July-Sept 2022

Family Matters

Family/Friends Council Newsletter

What's in this Issue?

Quote of Note

"Life is a limited resource with no guarantee of enough time to tell our loved ones what we want them to hear."

Anonymous

DEMENTIA: Stats/Fact or Fiction/Care specifics

In terms of **statistics**, the Canadian Institute of Health Research (2016) reported that 564,000 Canadians were living with dementia and that this number would increase to 937,000 by 2031. The report included the fact that, in Canada, 25,000 new cases are identified annually and that the cost to Canadians is $10.4 billion. It is also noteworthy that 65% of Canadians diagnosed with dementia over the age of 65 are women.

Fact or Fiction

#1 My mother had Alzheimer's, so I am going to have it too.

Not necessarily true. Although genetics play a role in disease, fewer than 7% of cases are associated with genes that cause the early onset inherited familial form of the disease. The majority of cases are of the late onset in which genes do play a role.

#2 Alzheimer's only affects the elderly.

Fiction. While age is the most significant known risk factor for this disease, most people do not develop the disease as they age. However, people have been diagnosed with this disease in their 40's and 50's. What's most important to understand is that Alzheimer's disease is not a normal part of aging.

Source: Alzheimer's Society of Ontario

Care specifics

In terms of care of persons with dementia, it is refreshing to report that the person-centred approach is being implemented across our communities in LTC and in retirement settings. We have learned the importance of embracing the person's reality rather than attempting to connect their minds with our reality. So, if your loved one states that she wants to go home, do not tell her she is at home here at the Grove because her reality is that she is definitely not at home. Instead, ask her to tell you about her home (which will be the only home she remembers) …where located, neighbours, vegetable garden, crops, etc.
As caregivers, we must always focus on resident enjoyment, meaningful activity, and functional competence within the limits of the person's physical and cognitive capacities. So, it is important for the person with dementia to be able to dress herself…she may not know the term 'blouse' but if you hold up a yellow blouse and a blue one and ask her which one she would like to wear, she can tell you. And if you model brushing your hair and then hand the brush to her, she will brush her hair because *the mind remembers what the body*

does! If she played the piano or violin when in good health, she will still be able to do so; thus, provide that opportunity for her. In relation to meaningful activity, it is critical for staff to complete a comprehensive and holistic assessment of the resident on move-in. Through this process, the staff learn what is meaningful to the resident. Was he a carpenter and perhaps would like to spend time repairing old pieces of furniture? Was he an architect and would enjoy studying architectural drawings? Was she a housewife on a farm and would like to prepare veggies or set the tables? Would the resident like to deliver the mail to resident's rooms? Would the resident like to call bingo or thank the entertainers? **How can each resident make a contribution to their home's functioning as opposed to sitting in one's room bored and discouraged because there is no enjoyment, no involvement, few opportunities to build relationships. Research has informed us that such inactivity and lack of human interaction contributes directly to the loss of physical and cognitive ability.** As well, let's not forget that quality of life essentials include the preservation of dignity regardless of whether or not the person can perceive indignities, autonomy in decision-making and spiritual well-being.

The person-centred approach requires a culture change within the Grove whereby the social model of care is applied so that care/service is centred on each **person's needs, expectations, and goals** versus the medical model which is provider-driven with the client a passive recipient of care. No doubt, every resident has a strong, healthy and natural desire to retain control over their lives. As families and staff, we must always support that need. **The LTC system embodies a partnership model. The residents, families, staff and volunteers partner to achieve the ultimate goal of care quality and quality living for each resident in their home at the Grove.**

Family and Friends Council: Terms of Reference

Name: The Council name is 'Family and Friends Council' and reflects the inclusion of family and friends, as identified by the residents. 'Family' is defined by the resident not by genetics or law. A family/friend partner (FP) is self-identified and implies the engagement of family and friends in the Grove processes with accountability to the FFC.
For our loved ones living at the Grove, we care about:

- their sense of belonging;
- their safety and security;
- supporting their autonomy;
- respectful and dignified relationships; and,
- their care quality and quality of life

As the FFC, our values are: CHOICE

- **C**-compassion
- **H**-holistic approach
- **O**-open-minded
- **I**-integrity
- **C**-caring
- **E**-equity

Our Vision:

- Families, friends and residents are equal partners with the staff of the Home and, as such, are engaged in all aspects of resident's care and service through application of the *family/friend partner* concept. We envision resident and family voices and values facilitating decision-making processes throughout their home at the Grove.

