forming first impressions. This is discussed in more detail below.

Transitioning to the building

Some residents named building brightness and cleanliness as an important factor in deciding to move in. Another was the absence of unpleasant odours, for which they appreciated the efforts of staff to ensure this was the case.

"Well, it's very clean for one thing. They're always cleaning in here and for one little person, I mean I don't really mess up the place at all. But they come in and they clean it every morning and in the afternoon they come in and they do some more dusting and what have you."

"Well, [family member] goes by the nose [when choosing a place to live]. When you walk in the front door how bad it smells and there was no smell."

Many praised a building design that enabled residents to retain a level of independence they were used to, and to maintain a sense of routine with such benefits as an on-site laundry room, mailbox, coffee shop, or salon.



COUNCIL OF ALBERTA

Experiences with transitioning into supportive living

Transitioning to continuing care is a major life event that involves adjusting to a different way of living. ^{1,2} It means leaving behind homes, personal belongings, and communities and reconciling expectations formed throughout a lifespan with current experience. Sometimes, this is not seamless or continuous, and some residents had more positive experiences than others. However, it is apparent that maintaining, as much as possible, an individual's sense of identity is crucial to a more positive experience.

"If you want to send a letter, they have a mailbox downstairs for outgoing mail. Reception picks it up and brings it inside and then when the mailman comes it goes out, so that's helpful."

"We've got our coffee shop downstairs."

"... and sometimes they have little goodies in a little closed up thing."

"We can have our friends come or our [family] and we take them down there and give them coffee or tea."

The location of the building enabled residents to continue to conduct their lives as they had in their communities previously. For example, several said they liked the building's close proximity to shopping centres and points of interest within walking distance. One resident was happy that he was able to walk a short distance to the same bank where he had done his banking most of his life. It was therefore important to residents that walkways were kept free of hazards like snow and ice to ensure they were able to continue to spend time outdoors as desired.

"And getting out here, like it's really hard with all of this stuff all going around outside too.
And the ice and, all of that for the winter. It's just hard to get out."

"I've got the dollar store, and a lot of people don't have, are not lucky enough, to have their bank.

My bank, the one I've dealt in for the last [number of] years or more, [is within walking distance]."

Residents also praised building designs that enabled frequent and easy socialization, in indoor and outdoor spaces that are accessible without the help of staff.

"The design of the building, it's not closed in. Like, you walk out the door and look up to the hallway there, and there's a big area that we curl in, and we have bowling, and all of this kind of stuff. I don't know, it's sort of—more area."

"They've got places where you can sit out on the balcony and that sort of thing. And people seem to do that more in the summer."

"I love being, like, at my house; I had a really nice place in the back and I had beautiful, big tall places where... the birds are all in there and it was really quiet, and it was just a really nice place... I went to [the balcony], they've got a really nice area."

These design aspects offered normalcy and comfort in their new environment, enhancing independence. Residents emphasized the importance of keeping familiar patterns and habits. But one resident mentioned the lack of large common areas to socialize in. Another felt outdoor spaces were not accessible without staff's help (e.g., doors were not automatic).



Experiences with transitioning into supportive living

- Provide bright lighting throughout the building and in resident rooms
- Frequently clean resident rooms and common areas
- Eliminate bad odours
- Provide on-site amenities like a laundry room, games room, mail services, salon, and a café
- Build close to shopping, entertainment, and banking
- Keep walkways clear of snow and ice
- Make common areas available
- Ensure doors are easily opened for residents of all capabilities (e.g., automatic doors)
- Provide access to outdoor spaces



Transitioning to a private room

The move from a house or apartment to a small room was a change in lifestyle for many residents, but the experience was made more positive if the individual had a private room and bathroom, with enough room for personal belongings.

Many also spoke of people's efforts, such as from staff or family, to help make their room feel like home, with their own furniture, pictures, and décor. Staff also helped to make the temperature in their room more comfortable. Residents also talked about conducting their lives in the privacy of their room, such as engaging in independent activities like knitting, visiting with family or friends, or watching television.

"Well, my [family member] has brought quite a few things from my house to make it like home you know."

"The rooms are great and nobody objects to how many pictures you put up. That's fantastic."

But if rooms seemed cramped and impersonal, with a shared bathroom and insufficient division between bedroom and living space, residents missed their old home.

"This is a private room, but I have to share a bathroom. And I don't like that, although I never have any problems. I mean okay, sometimes, like, I saw the light was on, and the door was closed. And when you see that you think, oh, somebody is in [there]... and I sat on the chair waiting and waiting and I don't hear any noise in there, and I went to open the door and it opened. They forget, and they close the door and leave the light on, and you think somebody is in it."



HEALTH QUALITY
COUNCIL OF ALBERTA

Transitioning to a private room

Positive experiences with supportive living were fostered by helping residents to feel comfortable in the space, and give them the opportunity to maintain their sense of self-identity. The concept of home is multifaceted, and includes the built environment, the ability to feel safe, and to be autonomous.³ Overall, when residents felt they were supported to make their room their home, and felt comfortable in their facility environment, their experiences were more positive.

Some residents mentioned the absence of a lock on their room and while some did not mind this, others said becoming used to it took time. Though, for several residents, it was particularly troubling that uninvited visits occurred at all hours.

"I've never not had a lock on my door in my life, right?"

"[Resident's] go into people's places in here in the middle of the night and wake you up and that sort of thing... right in our places. And there's no lock on these things, so I don't like it."

For some, this new residence was home. For others, not yet.

"This is a [facility]. It's never going to be home, but it's a home. It's where you hang your hat."

"You know I mean you can't expect this to be like home. You can't have a [pet] and you can't do lots of things."

While their new home may not have had the space they were used to, many were pleased that their room reflected who they were as a result of personalizing the space with their own furnishings and personal belongings, enhancing a sense of ownership and comfort.



Transitioning to a private room

- Provide assistance as needed with room maintenance (e.g., temperature, hanging pictures)
- Encourage and help residents to personalize rooms with décor and furniture (e.g., hanging pictures)
- Ensure temperature in resident's room is comfortable
- Provide private room with private bathroom
- Provide enough storage in rooms

Relationships

Relationships with staff

Residents constantly cited their relationships with staff as a key element for positive experiences. Needing assistance from staff with care tasks they may have been able to do for themselves was challenging. Though for many, building a relationship with staff based on trust, respect, and communication made them feel more comfortable with receiving staff's help.

