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Residential Care Services

Resident/Family Council or Family Support Group Guide

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- Vancouver Island Association of Family Councils
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Resident/Family Councils or Family Support Groups can provide opportunities for you to build friendships and expand support networks with others sharing your journey. This guide has been created to provide information and suggestions on how to create and maintain Resident/ Family Councils or Family Support Groups within Island Health residential care facilities. Helpful terminology and a 'Terms of Reference' template are included to assist you in forming a group.

What is a Resident/Family Council or Family Support Group?

The purpose of Resident/Family Councils or Family Support Groups is to advance the quality of life for the facility's residents. Groups are voluntary, self-led, self-determined and democratic groups with membership that can include residents as well as family, friends, legal representatives and/or contact people of residents of the facility. They meet regularly to discuss common interests, provide support, education and a forum to voice concerns or issues. The group may also include staff of the facility to lead discussions, provide information or answer questions.

Groups vary in purpose and structure depending on the interests/needs of the members and the facility's residents. Some groups will be small and informal, while others will be larger, more structured, and may include sub-committees or working groups focused on individual projects. Further, while some facility residents will want to join a group, others may not be interested or able to participate. Some groups may choose to combine both residents and families in one group, while others may have separate groups such as a Resident Council and a Family Council. The important thing is to organize in a way that best meets the needs of the group.

Groups can also play a valuable role in helping members understand chronic and life-limiting health conditions and frailty, supporting family members with the stress and uncertainty of the changes they are experiencing, and building partnerships between family members, facility staff and management. This may involve working together on projects that enrich the lives of residents, providing educational sessions for family members and friends, providing a caregiver's perspective to the facility, raising funds to support activities or buy something special to be used by the facility's residents, communicating questions and concerns, and sharing ideas.

What if there are no groups at the facility? Where do I begin?

If there is no group, you will need to gauge interest and promote enthusiasm among the residents and/or their families/friends at the facility.

Here are some ideas to increase interest for groups amongst residents and their families/friends:

- Create printed material that outlines your ideas for a group, and provides an invitation for people who are interested to contact the organizer, or attend an information meeting.
- Consider that many friends/family members may live at some distance, or may have work and/or have other family responsibilities that will affect their participation level or interest.
- Conduct a survey to determine whether there is ability and interest in participating in a group, and what topics and activities might be of most interest.
- Attend social events at the facility and invite people to an informal meeting to discuss formation of a group.
- Connect with the facility manager to ask if they can assist with a meeting space, suggest/provide a speaker who could talk about a topic of interest, and include your invitation to form a group in facility newsletters and facility bulletin boards, etc.

How can we keep the group focused and the momentum going?

Effective groups have a common purpose, structure and a way to determine and celebrate success. People volunteer to participate in activities that are meaningful to them, and continue to participate when they feel their involvement makes a difference.

To maintain a vibrant, successful group over time, it may be helpful to:

- Agree on common goals, and develop a purpose statement for the group.
- Outline basic details about meeting structure, agendas and processes in advance to make the most of the group's time.
- Ensure time on the agenda for reporting progress on projects or action items, to acknowledge important milestones and to celebrate successes.
- Establish a way for members to communicate with each other and the group as a whole – for example email newsletter, phone tree, social networking group, social media, etc.
- Maintain good communication with facility staff, and develop agreement on who will be the staff liaison, what they will do, and whether staff will regularly participate in meetings.

Revisit the group's goals, purpose, meeting schedule and structure regularly, to ensure it is keeping pace with the needs of members.

If difficult topics or disagreements arise in the group, what is the best way to resolve this?

The decision to move into a residential care facility is among the most difficult an individual – or their family – will make. Usually, a person moves to residential care when living at home is no longer possible due to declining health and ability to carry out activities of daily living. Declining health can also result in significant changes in the person's behaviour, mood and social relationships.

Family and friends play an important role for the resident by easing the adjustment to living in a facility, and supporting the resident in creating new relationships in the facility. Families also convey important information about the resident to facility staff.

Staff are committed to the care of the residents and their clinical knowledge, experience and skills are important in supporting residents' safety and quality of life. Groups help family, friends and staff build good relationships and maintain open, respectful dialogue to support the best possible care for residents.

From time to time, your group may need to discuss concerns about something at the facility, raise a difficult issue, or work through an area of disagreement. Especially if an issue is sensitive or challenging, a commitment to dialogue rather than debate is more likely to result in a positive outcome.

Dialogue is a distinctive kind of communication style that allows people to connect and build shared solutions. Debate is a collision of differing positions that can increase levels of disagreement and damage relationships. It isn't always easy, but good listening skills and building common ground are critical to building an effective group.