Our Mission:

- To improve the care quality and quality of life for all residents by partnering with staff to facilitate an atmosphere of respect, collaboration, sensitivity, and, caring and support among staff, residents, family members, volunteers and friends.

Our Philosophy:
We believe:

- That a safe, secure and healthy environment for our residents is a main priority;
- That communication, which is complete, comprehensive and timely from staff to residents, families, volunteers and the larger community is essential to achieving quality experiences for all stakeholders.

- That each resident is entitled to care/service that meets their biopsychosocial, spiritual, intellectual and cultural needs and expectations;
- That care provided is based on individual needs taking into account previous lifestyle and the right to independence and self-determination for as long as possible;
- That care and services are provided by an interdisciplinary/interservice team of qualified and caring staff in addition to volunteers, family members, friends and community partners;
- That residents, family members and friends are actively involved, as equal partners, in decisions that affect the resident's care/service;
- That meaningful connections with the local community are essential to each resident's quality of life;
- That residents/families have choices related to the end-of-life with the right to indicate their preferences through advanced care planning and directives, and that they are provided support and comfort through the dying process;
- That the residents and families are the best judges of quality care and quality of life as measured through resident experience and family/friends experience;
- That participation in research opportunities to enhance quality of life for our residents reflects a commitment to quality, enhances our reputation, and fosters community support.

Our Responsibilities and Opportunities as FP's and FFC:

- To inform and educate families and friends, residents, staff, and the community at large;
- To foster open lines of communication between residents, families, volunteers, friends, staff and the broader community;
- To advocate for resident's quality of care and quality of life on behalf of residents, families, friends and the community served;
- To provide feedback on, and ideas for, initiatives and programming with the potential for enhancing the person-centred model of care;
- To promote a positive attitude toward aging and the role of resident's families as essential caregivers;
- To welcome new families and friends and to assist with their orientation to the Home;
- To advise on potential quality improvement initiatives;
- To advance resident and family/friends engagement in decision-making;
- To engage in fund-raising, as appropriate, to support the residents' quality of life; and,
- To advocate for positive change within the LTC system.

Membership:
Members of the FFC are all family members and friends of those currently living at the Grove, or of those who previously lived there, as well as those persons with Power of Attorney.
A chair and co-chair are nominated or self-identified. Their role is to facilitate the *Family/Friend Partner* concept** including the quarterly sharing of partner activities, improvements realized and outcomes achieved and to act as the primary contacts for the Grove leadership team.
Meetings: Planned when the majority of families request one and/or there is an urgent need and desire for group discussion.

Approved February 2022

Family/Friends Council Acknowledges Staff

Thanks to the generosity of families and our community, we have been able to acknowledge our staff for their tireless efforts in caring for our loved ones during the pandemic. The staff were dedicated and committed to the residents amid ongoing changes to infection control practices from the MOH and the local Health Unit. We decided to treat all staff by providing a pizza day on April 6, and during Nurses' Week, a pizza day, sweet treats and gift baskets. We thank all staff from the bottom of our hearts….

Communication: A Negotiated Partnership

I would like to share information on the importance of effective communication among residents, families and the Grove's team of care and service providers. Good communication among all stakeholders is the cornerstone of a Person-centred culture.