"You know what amazed me, is one day I'm sitting down there just looking around, and this [other resident] came up to the desk, and I don't know who [the other resident] was, and [other resident] said, 'I'm taking my car out'. As soon as [other resident] walked out the door, [a staff member] got on the phone and I heard [them] say, 'will you send somebody out just to make sure. . . [other resident] is okay?' I thought, how much farther can they go to help people around here?"

"I feel that the staff around here goes out of their way to make me feel comfortable and everything like this, you know."

Residents especially liked staff who demonstrated they cared about them, and were kind, patient, and attentive. Especially if staff appeared to enjoy their work, helped without question or judgment, and did not rush care.

"... a person who is really devoted and who is really good with their client is different from one who walks in with [their] hand in [their] pocket and [snaps their fingers], 'what do you want done?' You know—it's the attitude. But most of them, most of them are very good."

"And they never contradict you or anything. They just avoid the thing that's bothering you. I like the treatment, [it's] positive you know, and they know what older people are like. They've all got grandmas and grandpas."

They wanted to be treated as people, not as patients or as tasks to be completed. This meant staff greeted them by name, showed an interest in their lives, and engaged them in meaningful conversation outside topics of their care.

"The girls come in to clean and they talk to you and ask you different things and if you're having a good day or a bad day. Yeah, it makes you feel good."

"And the [staff] from the kitchen, one always talks. Two of them always talk to me and no matter where they're meeting me."



Relationships with staff

Moving to continuing care, a shift in role expectation can occur from that of an independent person to a dependent person, requiring assistance with tasks of daily living.² When staff treated residents as persons rather than a care task to be completed, residents were more satisfied and had more positive experiences. Similarly, whether residents were able to form relationships with like-minded others was important to whether they felt they fit in in their facility.



It was also evident that this was a two-way relationship, with several mentioning they asked staff about their day as well and inquired about staff's family. Several mentioned purchasing small gifts or treats to show their appreciation for the staff. When staff left or were rotated throughout the building, it was felt as a loss, because residents had bonded with them.

"I just treat them all as friends. Like, I like to give them candies and at [holidays] I give them little, wee, \$2 gifts and stuff like that. So I like to do that."

"And sometimes they'll sit and talk to you if they have time, you know. And I don't know, I think one of my girls are leaving and I hope I get to see [staff member]. And we had one [staff member] leave, and I wish [staff member] would come back... I mean we all felt as if [staff member] was our grandchild." Like in any relationship, residents acknowledged staff had difficult days, too, because they were human, with challenging jobs, especially because there were many variables that changed daily when working with people who had differing needs. And because of this, residents typically understood when staff were not as patient or friendly as usual.

"Sometimes it gets a little dustier on the edges here or something like that, but that's not, it's really the people's fault, but I always figure they're tired or they're not feeling good that day. So you've got to give them a little keeway."

"Well, I think that first of all anybody that's living in supportive living has got to realize that in many times this is a very stressful job for the caregivers. And how they can put up, and doing what they have to do all the time, and I think not some of the staff but some of the residents in here, and even on this floor, some of the residents here should show the staff a hell of a lot more respect, because they deserve it."

In general, mutual respect and clear communication were seen to be crucial in cultivating positive relations between residents and staff. Negative ones stemmed from poor body language (e.g., stomping feet), lack of interest in residents personally, leaving an impression they dislike their job, and rushing through care tasks.



Relationships with staff

- Be kind, patient, respectful, and caring
- Be personable, greet residents by name and ask about their day
- Bring a positive attitude to work and demonstrate enjoyment in working with residents
- Engage residents in conversation
- Take the time to get to know residents personally; what they like and do not like
- Take the time to provide help so that help is not rushed

Relationships with other residents

Residents mentioned they were not always able to choose their facility – based on availability or a family member's decision – so their new home didn't reflect their lifestyle and interests. Examples include being too far from their old neighbourhood, and missing being able to go for walks on familiar pathways and to their favourite shops.

The extent to which they wanted to engage in the community in their facility varied, with some stating they engaged regularly in activities and social events, or participated in resident council meetings. However, a key barrier identified to feeling part of the community was residents' expectation that their neighbours would be similar to them in mental processes of perception, judgment, reasoning and memory. Many were disappointed when this was not the case.

"The ratio to people who are still mentally active, like they don't have dementia or they don't have Alzheimer's, I thought it was lower than what it is here... I mean, I could be talking to you and then tomorrow if you have that illness, you don't remember and you start all over again. But that took a while before you could filter out the people who were capable of remembering."

"You see each floor is for different medical problems. So on this floor when I moved in here, I understood that everybody was more or less not physically, but mentally [well] and that they were pretty good. But you've got people walking around here and they haven't got a clue where they are. They just wander around and wander around day and night."

Regardless, many residents formed friendships, performed favours, and advocated on behalf of other residents.

"I like to be around people and I like to intermingle with the residents and that you know. That way you get to know more people too. And I like that."

"I am the representative of all the residents on this floor. We have a meeting once a month and I collect all the forms if they've filled out any forms, plus I just speak to people in general. How are you doing and is everything okay? Have you got any complaints?"

While several residents spoke about limiting their community participation because of lifelong habits, at least one resident acknowledged feeling comfortable at his facility only after starting to interact with other residents.



HEALTH QUALITY COUNCIL OF ALBERTA

Relationships with other residents

Supportive living facilities can be thought of as small communities housing people who are similar in circumstance. While living in this community may or may not be voluntary (e.g., some residents conveyed they would choose to live in their own home if they were able), a sense of belonging is important. Belonging refers to how much a person feels they fit in a place or group and the degree to which the person feels welcomed and included.4 Feeling a sense of belonging to a community improves access to social support, health, provides a sense of purpose and resiliency,4 and when lacking, it can lead to isolation. As a result, it is important facilities encourage and foster a sense of belonging for its residents.



"I like living here, except I find it lonelier... [the people here are] a different group of people and we're all losing our memories and our ability to mix. I spend a lot of time by myself and I don't mind that."

"Once I got involved in recreation and getting to know people I felt very good."

In general, whether residents were able to form relationships with like-minded others was important to whether they felt they belonged in their facility.

PATHS to best experiences RESIDENTS' OBSERVATIONS

Relationships with other residents

- Assign residents to rooms next to other residents similar in cognitive ability
- Utilize resident-led welcoming committees to welcome new residents, provide an orientation to the building, and address any questions or concerns

Information and expressing concerns

Residents wanted information about their care and about any changes in their building, and most felt they were getting it.

"They took me off one medication for my [medical condition] and put me on another one and man, did I ever feel lousy. But I asked for an information sheet about my new medication and they gave me a sheet and I read up about it. I still have it in my top drawer there and I can look it up any time I want and that was good."