The following examples demonstrate how a change in approach and attitude when dealing with challenging topics can help create a more productive and positive meeting.

Debate:

- Adversarial – attempts to prove the other wrong
- Focused on winning – assuming there is a right answer, and one person or group has it
- Close minded attitude – dogmatic, determined to be right
- Listening for flaws - building counter-arguments
- Defending assumptions as fixed positions or 'truth'
- Criticizing the other's position or beliefs, or talking negatively about them
- Defending one's own views against others
- Communication as a transaction
- Affirming one's own point of view

Dialogue:

- Collaborative – working together to find a common understanding or a shared solution
- Focused on exploring – assuming there are many pieces to the answer, shared by many
- Open minded attitude – openness to change, and to being wrong
- Listening to understand – making links, and revealing shared views
- Surfacing assumptions for discussion and evaluation
- Re-examining all positions, understanding values, concern for others
  perspective
- Accepting others views may improve or broaden one's own
- Communication as a relationship
- Enlarging and possibly changing the views on all sides[1]

[1] Barry Winbolt, Dialogue vs. Debate, Workshop Handout 2010. Accessed at: www.barrywinbolt.com/2010/03/handout-dialogue-vs-debate

What is the best way to communicate to staff if we have concerns about the facility?

Situations may arise where members of the group have questions or concerns about facility policies, activities, services or care. Families have a unique perspective, and providing input to the facility is of most value when the focus is on what families are observing and experiencing.

Additionally, sharing from our own experience provides important information, and creates room for solutions that meet everyone's needs. When someone feels their motives or values are being questioned, or their work is being criticized or monitored, they are less likely to be open to constructive dialogue. They may become defensive and may even feel harassed or intimidated. Sharing experiences in a respectful manner contributes to dialogue and resolution. Some examples of a respectful approach include:

- 'With the change in staff rotations, we are finding we don't know who we should talk to and we are concerned that staff don't know our loved one's routines and needs"
  Focus: clarifying how communication will be supported, and how resident routines and knowledge will be shared to ensure consistency.

- 'I have noticed fewer people coming to our meetings in the last few months. I know I have felt like the meetings seem to be focused on this one topic primarily, and I wonder if there are other interests we should be reflecting'
  Focus: an observation and personal experience – with an invitation for dialogue on the topic, rather than telling the group what is wrong.

- 'We are concerned that the new policy will mean that XX will happen. How has input from families been considered, and how will it be evaluated?'
  Focus: understanding what the purpose of the policy is, how it was developed, and how results will be evaluated and communicated.

- 'I have concerns about XX. In my own experience, I have noticed the following. When we discussed this last week, 4 other family members indicated they have noticed similar things, such as the following…'
  Focus: specific issues and concerns that need investigating and a response, recognizing the root cause and solution may be different than assumed.

How do I bring up concerns to the group while maintaining the privacy of my loved one's health condition?

Everyone has a role to play in respecting and protecting privacy. There may be times where members of the group have questions or concerns about their loved one's care and a resident/family council or group can be an important source of information and support. However, it is very important to remember that an individual's personal and health information is confidential.

Discussion of an individual resident's personal details or issues should take place in a private meeting with the resident's family or representative and staff at the facility, rather than during a resident/family group meeting.

Appendix 1

Glossary of Terms

Understanding some of the language used in the health care system can be a challenge. Health care professionals often use terms and acronyms that can be confusing. We've listed some of the most common of these below— but if a phrase or acronym is used and you don't understand it—never be afraid to ask!

Some helpful translations:

What members of the public might say:	What the healthcare system calls this:
Getting better, feeling better	Positive outcomes of care
Getting the right care from the right people at the right time	Clinical quality
Having a say, receiving clear information, being able to actively participate in decisions about treatment	Engagement or Involvement
Assistance to access services, support with coordinating services, or managing transitions between different care settings	Navigation
Practical and emotional support	Psychosocial support
A safe clean, comfortable place to be	Environment of care
How long it took to receive the right service	Access time
A smooth journey between different elements of the health care system	Continuity of care
Having a family physician	Attachment
Having to stay in hospital when hospital care is no longer needed	Alternate Level of Care (or ALC)
Doctor, nurse, nurse practitioner or other health professional	Clinician
The health care provider or team who acts as the first point of care for patients (usually a family physician)	Primary Care
Specialist care, hospital or specialized services that a patient may be referred to by their family physician	Secondary Care
Very specialized care, such as a burn unit, intensive care unit or neurosurgery unit	Tertiary Care
Specialized care at the end of life provided at home or in residential care, hospice or hospital that focuses on quality of life, and relief of symptoms, pain, and stress, rather than on curative treatments	Palliative Care
An organization that has been contracted by Island Health to provide services to patients	Affiliate or Contracted Service Provider