As you know, the transition from home to a long-term care home can be challenging for the resident as well as the family. For instance, to whom do you speak when you have a concern? Likewise, to whom do you convey your gratitude when your loved one seems happy and content? How do you initiate and maintain contact with your loved one's attending physician?

I have always believed that effective and empathetic communication is the foundation of excellence in resident care. Within all long-term care homes, the complex nature of resident care and the overlay of emotions that families bring, make this setting one of the most challenging across the health system in terms of creating meaningful and honest dialogue among all parties. Poor communication contributes to loss of resident's well-being as it exacerbates the resident and family's sense of isolation, helplessness and anxiety. Good communication skills provide for your obtaining the information you need, advocating for your loved one, and for achieving a high level of satisfaction with the care your loved one is receiving.
These are some tips for you to consider:

- Ask to be introduced to staff to learn their names and their role in the Home. Who is providing direct care to the residents and who are the leaders to whom you can address your questions and relate any concerns? The managers for each department with their contact info has been forwarded to all families. Introduce yourself and let staff know your relationship to the person for whom they are caring, the significant others in their lives and how often you and other family/friends plan to visit.

- Review the move-in package provided to become acquainted with the Home and its policies and procedures. Identify any questions for the manager of a department or to be brought forward to the six-week care conference which will have a representative of each department.

- Let the team know how you prefer to communicate with the staff, your availability for urgent communication, secondary contacts, and expectations of staff regarding any care updates, changes in condition, significant events, incidents, etc. Do you want to receive phone calls, emails, text messages and/or print material by postal service?

- Use a notebook to keep track of staff names within the various departments, key questions to be asked and answers received to date, medications that your loved one is taking, key routines within the Home, personal hygiene items required, etc.

- Be sure to meet the attending physician for your loved one so that you develop a relationship of trust and an understanding regarding the physician's approach to care within a LTCH. For example, what is the view of the physician on medicating the elderly, transfers to hospital or on medical assistance in dying? How often does the physician visit the residents? Will the physician attend the care conferences? How does a family member contact the physician?

- I recommend that you make every effort to attend any scheduled family conferences and, if possible, identify any questions or concerns ahead of time to ensure an efficient and satisfying experience. This is an important opportunity to ask questions of the various team members from each department and to discuss different opinions regarding decisions that may affect the resident.

- An important and fundamental principle in terms of any communication with the team is to include your loved one in decisions that affect them. Give your loved one time to express their desires or wishes. If communication by language is no longer an option, then look for body language and non-verbal cues.

- Always remember to compliment the staff and to thank them on a regular basis. Their jobs are not easy; it takes special people to provide the tender loving care and service that each of us wants for our loved one. I do believe that we are fortunate to live in a closely-knit community where a job at the Grove is more than just a job…it entails giving of one's heart and soul to others…it is about staff who are passionate about delivering high quality care and quality of life for each resident within their care.

Effective communication entails a negotiated partnership among residents, families and staff. Staff responsibilities and accountabilities include:

- Ensuring the use of an assessment tool on move-in to determine and best understand the resident/family needs, expectations, life history including hobbies, celebrations, and tragedies, resident goals and how staff can provide support. The assessment and planning tool,' **My life to live',** is the one being recommended by families given its holistic approach and depth of information provided. This tool encompasses an assessment of the 'whole person' and their care/service plan;
- Developing, with the resident and family, a resident care plan based on the above information;
- Sharing the care plan with the resident and family, both verbally and in writing; and,

- Involving the resident/family in all discussions and decisions about their care, for example, including the resident and/or family in the related huddles.

In addition, residents and family members must be made aware of any changes being considered such as changes to policies, practices, schedules or the implementation of safety programs or other programming that might affect the care/service a resident is receiving. Residents and family members must be informed of the rationale, how these changes will impact the staff, the residents and the families and the timeline for implementation of the proposed change. Within a Person-centered culture, and the fact that this is the 'home' of each resident, the residents and families have the absolute right to refuse the proposed change providing such is a collective decision.

