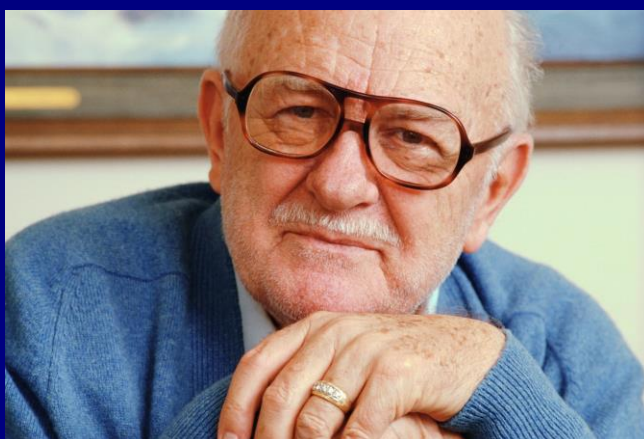




Family Councils Ontario

*Families working together to provide support,
share experiences and seek solutions to common problems.*



Your Guide to Starting and Maintaining a Family Council

Prepared in Partnership with Self-Help Resource Centre and Concerned Friends

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Ontario's Family Councils' Program, now Family Councils Ontario, began as a project in response to a need identified by Concerned Friends of Ontario Citizens in Care Facilities. Families, as primary caregivers, were asking for support and information on a broad range of topics once their family member became a resident of a Long-Term Care Home.

Increasing numbers of residents have some form of dementia, and are unable to participate meaningfully in Residents' Councils and speak for themselves. This shift in the Long-Term Care population underscored the need to develop autonomous Family Councils where families could come together and discuss their challenges and find support for their changing caregiver role and explore ways to improve the life of residents living in Long-Term Care Homes.

Family Councils' Program operated as a program of The Self Help Resource Center from its inception. The program grew from a pilot project funded by an Ontario Trillium Foundation Grant in 1998 into a program funded by the Ministry of Health and Long-Term Care (MOHLTC) in 2004. In January 2015, the program launched into independence as Family Councils of Ontario, a registered non-profit provincial organization and registered Canadian Charity. Family Councils Ontario continues to be funded by the Ontario Ministry of Health and Long-Term Care.

Selected material in this handbook was adapted from information prepared by the Association of Advocates for Care Reform in British Columbia.

We welcome those engaged in educational purpose to photocopy these materials.

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Chapter 1: Introduction



Introduction

Many individuals remain healthy and independent throughout their lifetimes. However, some people experience health problems in their later years that may be so limiting that they can no longer remain at home in their community. They may require nursing care that results in their moving into a Long-Term Care Home.

There are approximately 75,000 residents living in over 600 Long-Term Care Homes in Ontario. These numbers will surely increase as Statistics Canada predicts that there will be almost 2 million Canadians aged 85 and over in 2051 – almost 5 times the current figure.

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Our Services

Consultations: Family Councils Ontario (FCO) staff are available to help you to plan steps or address challenges via telephone or email.

Presentations: FCO has a variety of presentation and workshops that can be tailored to the specific needs of your Family Council or Home, including "Family Council 101," "Family Councils and the Act," and more.

Resources: FCO has collection of print and online resources to support your Family Council. Topics include starting a Family Council, Family Councils and the Long Term Care Homes Act, the role of staff in Family Councils, and more

Networking opportunities: Networking meetings provide an opportunity for Family Council members from different Homes to gather together to share experiences, learn through educational opportunities and explore issues of common concern.

Website: Our website, www.fco.ngo, offers a host of features such as: downloadable resources, upcoming events and Family Councils' Ontario updates.

Family Councils Ontario Mission, Vision & Values

Our Mission:

Leading and supporting families in improving quality of life in Long-Term Care.

Our Vision:

People in Long-Term Care have a vibrant experience and the best care.