"If there are some changes taking place. They post different bulletins and stuff like that. I think the information flow is pretty good."

Residents also expected their concerns to be heard and addressed in a timely manner. One way they did this was by providing feedback via comment cards if available, or at resident council meetings. For some, this resulted in positive changes.

"If you've got a problem, hanging on the wall out there and this floor and it's on every floor, but they've got a complaint sheet and then you've got to fold it up and put it in the box right next to it and then they clean them out like every day or every couple of days."

"We bring up different things at the meeting and usually they're worked on. Not every, sometimes people make complaints, but we don't feel that they're worthy of bringing them to the department head. So usually I don't know how they handle that. I think they go and speak to themselves, because they can't keep bothering the department head because someone thinks the toast is burnt in the morning. I mean that doesn't happen very often; once in a while. So things like that, you know you have to draw the line."

Second, sharing concerns directly with staff and management resulted in positive changes. However, there were barriers to staff's ability to help, such as limitations in their decision-making capacity. It was therefore important that residents be aware of staff's roles and responsibilities and the steps involved to escalate a concern.



HEALTH QUALITY COUNCIL OF ALBERTA

Information and expressing concerns

When transitioning to continuing care a shift in role expectation can occur from that of an independent person to that of a dependent person who requires assistance.² Residents had more positive experiences when they were engaged in reciprocal two-way communication with staff and were informed and involved in their care to the degree they wanted or were used to previous to supportive living. When residents were treated as if they were not capable of making their own decisions about their care it removed their control over their bodies and made them feel devalued as persons.

"I have access to the right people to solve the problems... If it doesn't work, then you'd have to go to the next level."

"I go down to talk to [the manager] I bring [a concern] up again and it's still under discussion and it's typical for them being a company, like; if [the manager] can make decisions some of it would be more likely to be done. But they've got a big corporation, so then you've got to go to the higher ups and do all that stuff."

Residents who did not have positive experiences talked about perceived attempts to communicate with staff and believing they hadn't been heard. This was akin to feeling dismissed. And some worried they risked negative repercussions if they were honest and open.

"They listen, but they don't hear. And they're running sometimes here, and I will tell them something very straight out and make it, to me, exceedingly plain. I'm not going around the bushes or something, and they just hear what worked yesterday. They're not hearing today."

"I mean you don't want to, yeah, you don't want to deal with the person that can make your life more miserable and literally someday might hold your life in their hands, right?"

In general, residents had positive experiences with getting needed information, and with staff addressing their questions and concerns.



Information and expressing concerns

- Provide answers to questions in a timely manner
- Provide updates about changes or events occurring in the building through notices or posted to a bulletin board in a public area
- Provide opportunities to hear resident feedback anonymously such as a comments box or through a resident council (e.g., designating a resident to represent their floor)
- Ensure residents know who to direct a question or concern to and how to escalate a question or concern if it is not resolved
- Ensure staff and management are receptive to receive feedback and resolve any concerns
- Utilize feedback collected from residents to make positive change

Receiving help

Receiving help was a key component in ensuring residents had a positive experience in supportive living, typically achieved by staff who frequently checked on residents, demonstrated genuine concern for their safety and comfort, and provided timely help.

"Like if you ask them to do something they will do it and it's not like they're giving you feedback that it's an obligation, it's their duty. But with my [family member] that's here, I feel, I ask when I have to, but I like to be quite independent."

"I'm amazed to get as much help as I get, which

"I'm amazed to get as much help as I get, which I need, but I never imagined I'd be able to get such help."

It was important to residents that they are able to do as much for themselves as they could, if desired, but to receive support from staff when needed. This sometimes required negotiations and compromises. For example, one resident insisted to staff that she make her own bed each morning, because this was a task she had accomplished by herself all of her life and was still capable of doing so. Some residents experienced dissatisfaction when staff took for granted that they required less assistance, and their needs were not prioritized.

"They've kind of let up lately because I told them that I do everything myself. So I figure well, I can do it myself; I'm going to do it." "I sit here and I wait for a while and okay, they're busy doing something or looking after somebody else or giving somebody a shower or doing whatever. So I'll turn around and [help] myself and eventually they show up... I'd like to get somebody in here to assist me, which is on the books that they're supposed to."

Another example common to many residents was mobility, and the degree to which residents felt supported to improve and/or maintain mobility (not limited to physical ability and included travel and outings). Mobility was often linked to feeling free to go wherever they wanted and to do the things they wanted to do. Immobile residents wanted physiotherapy, or assistance with walking or exercise, to end a feeling of being trapped.

"I still have it in the back of my mind that I'm going to need some healthcare, but at the same time as I'm going to need this healthcare; I still have to have the mobility to be able to get around. And without that mobility, I feel locked in."

"The [surgeon] wanted [the resident] walking and the physical therapist and the occupational therapist agreed that with a walker and with supervision, walking was good... And they have an occupational therapist here, but [they] can only seem to be able to work with [the resident] for two weeks and then [they're] gone." (Jamily member)



HEALTH QUALITY COUNCIL OF ALBERTA

Receiving help

It is important to residents that they are able to do as much for themselves as they can, because this enables them to maintain dignity and control over their bodies. For some residents, maintaining independence was how they were able to cope with living in supportive living. Specifically, it allowed them to acknowledge the help they did need to live as capable and able bodied persons. When residents are not enabled to maintain independence to the degree they desire, it can make them feel powerless.

When residents were unable to receive timely help with care tasks they were dependent on staff for help, and/or lacked support to maintain independence when able to do things for themselves, this contributed to feelings of powerlessness and loss of dignity. It is therefore important that staff acknowledge residents' need for help and provide assistance as soon as possible.

In contrast, some residents expressed concern when they did not receive help in a timely manner after ringing their call bell. For example, one resident talked about feeling frustrated with staff when needed help didn't arrive. Indeed, while residents who used their call bell for assistance did not expect help to arrive immediately, they did want staff to tell them when they would get help. When informed, residents were generally understanding and willing to wait. Overall, dissatisfaction with delays was somewhat mitigated by honest communication.

"Whenever I need them I call them on this button. They don't come right away because they're tied up with somebody else and if they can't be here in five minutes or more they'll call me on the telephone and say [name], we're busy right now, can you give us a few more minutes?"

"I wish they would tell me it will take a while...
If they come in five minutes I'll wait, but they
don't come when I phone. No, I mean some people
come if they don't have [anyone to help], but
10 minutes, right? If I can wait 10 minutes, I
wait. But sometimes I can't wait."