There are many ways to communicate information, including changes, to residents and family members and the broader community. Some common tools include the *Family Matters* newsletter, Family Partners collaboration, posters, town hall meetings, resident and family/friends councils, care conferences, individual meetings, local newspapers or television and an annual resident/family/staff forum.

Marilyn Colton

Editor and Chair, Family and Friends Council (and mama to my two girls!)

PERSON-CENTRED CARE (cont'd)

Many health care systems around the world are moving toward Person-centred care (PCC) or the social model of care. At the global level, the World Health Organization has developed a framework highlighting **person-centredness as a core competency of health care workers** within all sectors and as a **key component in the measurement of health care quality.**

To achieve person-centredness, culture change is essential. Culture change is about shifting the way we view aging and those who are aging or who have debilitating conditions as well as how we understand those responsible for caring for our residents. A necessary element is the empowerment of the residents, their families and their caretakers and a lesser focus on the administration of the Home as well as the traditional hierarchical leadership structure. Culture change means a fundamental philosophical shift from 'control' to 'collaboration and participation'; from the expert model 'to the 'partnership model'. Decision-making is placed in the hands of those who are most affected by the decisions: the residents, their families, and their caretakers.

Consequently, shifting to PCC requires services and roles to be re-designed and re-structured to be conducive to the PCC model so that staff do things '*with*' the residents and families, rather than '*to*' or '*for*' them. The medical model guarantees loss of control by residents and families and a downward spiral of apathy and dependence. The **social model** means the focus is on resident need, preference and choice and places a high value on human interaction, relationship-building and meaningful occupation in their home.

Within Long-term care, this means residents setting the direction of each day versus a staff focus on tasks and routines; this means that relating to each resident is everyone's job; this means resident choices and preferences are valued and accommodated; this means innovative 'learning circles' are in place giving voices and empowering residents, families and staff; this means elimination of the assembly line approach to care, such as, in medication administration; this means relationship-building is the number one priority; and, this means a strong culture of resident, family and community engagement to support quality care and quality of life for all residents. **Staff must acknowledge and accept the resident and family as experts in their own health and as a part of the care team.**

To continually improve resident care and quality of life we must work together with staff to effectively implement and measure person-centred care. Current measures include the # of falls, # of infections and # of residents on anti-psychotic meds. However, in terms of metrics, I believe we must also measure resident/family experiences. For example, when asked, a resident should be able to describe how they provide input into decisions that affect them or, when asked, the resident can describe what things they do that makes their life pleasant and enjoyable or, when asked, can state how they have been meaningfully occupied or contributed to the running of their home. These metrics relate to quality living. **Quality care is just one contributor to quality living so the goal must always be quality living.** Let's ask ourselves, "Have we provided the residents with the necessities for survival

but deprived them of the joy of living?" If the answer is, 'perhaps', then let's work together to ensure the implementation of PCC now.
Becoming older, living with dementia or a debilitating condition does not mean losing oneself, one's humanity, one's personhood. As a component of the social model of care, we must support our loved ones in retaining the distinct and integral place they hold in society. Contact Marilyn Colton or Barbara Mair for more info.

Greetings from Janice Dunn: Accreditation 2022

The Grove, along with Arnprior Regional Hospital, are busy preparing for our upcoming Accreditation Canada survey this September. We have been on an "Accreditation Journey" since our last survey in 2017. Two surveyors will visit visiting ARH -September 11-15th, to review and assess our organizational sites against the national standards. The Grove onsite survey will be September 14th for the day. Together, they will

provide feedback and leave a preliminary report on site when they depart on September 15th. We will receive a final report and an accreditation decision, based on what they have seen and verified during their on-site survey, within 2-3 weeks. This accreditation decision lasts until our next survey, which will be in another four years.