Our Values:

- Building capacity: We value and celebrate the perspectives and contributions that Family Council members bring. We are committed to providing information and supports that build their capacity to effectively advocate on behalf of people living in LTC.
- Strong engagement: We actively seek ways to welcome and engage stakeholders through engagement strategies that ensure that diverse perspectives will inform our work.
- Diversity: we embrace diversity in all its forms, including gender, age, ability, disability, race, gender identity and language in our programs and services and support collaboration and mutual respect amongst residents and their families.
- Constant learning: We continuously learn from our successes and mistakes and then apply them to do even better in our future endeavours. We regularly seek out feedback from family councils and other key stakeholders.
- Meaningful collaborations: We form and then actively nurture meaningful collaborations in order to leverage resources and increase our impact.
- Integrity: We are open and honest in all of our dealings and communications. We employ ethical oversight, and ensure that information is timely, appropriate and clear.
- Evidence informed: We believe that diverse sources of knowledge should inform our work. We are committed to mobilizing knowledge generation and exchange for this purpose.
- Good decision-making: We are rigorous in our decision-making processes. This means that we will be creative, thoughtful and decisive and are prepared to make tough decisions.

About This Guide

Purpose

This guide has been written to support the family members and friends who make up Family Councils as well as the Long-Term Care Home staff who work with Family Councils.

Family Councils Ontario has had the opportunity to work closely with many of you in the development of this guide. Thank you to all those who provided input over the past couple of years.

We have also looked at resources that were developed elsewhere. We have included references and links to these resources in the "Resources and Supports" chapter.

This guide is intended as the primary resource for emerging Family Councils as well as those that have been operating for a number of years. For those just getting started, you will want to review "Chapter 2: What is a Family Council?" and "Chapter 3: Getting Started." We also have a variety of samples and an introductory DVD that we can mail to you. For those that have been operating for a while, we suggest you may want to focus on "Chapter 4: Maintaining your Family Council."

Thank you to all those who have provided input to this guide over the past couple of years:

- Barbara Filipcic, Bennett Health Care Centre staff assistant
- Justine Welburn, Specialty Care Mississauga Road staff assistant
- Leonard Molczadski, staff assistant
- Barb Heward, Leisureworld Caregiving Centre-Brampton Woods staff assistant
- Cindy Ingram-Lloyd, staff assistant
- Lisa Herjavec, Versa-Care Centre, Cornwall staff assistant
- Lindsay Webber, Royal Ottawa Place Staff assistant
- Carmen Cyr, staff assistant
- Barb Martin, Leisureworld Caregiving Centre-Etobicoke Family Council member
- John Morton, Chateau Gardens Long Term Care Residence Family Council member
- Angela Shaw, Cawthra Gardens Long Term Care Family Council member
- Diane Sheldon, Malden Park Continuing Care Centre Family Council member
- Teresa Tasse, Extendicare Tri-Town Family Council member
- Steffanie Wong, Mon Sheong Home For The Aged Family Council member
- Ontario Long-Term Care Association (OLTCA)
- Ontario Association of Non-Profit Homes & Services for Seniors (OANHSS)
- Ontario Association of Residents' Councils
- Eldercare Rights Alliance (USA)
- Association of Advocates for Care Reform (ACR)
- Pamela Bailey, Family Councils' Program volunteer

At the same time, we have assumed that whatever your Council's stage of development, you may want to sample the materials in this guide in an order that is directed by your own needs and interests, moving back and forth among the chapters. For this reason, we have repeated some information from chapter to chapter where this makes sense and inserted cross references.

Whatever the stage of development or evolution of your Family Council, Family Councils Ontario staff are available to direct you to helpful information and resources and other supports to groups interested in forming Family Councils. For further assistances or if you have any further questions, please feel free to contact us or visit our website, at your convenience.

We welcome anything you would like to share about your own Family Council experience. To assist you a feedback form has been provided at the end of this guide.

How This Guide is Organized

Chapters 1 and 2

This brief introductory chapter is followed by a description of what constitutes a Family Council and the benefits of Councils in Chapter 2.