Appendix 1

Glossary of Terms

Commonly used acronyms heard in residential care settings:

Acronym	Full Definition
ACP	**Advance Care Planning –** a process of discussing and writing down values, beliefs and wishes to instruct providers on future healthcare decisions
AL	**Assisted Living**
ALC	**Alternate Level of Care**
BCAS	**BC Ambulance Service**
CNS	**Clinical Nurse Specialist**
CHS	**Continuing Health Services**
CRN	**Clinical Resource Nurse**
DoC	**Director of Care** – a clinician responsible for daily care provision in a unit or facility
ED	**Emergency Department**
EOL	**End of Life**
FTE	**Full Time Equivalent** – Working equivalent of one employee working 5 days/week
LO	**Licensing Officer –** a person designated by the Medical Health Officer to inspect residential care facilities, and ensure quality and safety requirements are met
LOS	**Length of Stay**
LPN	**Licensed Practical Nurse**
LTCA	**Long Term Care Aide**
MD	**Medical Director –** physician responsible for the clinical oversight of care in a residential care facility or program
MHO	**Medical Health Officer –** physician responsible for public health activities, and the licensing of residential care facilities.
PCQO	**Patient Care Quality Office –** health authority program responsible for responding to complaints which have not been resolved locally
RN	**Registered Nurse**
RS	**Residential Services**

Appendix 2

TERMS OF REFERENCE TEMPLATE
RESIDENT/ FAMILY COUNCIL or SUPPORT GROUP

Instructions: *Creating a Terms of Reference in forming Resident/Family Councils or Family Support Groups is entirely optional; however, Terms of Reference can be a useful tool to help clarify a group's purpose, goals and structure. This sample template can be used as a starting point for your group. Each section includes questions for discussion with some draft wording that can be adopted, amended or omitted depending on the consensus of the membership.*

1. **NAME**[1] (*Insert Facility Name and note whether it is a Resident/Family Council or Family Support Group)*

- the name should reflect whether the group represents members from the whole facility, a specific unit, includes residents and/or family members, and the role the group sees for itself
- Most groups call themselves the (*Facility Name*) Family Council but your group's members may choose whatever name they like best.

2. **PURPOSE** *(Clarifying the purpose of the group is valuable to ensure members are in agreement, and it helps communicate to potential new members what value the group may have for them.)*
   - *Sample purpose statement:*
     - ◊ The *(group)* meets monthly to provide an opportunity for residents, family, friends or representatives and facility staff to share information, provide support and to collaborate in developing and maintaining an atmosphere of respect, partnership, and caring at (*the facility*).

3. **GOALS** (*Identifying the priorities or goals for the group helps focus meetings and activities.)*
   - *Sample goals:*

     - ◊ To provide information to family members about the facility, its programs and services.
     - ◊ To provide education and support for family members, friends or representatives of residents regarding health care conditions, self-management and advance care planning.
     - ◊ To provide information and a forum for discussing and resolving issues and concerns while respecting and upholding the confidentiality and privacy of residents.
     - ◊ To build relationships and maintain open, respectful communication between residents, families, and staff as partners in care.
     - ◊ To collaborate with facility staff, families and residents on activities of interest to residents and families.
     - ◊ To provide mutual support for all residents and their families regardless of their participation with the Council/Group.

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[1] Terms of Reference based on Ministry of Health, Home and Community Care, Guidelines for the Development of Resident or Family Council January 2011: www2.gov.bc.ca/assets/gov/topic/D3E0B9FAB55484D135A5C5201D799D96/pdf/guidelines_resident__family_councils.pdf

Appendix 2

TERMS OF REFERENCE TEMPLATE: Page 2

4. **MEMBERSHIP** *(Clarity with membership can save misunderstandings over time. There are several things to consider regarding the participation of residents, family members and staff in the group.)*

Questions to consider:

- Does the group wish to include both residents and family members – or restrict membership to only one of these?

- For family members, close friends or legal representatives:
  - ◊ Will there be limits or guidelines regarding how many people representing a single resident can participate, especially when decisions are made or the group is voting on something (i.e. one vote per resident represented)?
  - ◊ How will the group invite families to participate and/or become members when a new resident is admitted?
  - ◊ When a resident is no longer in care, will family, friends or representatives of the resident be permitted to continue to be members? If so, for how long? Are there other opportunities for members who wish to stay involved with the group/facility but no longer have a loved one in care?
  - ◊ Are there any expectations or criteria for family, friends or representatives who wish to participate in the group? How formal or informal is participation in meetings? How will this information be circulated?

