

Community Engagement



‘Goals of Care’ – Family and Resident Perspective on Care Planning in Residential Care

Executive Summary

*Prepared by Andi Cuddington,
Vancouver Coastal Health Community Engagement*



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Introduction to Goals of Care

'Goals of Care' is a term used in health care to refer to the general direction for the care plan developed. Goals of care encompasses both the patient/family experience with their illness which includes their wishes, values and beliefs, related to their care and the medical interventions which can be appropriately offered given the patient's medical status.

In residential care, care planning conversations are part of an ongoing dialogue with the patient/resident and their families to determine goals of care. It is the health care team's role to communicate with the patient and family, clarify their goals and priorities, and develop a plan of care based on this information. Establishing goals of care is a key step in the delivery of person-centered care.

Vancouver Coastal Health's Goals of Care Project

Across the Vancouver Coastal Health (VCH) region, there are diverse approaches to these conversations between staff, residents and family/loved ones. As a result, VCH has initiated a project to develop a regional approach for the ongoing establishment of goals of care within residential care. The purpose of the Goals of Care (GOC) project is to develop a pathway representing best practice in establishing goals of care in residential care facilities.

The Goals of Care in Residential Care project team is being lead by VCH staff from Residential Care and Palliative Care. Using LEAN methodology to guide the project, the first step of the GOC project, led by VCH Community Engagement, was to conduct consultations with residents and family members. The next step is to discuss these results with staff from residential care facilities. The results from the two phases of consultation will then be synthesized into best practices in establishing Goals of Care for VCH residential care facilities.

Methods

Community Engagement, in collaboration with members from the Goals of Care in Residential Care project team, designed a consultation featuring:

- One-to-one interviews with residents and family members (who have had or currently have loved ones in a residential care facility) and;

- Discussion group with members of the VCH Regional Palliative Care Community Reference Committee, VCH Community Engagement Advisory Network (CEAN) and Patient Voices Network.

Key Themes

'Goals of Care' (GOC) is a healthcare term used to refer to the general direction for the care plan developed. However, this phrase is a healthcare construct and does not resonate with residents and families – their understanding is framed in terms of *care planning*.

There was significant variation between participants (family members and residents) in their understanding of care planning processes used to determine 'goals of care'. Moreover, participants had differing needs with respect to the frequency of care planning conversations, who should be involved, and what topics should be discussed.

Frequency and Timing of Care Planning

Overall, family members believed that care planning conversations need to be held more regularly but there was no consensus from participants on the preferred length of time of the care conference or the desired frequency. All participants liked the round-table format for care conferences that included members from each team/department involved in the resident's care. Informal conversations with staff when family members visit the facility are also an essential part of staying current on their loved one's care plan, monitoring their loved one's health status and advocating for quality care.

Who to Involve in Care Planning

Many relatives are making important care decisions on behalf of their loved one and very few families reported that their loved one participated in the annual care conference. This decision was commonly made by family members on behalf of the resident, either because they thought:

- the conversation would upset the resident;
- their loved one was not able to keep up with the exchange of information, or;
- the best use of the short time available was if the family interacted with health care staff.

However, not all families shared the belief that the resident should be excluded from the care planning process, and emphasized that residents, as well as family members, needed extra support or time in order to participate in a meaningful way. Below are some suggestions from relatives on how to support meaningful family and resident participation in care planning conversations:

- Provide an agenda for the care conference in advance so the family can review and make a list of questions, including a list of which staff will be attending the care conference
- Provide a list of suggested questions for family members to ask

- Advise family members to bring a notebook to make notes and record medical terminology that need review
- Provide a hard copy of the care plan to family members
- If a resident has any favorite staff persons, ask that they be invited

Topics to Discuss in Care Planning

Participants reported that care conferences primarily focused on three areas:

- changes in health or functioning
- medications
- daily living (diet, exercise, hygiene, and activities).

Family members also acknowledged the importance of psychological, social, spiritual, and cultural needs/wishes. Family members did not feel that these were placed as priority in care planning conversations and emphasized the need to do so.

End of Life Planning in Goals of Care Conversations

Amongst family members and residents interviewed, some have spoken to loved ones about end of life (EOL) care, and some have not. The overall trend suggests that residents and families are reluctant to talk about end of life for number of reasons, even when they recognize the importance of these discussions.

Many relatives shared that the only end of life planning they had experienced in residential care was setting the 'Level of Intervention.' As a result, they felt unprepared for their loved ones journey toward death. One of the main challenges identified in this consultation was the lack of communication around variety of issues including, but not limited to, the continuum of physical/mental decline, available treatments and care and the implications, and wishes around medical interventions and end of life care.

Many relatives shared that they appreciated guidance from care staff as to what they can expect (in terms of the dying process) and what they can do (in terms of being with their loved one and assisting in care) at end of life. When prompted, family members believed the following areas of end of life planning were most important:

- Options to control pain and other symptoms
- Shared understanding of when death is approaching and what can be expected
- Time to say goodbye and to arrange important things
- Choice and control over where death occurs and how create peaceful atmosphere
- Access to any spiritual or emotional support required (for both resident and family members)
- Maintenance of resident's dignity
- Privacy expectations and control over who is present and who shares the end.

These findings reinforce the important role care staff have in educating and preparing families for end of life. Although a few participants felt that end of life is private discussion

for family only, many stated that they would be cooperative if staff initiated a conversation about end of life care.

Conclusion

Despite the variation in care planning needs, all participants felt that staff, residents and family should have the opportunity to discuss expectations. An early discussion of expectations would provide families and residents a chance to voice their hopes and preferences while facilities would be able to articulate what they can reasonably offer.

Straightforward, sensitive and open communication between residential care staff, the individuals they support - and their families and friends - underpins all health services in residential care. This theme was reiterated as a fundamental principle to successful end of life planning and care.

Comprehensive end-of-life care will not be a priority in our health care system until it is a priority for Canadians. With the aging of the population, more attention will be focused on this issue. The type and quality of care that people receive at end of life depends in large part on their ability and willingness to talk about and plan for death while still enjoying life.