Chapters 3 and 4

- Getting started – for example, forming a planning team, planning an introductory open meeting and anticipating some of the things that might lie ahead for your Family Council.
- Laying a solid foundation for your Council that includes developing a Terms of Reference for your Council, identifying realistic goals, dealing with roles and responsibilities of Council members, and being an effective voice by processing concerns in a positive way

Chapter 5

We have highlighted the role of Long-Term Care staff in a chapter on its own – “Chapter 5: The Role of Staff.”

Chapter 6

In Chapter 6, we have listed other resources and supports. A glossary of common terms that you will encounter along your way appears following this final chapter.

Don't forget to fill out our suggestion sheet at the end of the guide. We can always learn from your comments.

Features

The guide includes a number of features – some from our previous edition and some new. For example, we have continued to include sample materials. These are positioned at the ends of relevant chapters and noted in the table of contents. Additional samples are available through Family Councils Ontario.

We have also included more tips (based on the experience of existing Family Councils) and answers to frequently asked questions (FAQs) as ways of giving you a quick overview of particular topics, and anticipating and addressing any challenges.

If you are accessing the guide on a computer or on-line, hyperlinks have been added to help you locate topics identified in the table of contents. Hyperlinks have also been used to allow you connect on-line to other resources and supports.

Use the icons to help you find these features:



Cross-References



Frequently Asked Questions (FAQs)



Resources



Tips and Ideas



Chapter 2: What is a Family Council?



What is a Family Council?

What is a Family Council?

A Family Council is an organized, self-led, self-determining, democratic group composed of family and friends of the residents of Long-Term Care Homes.

The main purpose of a Family Council is to improve the quality of life of Long-Term Care residents and to give families and friends a forum for sharing their experiences, learning and exchanging information.

A Family Council works with residents' family members or friends and the Long-Term Care Home to identify and resolve issues that affect residents' quality of life. Most Family Councils relate to a staff assistant (also called a "Family Council Assistant" in Ontario's *Long-Term Care Homes Act*). This is a person that the Home appoints at the request of the Family Council to assist the Council and attend meetings on request.



More information about the role of staff assistant is provided in Chapter 5.

While each Family Council is unique, Family Councils in general focus on improving the quality of life and assuring quality of care for all residents and supporting each other. This includes activities that:

- Promote mutual support among Council members and other families and friends involved with the Home's residents often through sharing information and experiences as well as educating Council members on issues affecting residents and families – sometimes by engaging guest speakers
- Facilitate communication and promote partnerships with Home staff and residents as well as residents' families and friends who are not involved directly on the Council
- Advocate regarding collective concerns. Advocacy can focus on issues within the Home or occasionally broader concerns

Specific activities will vary depending on the interests and experiences of Council members and the characteristics of the Home (level of care, level of staff support, role of Residents' Council etc...). These factors will help shape the Council's goals.

Family Councils are groups whose members share a common concern about the quality of the lives of their relatives or friends and provide mutual support, empowerment and advocacy to the family and friends of the residents of Long-Term Care Homes.

They are organized, self-led, self-determining, democratic groups composed of family and friends of the residents of Long-Term Care Homes.



See Chapter 4 for more information about how groups work.



See more about developing goals in Chapter 4.

What Are the Benefits of a Family Council?

What are Some of the Benefits of a Family Council?

A Family Council:

- Allows families to give each other ongoing mutual support and encouragement. Sharing thoughts and feelings with others who are in the same situation can help family members cope – e.g., when experiencing difficulties in adjusting to having a loved one in Long-Term Care
- Provides a forum for learning – e.g., regarding residents' rights, the health issues affecting residents (e.g., Alzheimer's disease), or other relevant topics
- Provides an opportunity to become knowledgeable about the Home's operations, policies and rules. This can be especially helpful for families of new residents
- Can help families and the Home form a positive partnership aimed at improving resident care
- Offers family members a chance to express their collective concerns – a “united voice” supporting a “united effort.” In this way, a Family Council can be a catalyst for positive changes in residents' daily lives, families' experiences and in the Home in general
- Can benefit residents who are physically or mentally unable to voice their needs and concerns as well as those without family
- Can benefit the Long-Term Care Home by providing a means for staff to deal directly with families as a group and establish meaningful ongoing lines of communication. For example, staff may be able to use the Family Council as a sounding board for new ideas
- Ultimately, improves residents' quality of life and supports families of residents