Accreditation is an ongoing process of evaluating and recognizing service that meet established standards. It is one of many tools we use to showcase quality. Accreditation is not meant to be a standalone activity or event that coincidentally occurs every four years and is then forgotten about. It is integrated into the quality improvement strategies of Arnprior Regional Health and is a one of our strategic goals.

As part of our accreditation journey at the Grove, we are working together toward moving our home toward the highest standards of quality care and services. We are being intentional to ensure the surveyors that will be visiting September 11-15th will see and hear about all the quality initiatives we are involved in. Some will be demonstrated on our bulletin boards throughout the home, others by means of testimony or experience, data collection, high satisfaction rates, leading practices and Required Organizational Practices or ROP's. Many have already read about the number of ROP's we are working on and introduced in our Accreditation Newsletter. Our goal is to achieve Exemplary Status, which requires us to meet the standards and ROP's for Long Term Care.

As a result of being involved in this Accreditation process, we are finding that our teams are getting stronger. More effective teams lead to better outcomes all around. By shining a spotlight on our processes that work well, we then can identify opportunities to improve by reducing risk and enhancing quality even more. It is a win/win for our residents and the Home, as we continuously work together to improve.

As a family member, some of you may have already joined one of our Standards Teams. In the event you are interested in partnering with us in this way, please be sure to let us know so we can help you be an active contributor at the Grove, both for our accreditation process and ongoing.

Please do not hesitate to reach out if you have any questions about the survey or the process. Thank you in advance for the part you play, as part of the team, in enhancing quality care and services at The Grove.

Chair's Report: Family Partners

As families and friends of the residents, we have a voice in their home and directly to the leadership team. Through this voice, we are partnering with all staff to establish the vision of the home, consistent with a family-centric and resident-centric culture, and to ensure that everyone including staff, residents, families and volunteers, see themselves in that vision. According to Family Councils Ontario, diverse and empowering means of family engagement are preferred. As families and friends of the residents, we are collectively empowered to have our voices heard in the operation of the home of our loved ones and in the improvement in resident care/service.

Currently, the following Family Partners (FP) are advocating for all residents and families through direct collaboration with staff:

Quality Committee: Theresa Whitwell whitwell_theresa@hotmail.com and Terry McCormick

Hiring Panels: Barbara Mair barald@sympatico.ca and interested resident(s)

Orientation of new families: Jodie McGetchie jomcgetch@gmail.com

Renovation to the former Grove building: Susan Reid susan.reidheurter@gmail.com and Barbara Mair

Accreditation Committee: Marilyn Colton mcolton@xplornet.com

Policy/practice development/revision: Residents' Council/Marilyn Colton

Falls Prevention: Bernie Culhane bculhane18@gmail.com

Continence Team: Connie Legg connie.legg@gmail.com

Pain Management: Melba Cavanagh melbacavanagh@outlook.com and Connie Legg

Food for Thought committee: Bill Thompson and Marjorie Kelly marjoriekelly55@hotmail.com

Skin/Wound Care: Ann Fuisz amfuisz@gmail.com

Responsive Behaviours team: Jennifer MacElwee jlmacelwee@gmail.com

Recreation Services: Melba Cavanagh melbacavanagh@outlook.com

Human Resource Management: Michelle Tilley mtilley273@gmail.com

Firstly, we strongly encourage other family members to self-identify in the above areas, according to your interest and availability, as well as to provide relief when one of the above partners is unavailable.
Secondly, when concerned about the quality of any aspect of resident care or service, please make contact with the appropriate manager and/or the administrator. However, if the issue remains unresolved and becomes a concern among a number of families, the FFC chair/co-chair will call a special meeting of families with an invitation to the appropriate members of the leadership team. As stated in the **LTCH Act, 2007, section 63,** the licensee (administrator) must meet with the Family and Friends Council when invited to do so.

Contact

Do you have suggestions for content? Do you have something to share? Feel free to contact the editor, Marilyn Colton, at mcolton@xplornet.com or 613-839-5735 or co-chair Barbara Mair at barald@sympatico.ca