Residents also felt the timeliness of scheduled help seemed designed to fit a staff member's schedule rather than their own. Some felt they were "competing" for staff's attention with other residents. For example, several residents mentioned having to wait in bed too late, sometimes missing breakfast, because of delays in staff providing morning care. Residents perceived that the number of staff available, and scheduling of staff at high-needs times of day, were contributing factors to how help was scheduled.

"I certainly wouldn't want to get up at seven a.m. and go to bed at six p.m. But you know if there's ten people on my floor that need help getting into bed and the [staff] all leave at eight-thirty or whatever, then so be it. So yeah, I mean you fit into their schedule versus vice-versa."

"They're taking people that are sicker, but the only thing they haven't done is upgraded their nursing. I think even one [more] person on each shift. I think there should be two [staff] on nights. You know that's forty patients for one person..."

Finally, continuity of staff was important to residents' experience receiving help, especially when staff turnover was high or staff were frequently rotated through the building and unable to become familiar with the residents in their care. Sometimes it fell to residents to "train" staff on how to best provide them with the care they needed.

"You do get used to the person who is taking care of you... It's a change... It's a little getting used to, but you have to retell them what you like... But it's an adaptation like anything else. It's not life-threatening. It's just repetition for about a week. And they have so many patients, you know."



Receiving help

- Provide help when needed, without question or judgment
- Encourage residents to do the things they could for themselves, and provide support when needed
- Support residents to become more mobile through exercise, help with walking, and accessing therapies (how to access resources, such as physiotherapy)
- Communicate with residents when they ask for help, to check the urgency of their need and provide an approximate wait time for help
- Learn and share amongst the team, residents' unique care needs and how best to help residents in the way they prefer
- Ensure scheduling of staff breaks and shifts do not conflict with times of day that residents need the most help (i.e., early morning, evening hours after dinner, and during meal times)
- Provide help during times of day that are reasonable for the resident
- Ensure continuity of staff, so that the same staff provide help to residents

Receiving help - continued

"I feel the girls are getting paid for what they're supposed to be doing and why should some of the girls do it and the others not? That's the way I look at it. I mean they're doing the same job, right? And both of them should both be able to do the same thing."

Overall, it was important to residents that they be supported to do as much for themselves as they are able, and to receive support from staff when they needed it. Relatedly, dissatisfaction with delays in wait times to receive help on demand can be mitigated, at least in part, by communicating with residents about the urgency of their need and an anticipated wait time.

Meals and dining experience

Among the most frequently mentioned areas for improvement were meals. For many, mealtime encompassed the service (i.e., whether staff assisted residents to get to meals on time, and served meals at the scheduled time), the opportunity to socialize with other residents (who was seated where was important), and the food. However, the most discussed topic was the food itself. The food did not always align with residents' past experiences or expectations. For example, food experiences from travelling, or meals residents were used to making or receiving when eating with family. This affected why they felt there was room for improvement. For example, one resident said the ethnic dishes the facility created were not reminiscent of the meals he ate on his travels. Many others said they were used to get this type of meal a handful of times per rotated meal schedule. Ultimately, these experiences shaped their expectations of the food, and resulted in recommended improvements.

"Well, I was brought up on a farm and I like plain, just plain, and it's nothing like we ate."

"I mean they've got the chicken and they use ground beef. It's just the way they prepare it. It's tasteless. I'm a good cook that's my problem."

"It's because we [traveled], so I had the experience. And so, when they deliver stuff to our table these days and there's a name on it and it will say some name that the other people don't understand and they say what the hell is that? And I said it's supposed to be Spanish food, but it really isn't."

First, meal planning was identified as an area for improvement. Residents felt inexpensive and poor-quality meats and produce were ordered to save money, which diminished taste and nutritional



Meals and dining experience

For most, cooking was previously a normal part of their day. It served to provide a sense of self-identity, and autonomy. Food and how it is provided in supportive living, is therefore a major shift for many residents, both in lifestyle and self-expression. As a result, when meals did not meet their expectations it became a primary source of dissatisfaction.



value, often leading to food waste. This was of particular concern when medical dietary restrictions or health goals were not facilitated. Meal plans were also repetitious and lacking variety, causing meals to become predictable and boring. While several residents said their suggestions for change weren't successful, some felt the food may not be within the control of their facility management but rather the corporate owners or the food contractor, making it difficult to effect improvements.

"There's quite a bit of concern about the food services period. And no matter where you are, if you want to have a happy group, you've got to give them good food. Don't expect hotel-style, but I expect something decent."

"I don't think there's very much variety, but then they aren't in a position to pay for just anything. So you have to leave it to them to spend the money and I think that as it goes there is a great deal of food wasted here. That's one thing that really I find rather appalling. There is no reason for wasting all that. If they would go around and ask you what you want before serving them it would save a lot of food. But they serve people that just push the plate aside and it goes into the garbage."

Others felt their facility was doing its best to provide for a large variation in resident taste and dietary needs; however, these were a minority of residents. For example, several mentioned participating in food councils or sharing feedback with cooking staff or management and seeing positive change as a result. In addition, they expressed appreciation when staff proactively identified what they liked and did not like, and ordered food according to their preference. These examples indicate this worked well for some residents and can inform positive change.



Meals and dining experience

- Provide information about the food served; avoid extravagant naming of meals (e.g., chicken cacciatore as opposed to chicken with tomato sauce)
- Seat residents immediately before meals are to be served
- Seat residents who are similar in cognitive level together and/or let residents choose whom they sit with
- Ensure residents have enough time to eat their meal before removing plates from the table
- Account for residents' dietary needs as well as health and wellness goals when meal planning
- Improve variety of meals and drinks
- Provide two meal choices at each meal
- Ensure quality fresh produce and meats are used
- Ensure food is flavourful by spicing appropriately

... continued



Meals and dining experience - continued

- Ensure appropriate condiments are available at each meal (e.g., jam at breakfast and ketchup at lunch)
- Cook meals in the kitchen on-site
- Ensure food is cooked appropriately (e.g., grilling rather than baking meats)
- Ensure food arrives at the appropriate temperature
- Ensure plating of food is done thoughtfully
- Do not overload food with sauces; (e.g., put gravy in a separate container to add if desired)
- Collect input from residents and use this information to plan meals
- ▶ Take note of when food waste is high and use this information to inform meal planning
- Ask for, and be receptive to, resident feedback about the food and use such comments to make changes

Meals and dining experience - continued

"They do their best and [staff] is very, very open-minded when it comes to, [a member of the kitchen staff] even brought in, like I take bran bud cereal. Like I was willing to buy my own, but [the staff member] ordered it in and now [other] people at my table are all eating it and it's very good."