What Some Family Councils Have Accomplished

Here are some examples of what some Family Councils have accomplished:

- Representatives from one Council worked with the Home's planning team regarding the building of a new Long-Term Care Home. Their input was particularly important in the layout of the new resident rooms, making them "wheelchair friendly" spaces.
- Another Council's work with the local municipality saw wheelchair curb ramps incorporated into the sidewalks around the Home so that residents using wheelchairs could leave the property.
- Members of one Council advocated for new doors in the Alzheimer unit to improve resident safety.
- A Council's members worked with the Community Care Access Centre to develop user friendly manuals regarding the placement process, respite care and the Long-Term Care Home.
- Air-conditioning was installed in one Home at a Family Council's recommendation.
- Families in one Home noticed that many of the residents' were wearing clothes that were not their own. The Council offered to clean out the storage closets and in so doing was able to return misplaced garments to their rightful owners.
- At the urging of a Family Council, a Home agreed to assign the same nursing assistants to the same residents. Both residents and personal support workers (PSWs) reported that they liked the system.
- Family Council representatives were asked to attend a Home's strategic planning meeting to ensure family input was incorporated into the plan.
- Another Home invited Family Council members to help them review and revise the placement process.
- Members of another Council provided advice to their Long-Term Care Home in preparing for accreditation.



Recent Projects

Read how Family Councils have benefited Long-Term Care residents and families in our newsletter. Also, check out our newsletter archives. You can learn more by going to www.fco.ngo

Family Councils and the Long-Term Care Homes Act, 2007

Family Councils are also described in Ontario's *Long-Term Care Homes Act, 2007* (*LTCHA* or The Act).

The Ministry of Health and Long-Term Care has asked all Long-Term Care Homes to make a copy of the Act available and to provide a copy to both the residents and Family Councils. All Local Health Integration Network (LHIN) offices will also have copies available for members of the public.



In addition, the full text of the *Long-Term Care Homes Act (LTCHA)* is available through [Service Ontario kiosks](#), and on-line at the [Government of Ontario's e-laws site](#).

Membership in a Family Council

LTCHA Section 59 (5) states who has the right to be a Family Council member, and Section 59(6) lists those who cannot be members. When established, a Family Council becomes a self-led, autonomous group with the powers outlined in Section 60. A Family Council may set provisions within its Terms of Reference for continuing the membership of a Family Council member who no longer has a family member/friend who is a resident in that Home.

What the Legislation Says

The *LTCHA* provides for a Long-Term Care Home to have a Family Council. In fact, a Home must assist in the establishment of a Council within 30 days of receiving a request from a family member of a resident or a person of importance to a resident (i.e. a friend or other person with a close relationship with the resident).

If there is no Family Council (and no request before the Home), the Long-Term Care Home must advise residents' families and persons of importance of the right to establish a Family Council. The Home must convene semi-annual meetings to advise family members and persons of importance of the right to establish a Family Council.

Under the *LTCHA*, a Family Council of a Long-Term Care Home has the following discretionary powers. This can include:

1. Providing assistance, information and advice to families and friends when new residents are admitted to the Home
2. Providing information and advice to families and friends about their rights and obligations under the *LTCHA*
3. Providing information and advice regarding the rights and obligations of the Home
4. Helping to resolve disputes between the Home and residents
5. Sponsoring and planning activities for residents
6. Collaborating with community groups and volunteers concerning activities for residents

7. Reviewing
 - i) inspection reports and summaries prepared by Ministry of Health and Long-Term Care inspectors involved in the process of licensing the Home ¹
 - ii) the detailed allocation of funding received by the Home under the *LTCHA* and amounts paid by residents,
 - iii) the Home's official financial statements.
8. Advising the Home of any concerns or recommendations the Council has about the operation of the Home. (Within 10 days of receiving these concerns or recommendations, the Home must respond in writing to the Family Council.)
9. Reporting to a person appointed by the Minister of Health and Long-Term Care any concerns and recommendations that in the Council's opinion ought to be brought to that authority's attention.