- Commonly, a member of staff is identified as a liaison for the group, but the expectations of what this involves can vary greatly:
  - ◊ Does the group wish to have a staff representative participate as a regular member of the group, by attending a part of each meeting only, or by invitation?
  - ◊ What type and frequency of communication works best between the group and the staff member?
  - ◊ If the group wishes the staff member to participate regularly, are there any specifics around availability or scheduling that need to be considered?

- If the group decides to dissolve, what will that process be? What happens to any properties or funds of the group?

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TERMS OF REFERENCE TEMPLATE: Page 3

5. **ROLES & RESPONSIBILITIES** (*Clarify who will be responsibility for carrying out the duties and the activities of the group, including how leadership roles will be determined and how members will be notified of opportunities to take on leadership)*

- Common positions identified for a group include:
  - ◊ Chair or two co-chairs to plan and facilitate meetings
  - ◊ Secretary to record and distribute minutes, communications and other records
  - ◊ Treasurer to manage any funds
  - ◊ Committee or working group leaders for specific group projects or activities

Questions to consider:

- For residents, family members, friends or representatives:
  - ◊ What are the leadership roles that best suit the group?
  - ◊ What is the process for appointing a leader(s) for the group? *(i.e. annual election, discussion and agreement, vote, or a rotation/sharing of leadership roles)*
  - ◊ How long will the terms be for these positions?
  - ◊ How will information be circulated to residents and/or families regarding election of leadership positions?
  - ◊ Will there be limits on the number of times an individual may be re-elected to a position?
  - ◊ What is the process to replace someone if they are not able to continue in their role?
- For the facility and/or staff liaison:
  - ◊ Will the facility provide assistance with meeting planning/set-up?
  - ◊ If a staff liaison is appointed to the group, what are the expectations? *(i.e. co-chair meetings, provide regular reports on facility activities, ensure two-way communications between group and administration, advise on specific topics, help organize activities, speakers role, etc.)*

6. **MEETING FORMAT & LOGISTICS** (*Establishing agreement for how meetings will be run can save confusion, and ensure that the structure works for both the facility and the members.)*

***Questions to consider*:**

- How will decisions be made? *(i.e. vote or consensus decision making)*
- Does the facility have meeting space available and how will this be coordinated?
- How often will the group meet?
- How will meetings be advertised to family members, friends and/or representatives?
- If meetings include a social opportunity and/or refreshments, who is going to arrange this?
- If the group is interested in educational opportunities how will the topics be determined?
- Will there be a regular pattern to the development of meeting agendas? *(i.e. the agenda is sent out a week prior to meeting, is agreed to at the close of the previous meeting, or informally agreed to at the start of each meeting)*
- Does the date, time and format of meetings allow for participation of family members, friends and representatives that may have to work or travel to attend?
- If members wish to invite speakers or guests to participate, will they need to be approved by the chair(s) in advance or will the group have a process/guidelines for guests?

Appendix 2

TERMS OF REFERENCE TEMPLATE: Page 4

7. **AMENDMENTS** *(Even when things are running well, taking a few moments to review and affirm, or make changes to the Terms of Reference on a regular basis can help keep the group working effectively as leaders and active participants change over time)*

Questions to consider:

- How often will the Terms of Reference be reviewed and/or amended?
- Do changes have to be approved by all members or a majority of those attending the meeting?
- Has the group received input from family members, friends and/or representatives over the past several months that should be considered when reviewing the Terms of Reference?
- Does the group want to provide a copy of the Terms of Reference to residents/families to gather their input or notify them of proposed changes before any changes are voted on?

7. **SHARING INFORMATION, CONCERNS and ISSUES** *(It is good practice to establish agreement on how information will be shared, how any conflicts or disagreements will be resolved, and to establish ground rules for discussion of difficult issues. These can help foster an atmosphere of respect and authentic communication, and builds confidence in working together.)*

Questions to consider:

- How can members protect the privacy of individuals and the confidentiality of their personal information while discussing topics of interest or concern?
- How will privacy also be maintained through any written communication, such as minutes or notes?
- How will information, concerns and topics of interest to the group be shared with the facility? Is there agreement with the facility on who should be the contact for this, and what the process might look like?
- Are there specific activities the group wants to include to ensure all members have an opportunity to speak and provide their input, such as passing the gavel, a round table or feedback on the meeting?
- How will the group resolve any conflicts that may arise amongst members on a particular topic?
- How will the group communicate and circulate information such as notice of meetings, agendas or meeting notes?
- If there is more than one group at the facility, how will they share information?
- Where a member has an individual concern or issue, how will the group assist them in identifying the right process or person to direct it to?
- Are there other opportunities for input or engagement of residents at the facility, and how will these be communicated?