"The food is generally pretty good and if we don't like something, we can notify the chef and let [the chef] know and [they] will do [their] best to change it to improve it."

In addition, food preparation was identified as an area for improvement. Specifically, food could be bland, unappetizing, overcooked or undercooked, and hot food was not hot and cold food was not always cold. Transport and plating of meals was also an area for improvement. Food was not always thoughtfully plated (e.g., hot food on cold plates or cold food on hot plates) and presented, or was difficult to identify (e.g., if overladen in sauces), which for residents, demonstrated a lack of caring on the part of the chef. When food did not taste good, look appealing, or arrive at the correct temperature, residents said they lost their appetite and refused to eat their food, an unwelcome result for their health.

"I don't care who you are or where you go, food is an important thing and it should have some taste. And we're lacking both good food and taste. Like it doesn't really appeal to you. If it's appealing you don't mind eating it."

"And some of the food they do serve, how should I say? It's under cooked and its cold and everything like that."

"When we do have something that's got a salad on it, they put a nice ice cold salad that should be nice and fresh and tasty and everything like that, but they pour it on these very warm plates and you can just look at it and you can see the lettuce kind of shrivel up."

In general, food was identified as one area for improvement for most residents regardless of where they lived. Residents felt facilities could make better choices regarding the food they ordered and how meals were created and prepared. For most, expectations of the food were shaped by their experiences growing up, traveling, and work. Ultimately, these experiences shaped their expectations of the food, and resulted in recommended improvements.

Activities and opportunities for socialization

Many residents emphasized activities and opportunities to socialize with other residents were a central part of their day, and one area for improvement. These activities were important because they provided opportunities for socialization, prevented boredom and isolation, promoted movement through exercise, and challenged memory, such as through word games.

"It's only boring people who get bored anyway... Sometimes I sit here and I think oh, what am I going to do? And I say get off your derriere and get out and walk and do something. And it's all up to yourself, because they give you... you look and you'll see we have a lot of opportunities. We don't have to sit in our room unless we want to."

There were many residents who had positive experiences with the available activities. Contributing factors included recreation staff who ensured scheduled activities were available daily and communicated this schedule to residents, and with enough variety to suit their diverse capabilities. It was especially evident that residents enjoyed entertainment that was brought into their facility, such as live bands, as well as holiday and birthday celebrations, and outings that afforded them the opportunity to get out of their facility. It was also important to them that they were able to participate and choose which activities they engaged in, regardless of their location in the building – with access to available independent activities, such as puzzles, the internet, and books.

"When this place puts on a party, they put on a party. They go all the way, so you've got to respect them for that... When Stampede was on we all had hamburgers and whatnot and they had a country and western band come into play. And they were, like they're not just some amateurs; they're people that play for a living. So those things kind of help break up the time."

"I still like to use my computer and WiFi and all that stuff, so I mean this place has WiFi."

Still, some saw opportunities for improvement, such as choices matched to a resident's lifelong interests, including photography, debate, educational courses or workshops, nature-based outings, group walks, cooking, baking, wood working, pottery, card games like Cribbage or Hearts, and painting. One resident remarked that his hobbies and interests did not dissolve simply because of advanced age; in fact, they had become even more important to him. This sentiment was echoed by others. One resident liked to build things but was not satisfied with gluing precut pieces of wood together.

"They need the same things that interested them before they came in here and not to feel inadequate just because they're in a [facility]."



Activities and opportunities for socialization

When designing activities, it is important to consider resident's preferences and to ensure these are consistent with what residents enjoy doing. Activities that were important and meaningful to residents previous to supportive living continued to be important, but not always facilitated or supported by their facility. Residents wanted to engage in meaningful activities that enabled them to pursue their interests, allow them to express their identity, and socialize with like-individuals; such criteria should inform how activities are programmed.



Activities and opportunities for socialization

- Ask residents about their interests and design an activities program that fulfills those interests
- Offer activities that are engaging and creative
- Provide a variety of activities and exercise that are challenging for all physical and cognitive capabilities (e.g., floor curling, chair basketball, group walking, chair exercise)
- Provide live entertainment and celebration events
- Ensure availability of outings to areas of interest; and fair processes so that all residents can be included
- If the facility is a large facility, provide activities on multiple floors to improve access for all residents; and invite residents to take part in an activity regardless of where it is being held in the building
- Provide a calendar of activities that includes dates, times, and locations of activities and events
- Provide scheduled activities daily
- Schedule activities for a minimum of one hour to allow time for residents to participate in the activity
- ▶ Ensure there are staff available to assist residents to get to activities
- Provide access to activities that can be done independently like puzzles and reading
- ▶ Host community programs (e.g., yoga and paint workshops in-house)

Activities and opportunities for socialization - continued

"Just because you're getting older doesn't mean that's the end of all your interests in life you know. In fact, even more so."

"I mean if you had a workshop, you don't have any workshops here at all. They're just non-existent. Like I mean a lot of places will have rooms like woodworking and they'll have all kinds of tools there where you can really make something, like a table or something. But not [do a craft which is] done in five minutes."

While it is important to ensure all residents, regardless of ability, have access to activities, sometimes this came at the expense of providing mentally stimulating activities to residents who were cognitively well. As a result, these residents expressed concern that activities were not challenging enough and they were unable to participate to the full extent of their ability. One resident had to refrain from answering questions in a game when it became clear other players weren't getting any answers. Similarly, physical exercises were not always challenging enough, and as a result, limited residents' ability to stay as fit as they wanted. Some sought solutions such as going for a walk or accessing a community gym, or buying their own exercise equipment.

"So I've gone sometimes [to activities] and I notice [the recreation staff] has a Jeopardy game and I'd get all the answers, so it's not fair, so I don't go to that either."

"Exercise is good. Even if [residents who are not cognitively well] are brought here, it's good for them. And that doesn't require a lot of mental focusing. But I don't know if they should be separated, because I've heard a lot of people saying well, it's no use going because it takes too long to explain to the person over and over and over again. And it's not their fault, so it sort of discourages the people who are capable of going. It's a difficult thing."



Residents said it was important that the activities scheduled suit their interests and preferences and are tailored to different capabilities, including the cognitively well or physically able. Many residents organized their days around the activities calendar to avoid becoming isolated to their room. As a result, activities programming could better reflect what is meaningful and important to residents themselves.