If the Family Council requests staff assistance from the Home, the Home must appoint a staff person who is acceptable to the Council to assist. We have included additional information about the role of "Family Council Assistant" under the legislation in this guide.



See Chapter 5: The Role of Staff.

Impact of Legislation on Family Councils

As Family Councils are included in the legislation governing Long-Term Care Homes, it is more important than ever to think about the structure and operating procedures of your Family Council, including its membership. As the Terms of Reference outline the structure and direction of your Council, make sure that your Council's Terms of Reference clearly define the membership and terms of office, such as how long an individual can hold the position of chair and if an individual who no longer has a family member/friend as a resident in the Home may continue to be a member of the Family Council.

It is important for the entire Family Council to discuss and vote on the Terms of Reference in order to ensure that everyone's voice is heard and that your Terms of Reference best serves the needs of your Council. Each Council is unique and your Terms of Reference should be tailored to fit your Council.



See Chapter 4 for more information about Terms of Reference.



Do you still have questions about what is a Family Council and what it does? See if your question is included below.

1. The Ministry of Health and Long-Term Care ensures that Long-Term Care Homes are inspected annually. These inspections are unannounced inspections. The Ministry may also conduct an inspection if it receives a complaint about a Home.

Q: If a family member has a concern, should that go to the Family Council?

A: It is important to be clear about what a Family Council can and cannot do. A Family Council handles group concerns, not individual concerns. Family members with specific concerns should speak to Long-Term Care Home staff and administration. Every Home is required to have a process for addressing individual concerns. See “Chapter 4: Maintaining Your Family Council,” which includes a section titled, “Being an Effective Voice: Processing Concerns.”

Q: Do Long-Term Care Home staff chair the Family Council?

A: A Family Council may require that the Home assign a staff assistant (“Family Council Assistant” according to Ontario’s *Long-Term Care Act*). The Council may invite the staff assistant to attend meetings. The Family Council is an autonomous family-led group where Home staff plays an important, supportive role. As such, Family Council meetings generally should be chaired by a family member.



See Chapter 5: The Role of Staff.

Q: Do residents participate in the Family Council?

A: Many Homes have Residents’ Councils. It may seem that a Family Council and a Residents’ Council have much the same purpose and that they should be combined into one group. However, experience shows that many residents and family members have very different needs, interests and abilities. Family members, who are often quicker and better able to express themselves, soon dominate a combined Council. Residents and families need their own separate Councils geared to their special situations and interests. Ideally a Family Council and the Home’s Residents’ Council will keep each other informed and sometimes work in partnership.

Q: Do Family Council members act as volunteers in the Home?

A: Family Council participants volunteer their personal time to support Family Council activities in a Home. This is not the same as the Home’s volunteer program. Individuals who wish to pursue volunteer opportunities in a Home should approach the Home’s volunteer coordinator or other contact person. Some individuals may be both a Family Council member and a volunteer in the Home. The two roles are related but distinct. The Family Council as noted elsewhere is an autonomous organized group, whereas volunteers take direction from staff.

Q: If our Home has a Family Advisory Committee, do we need a Family Council?

A: Some Homes may have a Family Advisory Committee that provides advice exclusively to the Home. Family members, staff, community members and other community agency representatives may sit on the Committee. This is not the same as a Family Council which provides assistance and advice to families/friends and residents in the Home and makes recommendations to the Home in the interests of residents and their families.

Q: Should Family Councils fundraise?