Healthcare needs

The improvement or maintenance of residents' health and wellbeing, especially when done in a timely manner, contributed positively to residents' experience with supportive living. It was also enabled through trusting relationships with staff who understood residents' needs, addressed their health questions and concerns, and assisted in managing and monitoring their health according to their care plan.

"If any of the residents have any kind of problem with their health all they have to do is contact a nurse, and let's say they want to have their toenails clipped. All they have to do is tell the nurse and the nurse arranges for them to see the podiatrist who comes here twice a month or something. Whatever your problem is, you tell the nurse and the nurse will contact whatever department."

"You know the [staff] look after me with what I've got now, but if I had a bad ailment, of course, I think they'd send me to the hospital. But no, I've got everything I need here."

As mentioned above, an important aspect of residents getting their healthcare needs met was fostered in the relationships staff built with them. When staff took the time to get to know residents personally, they were more knowledgeable about residents' health needs and were attentive in recognizing health changes as they occurred. These relationships



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Healthcare needs

It was important to residents that they be involved in, and informed about, their healthcare to the degree they wanted. This was fostered through the two-way relationship between staff and residents, and worked best when staff listened to residents, respected resident's knowledge of their bodies and took this knowledge into consideration, and were responsive. When this did not occur, this resulted for some residents in feeling they were being dismissed. In addition, when they did not receive appropriate healthcare, their trust was broken.

Healthcare needs - continued

provided residents the opportunity to be informed and involved in their care, to ask questions, voice concerns, and have their needs appropriately addressed by staff who were their first point of contact in the line of care.

"The girls are pretty good in here and they all take turns of giving you pills and of course there's a picture of myself on my medical page in their book. So everybody knows the name and who they are by the picture they have. So they can't mess up."

"When they bring it to me I look at it and if there's a pill I don't recognize. I know what all the pills are for and if there's one I don't recognize I want to know what it is."

Additionally, it was important that staff be accessible, physicians be available for appointments, and medication procedures be followed.

"It was a pleasant surprise that there's doctors that come here. I mean that was a pleasant surprise that I don't have to go to a doctor because I take Handi-Bus and that's a pain."

"And you take like the medicine and stuff it's all by the book and it's all at the proper time. And it's done so that there's very little chance for a mistake."

When staff members were unavailable and perceived to be lacking knowledge, and communication was poor, residents expressed dissatisfaction.

"Sometimes you put in for [an appointment with the doctor] and they don't come."

"I get really worried about my [health] and stuff like that because I can't trust them to not put the right pills in. Like, it's like me and I have to do it. That's what [doctor] said. Well, why can't you tell them?' I do, but they won't listen."

Trusting relationships with knowledgeable and available staff enabled residents to have confidence in the care and support they were receiving. Thus, it is important that residents be included and supported in the management of their care with staff to ensure care accurately reflects their needs.



Healthcare needs

- Communicate a schedule of visiting physicians to residents
- Make it easy to book an appointment with the visiting physician
- Communicate physicians' scheduling changes
- Continue to provide medications at the correct time of day, and at correct intervals (including PRN)
- Provide answers to questions and resolve concerns about medications in a timely manner
- Provide training to all staff when residents have healthcare needs that are more specialized so that all staff are able to comfortably assist
- Continue to ensure practices that reduce the risk of medication error are in place and communicated to residents (e.g., one person operating one medication cart; a binder documenting each resident's picture next to their medication list)



SUMMARY

Transitioning to supportive living is a major life event that involves adjusting to a different way of living. For many, the transition to supportive living was challenging because it involved leaving behind homes, personal belongings, communities, and reconciling expectations formed throughout a lifespan with current experience. How residents are treated and supported through this life change was important. And in particular, maintaining a sense of self and identity as much as possible.

Regardless of the facility in which residents lived, they consistently identified two elements that contributed to a more positive experience. These include positive relationships with staff, and open two-way communication. These elements are integral to ensuring residents are treated as autonomous persons and not as a patient or care task to be completed.

In addition, and regardless of the facility in which they lived, residents consistently identified the meals provided to them, and the number and type of activities available as areas for improvement. Previous experiences impacted their expectations of these areas, and for most, their expectations were not met. Specifically, meals served were not always reflective of what they liked to eat or were

used to eating, and scheduled activities did not always satisfy their personal interests. Preferences and interests do not go away upon entry to supportive living.

Overall, residents recognized there were challenges associated with communal living, particularly when residents had varying needs and physical and cognitive capabilities. They acknowledged the large number of tasks staff were responsible for on a daily basis, and trusted that staff were able to prioritize resident needs accordingly. They also recognized that facility owners and operators were doing their best with the resources available to meet their needs.

What is important and meaningful to each resident will vary and depend on many factors, such as their health, their values and beliefs, and their previous life experience. Engaging with and listening to residents, while considering the unique context of the facility in which they live, may help directly inform improvement opportunities that are most beneficial.

SUMMARY - continued

Why aren't there differences between facilities?

Regardless of the facility residents resided in, they had positive things to say as well as provided constructive feedback. This finding is consistent with the 2016 HQCA Designated Supportive Living Resident and Family Experience Survey results, which indicated that regardless of facility type, all facilities had things to be proud of, and areas for improvement.

Findings were also analyzed to identify any differences between high- and low-scoring facilities based on the Global Overall Care rating from the 2016 HQCA Designated Supportive Living Resident Experience Survey results. However, this study revealed no discernable differences in their experiences based on where they lived. In fact, consistencies were seen across facilities that contributed to residents' positive experiences and areas identified for improvement, and are the focus of this report.

There are several possible reasons for this. First, an uneven number of residents representing highand low-scoring facilities were recruited. Specifically, there were a greater number of residents living in high-performing facilities as opposed to low-scoring facilities. In addition, an unanticipated "middle" scoring facility category was developed during recruitment. Residents at some facilities were more interested in participating than those at others, and some of the invited facilities had no interest from residents to participate in an interview.

In addition, more male residents participated in low-scoring facilities than female residents (seven males compared with three females). Similarly, more female than male residents participated in high-performing facilities (10 females compared with five males). It is possible the gender of the residents influenced their interview responses. In addition, residents' respective ages may have affected the findings. Also, residents who participated may have been more cognitively well and able to participate in an hour-long conversation than others.

With these considerations in mind, no conclusions could be made about differences between facilities. An expanded project could be undertaken in the future, with equal representation of high- and low-scoring facilities, across the province, to determine if differences occur between facilities.

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APPENDIX

Method

This project was piloted only in Calgary and surrounding area, and its goals included determining the feasibility of conducting similar work throughout Alberta. A total of 10 facilities scoring high, medium, or low based on the Global Overall Care rating from the 2016 HQCA Designated Supportive Living Resident Experience Survey were selected to identify if there were differences among resident experiences based on where they lived. The Global Overall Care Rating question asks residents: *Using any number* from 0 to 10, where 0 is the worst and 10 is the best, what number would you use to rate your home. A mix of rural and urban and large- and small-sized facilities took part, as can be seen in Table 1. Facilities were not approached to participate if they were too new or undergoing improvements at the time of the pilot project. To protect their anonymity, participating facilities were not named in this report.

Resident eligibility for the pilot project was consistent with criteria for participation in the 2016 HQCA Designated Supportive Living Resident Experience Survey, and included designated supportive living levels 3 and 4 residents. Residents in dementia-only units or facilities (SLAD) were not included.

A contact at each facility confirmed a list of residents eligible to take part in an interview, and these residents were then recruited by the HQCA with a letter that outlined the purpose of the project as well as the risks and benefits to their participation (see **Figure 2**), and via a resident council meeting. Residents were invited to also include a family member or a trusted person in the interview if they desired, but were informed the focus of the conversation was their own experience. After agreeing to take part in an interview, residents contacted the primary interviewer at the HQCA to arrange a meeting at their facility – usually in their own rooms – at a time and date that was convenient to them.

Recruitment and interviewing took place between January and May 2017. In total, 32 residents from eight facilities took part in semi-structured interviews (see guide, **Figure 3**) for the pilot project, as well as four family members. A breakdown of the number of participating facilities and residents by facility ranking according to the Global Overall Care rating can be found in **Table 1**.

TABLE 1: Number of facilities and residents by facility ranking

FACILITY RANKING BASED ON GLOBAL OVERALL CARE RATING	NUMBER OF FACILITY PARTICIPANTS	NUMBER OF RESIDENT PARTICIPANTS
High scoring	4	15
Middle scoring	1	7
Low scoring	3	10

Questions were informed by themes identified in family members' comments in response to the 2013-14 HQCA Designated Supportive Living Family Experience Survey, questions in the 2016 HQCA Designated Supportive Living Resident Experience Survey, and questions identified through consultation with the HQCA Patient/Family Safety Advisory Panel. At the start of the interview, residents were asked to discuss topics that were meaningful to them, and as a result were asked questions that were relevant to those topics. Consequently, the interview guide was used primarily for probing, where relevant. However, residents were consistently asked three questions:

- 1. How did you come to live at this supportive living facility? And, what were your impressions of this place when you came here?
- 2. What in your opinion do they do well here?
- 3. What in your opinion do you think they could improve/work on here?

Before each interview, to achieve informed consent, the interviewer reviewed for the resident the pilot project's purpose. Interviews were thenaudio recorded, with the exception of those residents who did

APPENDIX - continued

not want to be recorded, in which case notes were taken. On average, interviews lasted approximately 30 to 45 minutes.

Audio recordings were transcribed with assured anonymity, and analyzed for themes by two analysts to ensure validity of the findings.

Continuity of self and analyst insights

One way to interpret residents' experiences with supportive living is through the lens of continuity theory, which states that adults successfully adapt to change throughout their lifespan by preserving or maintaining their personal characteristics and drawing on previous experience.1 Moving to a permanent residential care setting can challenge this continuity because it involves a change in lifestyle and role expectation from one of an autonomous person to that of the patient.² This theory can be used to help explain elements of what was important to residents' experience that contributed to a more positive outcome, or to a negative one that could be improved. Where relevant, this lens is applied throughout the report, and can be found in the "insights" text boxes.

Ethics protocol

This project was reviewed using the A Project Ethics Community Consensus Initiative (ARECCI) tool, and by a second-opinion reviewer through ARECCI. As a part of the informed consent process, each eligible resident was provided with a letter detailing the purpose of the pilot project, risks and benefits to their participation, steps that would be taken to protect their confidentiality and anonymity, and how the HQCA would be using the information they provided. Eligibility was restricted to residents who were able to provide their informed consent. Family members who participated in an interview provided their own consent. Interviewers reiterated the project's purpose and told residents they could retract any information they provided.

In each case, the interviewer scheduled a time and date at the participating resident's earliest convenience.

Invitation to participate

All eligible residents, as identified by the participating facility, received the invitation letter below. If interested, they were asked to contact the interviewer at the HQCA to schedule a meeting.

FIGURE 2: Interview information sheet

INTERVIEW INFORMATION SHEET

Contact Information:

210, 811 – 14th Street NW Calgary, Alberta T2N 2A4

About the Health Quality Council of Alberta

This project is sponsored and conducted by the Health Quality Council of Alberta (HQCA). The HQCA is a provincial agency that pursues opportunities to improve patient safety and health service quality for Albertans.

The HQCA is independent of Alberta Health Services, and does not oversee or provide care to supportive living residents.

Why have I been invited to participate?

You have been invited to take part in this interview because you are able to talk with us about the care and services that are provided here. The Health Quality Council of Alberta wants to

¹ Atchley, R.C. (1989). A continuity theory of normal aging *The Gerontologist*, 29 (2). 183-190.

² Pirhonen, J., & Pietila, I. (2015). Patient, resident, or person: Recognition and the continuity of self in long-term care for older people. *Journal of Aging Studies*, 35, 95-103.

speak with residents like you so we can better understand what you do or do not like about living here and where you think things can improve.

Why are we doing this?

We want to understand and learn more about the details of your day-to-day life and what you like or don't like about living here. We also hope that this information will help identify areas of excellence and areas where improvements can be made to the care and services that are provided to the residents.

What do I need to do?

First, you can ask the HQCA staff member that will be conducting the interviews any questions you may have. Then [the HQCA staff member] will arrange a time to come back and interview you at a time that is convenient for you. If you do not wish to speak with [the HQCA staff member] at your facility, they can meet you at another location that is preferable to you ([the HQCA staff member] is unable to drive you anywhere). Or, if you would prefer, you may come to the HQCA Calgary office in order to be interviewed if that works better for you and you are able to attend. You must arrange your own transportation. We will reimburse for Access Calgary costs only.

We expect that this conversation will take about an hour. With your permission, [the HQCA staff member] will audio record the conversation and type it out later. This lets [the HQCA staff member] give you [their] full attention during the interview without having to take notes. If you would like to participate, but don't want [the HQCA staff member] to record you, please let [the HQCA staff member] know and [the HQCA staff member] can accommodate that request.

If you are willing to participate, [the HQCA staff member] will need you to sign a consent form. If you would like a family member to participate with you they will need to sign a consent form too.

You can stop the interview at any point. You do not have to give a reason, and it will not affect the care you receive. Simply inform [the HQCA staff

member] that you no longer wish to take part.

Benefits

Information you provide will help us to better understand your experiences of what it is like to live in supportive living and may also help to improve services for supportive living residents.

Risks

There are no known risks associated with this type of interview. All information about you will be kept completely confidential. Interviews are a common way of finding out about people's experiences. If at any time anything we talk about is upsetting to you, we can take as many breaks as you need or stop the discussion. Simply tell [the HQCA staff member] you wish to stop.

Voluntary participation

Taking part is entirely up to you. If you don't want to participate you do not have to give a reason. You can also refuse to answer any questions you do not feel comfortable with at any point in the interview. If you agree now and later change your mind you can do that at any time without giving a reason. Your care and support will not be affected in any way if you do not wish to participate.

Confidentiality and Anonymity

All information about you or anyone else that you speak about will be kept completely confidential. All names and identifying details will be kept confidential. Results from this project may be used in a report about what it is like to live in supportive living in Alberta, but no names or identifying details will be included. It is important to know that the HQCA cannot guarantee your anonymity when we are at the facility conducting an interview. For example, a staff member may see [the HQCA staff member] enter your room or may enter the room while [the HQCA staff member] is present. If you do not wish to speak with [the HQCA staff member] at your facility, [they] can meet you at another location that is preferable to you ([the HQCA staff member] is unable to drive you anywhere). Or,

FIGURE 2 - continued

if you would prefer, you may come to the HQCA Calgary office in order to be interviewed if that works better for you and you are able to attend. You must arrange your own transportation. We will reimburse for Access Calgary costs only.

No one involved with your care will have access to what you say during the interview

All the information collected about you during the course of the interview will remain completely confidential. Only certain individuals at the Health Quality Council of Alberta will have access to the information you share. Any information, including recordings that [the HQCA staff member] collects from you will be kept secured at the HQCA office. Recordings will be destroyed within three months of when the project is completed.

In accordance with the Alberta Protection for Persons in Care Act we are legally obligated to report any abuse or neglect, which we are informed about, to the appropriate authorities.

What do I do next?

If you would like to participate, please contact [the HQCA staff member] listed on the first page of this document if you have not already told [the HQCA staff member] that you are interested.

Interview guide

Interviews were semi-structured. Questions one to three were asked of each resident consistently. The remaining questions in the interview guide were used as probes when relevant to the conversation.

FIGURE 3: Interview guide

INTERVIEW GUIDE



Questions

- 1. How did you come to live at this supportive living facility? And, what were your impressions of this place when you came here?
 - a. Did you choose this facility (and why/why not)?
 - b. Tell me about what it's like to live here.
- 2. What in your opinion do they do well here?
 - a. Why is that important to you?
 - b. If you lived in a different facility, how did they do things differently that you liked/disliked how was the facility different to here?
 - c. How do you feel you belong here?
 - d. How do you find meaning in your day to day life? What's important?
 - e. Does the facility help you to feel emotionally healthy? (How so?)
 - f. What is the most important thing you would keep the same if you could?
- 3. What in your opinion do you think they could improve/work on here?
 - a. Why is that important to you?
 - b. How would that change your experience?

Probes

Medications

Tell me about how you get medications here. Is there anything you might change?

- Timing.
- Correct medications.
- Staff knowledge about medications and/or side effects.

Food

Tell me about the food here.

- Tell me more about what it is you do/don't like...
- How could this be improved? (examples include: presentation, temperature, access, variety, specific food, taste, nutritional value).
- Watch for context does this person like to cook/is this person a foodie?

Staff

Tell me about the number of staff here. How many would be enough? How come?

- Tell me more about your relationships with the staff...
- What kind of relationship do you want with the staff?
- Is this different for different types of staff? And how?
- How could staff show you this type of relationship?
- Do you feel the staff do their jobs here? If so, how? If not, how come?

Communications

Tell me about a time you had a complaint/concern here.

- How do you go about getting a complaint/concern resolved?
 - Do you feel your complaint/concern gets resolved? How so?
 - Do you feel your complaint/concern is handled in a timely manner?
 How so?
- Who do you talk to if you have a complaint or concern?
 - How easy is it for you to find them?
- How are you able to communicate to the people in charge?
 - Is this comfortable for you to do? Can you tell me about that?
- Tell me about how informed you feel here.
 - How much information do you want to receive, and about what?
 - How informed do you feel about your care?
 - How informed do you feel about the day-to-day activities going on in the facility?

Receiving help

Tell me about a time when you needed help, and how you went about getting help.

- How long does it usually take for staff to come and help you?
- Do you feel the staff are around when you need them?
 - How would you change this? (If more how many? Times of day?)
- Do you feel the staff do a good job providing you with assistance? If so, how? If not, how come?

Healthcare

Tell me about a time you needed to access a healthcare provider (e.g., physiotherapist or physician).

Hygiene and grooming

Tell me about your hygiene and grooming needs and whether they are met here.

Information and involvement

How involved are you in your care?

- How do you want to be more involved? (if they do)
- How do you participate in care conferences?
- How well informed do you feel you are about your care?

Environment

- How do you like the building and your room here?
- How do you like the neighbourhood you live in?

Activities

What kind of activities do you like and do they do those here?

- How stimulating do you find the activities here?
- Tell me about the kinds of activities you like.

Cost

Do you find the cost of living reasonable here – can you tell me more about that?

FIGURE 3 - continued

Safety and security

- Tell me about how safe you feel living here?
- How secure are your personal belongings here?
- Does the facility help you ensure your personal belongings are secure? If so, how?
- What could they do here to make residents feel safe/r?



Limitations

This was a pilot project, limited to Calgary and the surrounding area. While insights gained from these interviews could be used to inform quality improvement opportunities, we caution against solely using this information to do so. Residents who self-selected to participate in this project, for example, were those capable of taking part in a one-hour long conversation and may have had experiences and interests that differed from those of other residents. As a result, it is encouraged to assess the findings in context and use this information in conjunction with other data such as facility results from the 2016 HQCA Designated Supportive Living Family and Resident Experience Survey.

Another limitation is that the number of residents representing high-, middle-, and low-scoring facilities based on the 2016 HQCA Designated Supportive Living Resident Experience Survey, Global Overall Care rating, was unequal. No conclusions were made concerning differences between facilities.





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