A: The purpose of a Family Council is not to fundraise. Some Family Councils choose to engage in fundraising to provide for activities for items above what the Home provides. The Family Council should not be raising funds for items that the Home is required to provide. A Long-Term Care Home should provide funds for any activities that are part of the Home’s own programming. For example, the Home may have its own art therapy program and will provide art supplies as part of that program. However, a Family Council may wish to provide special treats or activities for residents that are over and above what a Home provides. The Family Council may also wish to

provide residents with luxury items or upgrades that are over and above what a Home has been providing.

Wherever money is concerned, you need to be very clear about what you want to achieve and how you go about achieving it. Before you fundraise, tap into some of the resources available on the internet. A good place to start is Imagine Canada's Nonprofit Library Commons: <http://nonprofitscan.imaginecanada.ca>

Chapter 3: Getting Started



Getting Started

Introduction

Every Family Council is unique. There is no “cookie cutter” approach to starting a Council. However, the experience of Family Councils Ontario is that the effectiveness and ongoing success of a Family Council has much to do with the initial organizing.

If you and others are interested in starting a Family Council, you may want to reflect on the information in this chapter and identify the steps that you think you should take and resources that may be useful to you given the particular context in which you will be working.

We have identified the following preliminary steps in forming a Family Council:

- Sharing your ideas with others
- Forming a planning team
- Planning and holding an introductory open meeting



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Learn More about Family Councils

In addition to this guide, there are a number of resources available that can help those who want to start a Family Council.



Tips for Getting Started

Check out Family Councils Ontario on the web. Our web site includes this guide, training materials, our newsletter, research documents, reports, links to regional networking information and opportunities, the Family Councils Ontario Introductory DVD, and many more resources and links.

Talk to staff in Family Councils Ontario. They can help you think through the steps you might want to take in starting a Council. They can be useful resources and they can also refer you to people involved in other Councils in your own community or nearby.

Meet with and talk to other Family Council participants by attending networking meetings or contacting other Homes that have a Family Council.

Reflect

Think About the Role of a Family Council

You may feel that the Long-Term Care Home where your family member or friend lives could benefit from a Family Council for a number of reasons. What are some the benefits that you see for families and residents?

The role of Family Councils is described in the previous chapter. Briefly, the role includes:

- Promoting mutual support among Council members and other families and friends of residents
- Facilitating communication and promoting partnerships with Home staff and residents as well as residents' families and friends not involved directly on the Council
- Advocating regarding collective concerns

How do your ideas fit with this particular role and the other things that you have read about Family Councils? What would you emphasize at least in the short-term? What would you add?

Review the Family Councils Ontario Mission, Vision and Values

Another good place to start thinking about a Family Council is to consider the Mission, Vision and Values that appear in “Chapter 1: Introduction.”



Review the Family Councils Ontario Mission, Vision and Values in Chapter 1.

The Mission, Vision and Values guide Family Councils Ontario in its work across the province.

Consider Putting Values into Action

Discuss the implications for how you will approach getting your Council started and ultimately maintaining your Council.

For example:

- Supporting inclusive practices could encompass:
 - Publicly posting information and being open to all families
 - Handling disagreements.



See the section on “Promoting Diversity” in “Chapter 4: Maintaining Your Family Council” for further ideas.

- Accepting the principle of working collaboratively can guide:
 - Working within the planning team or emerging Family Council
 - Working with Long-Term Care Home administration and staff
 - Working within a larger regional and provincial Family Councils' framework.

Share Your Ideas

Talk Informally to Other Families and Friends of Residents

You likely know some of the other family members and friends of residents in the Long-Term Care Home. You may want to see if they share your interest and if they have heard about Family Councils. Here are some suggestions for connecting with others and building momentum:

- Use your contacts to help you connect with additional people who might be interested.
- Talk to staff in the Home, no matter what their role. Staff can help you connect with other family members and friends who may want to start the Council. Ask each staff person that you approach to identify two names of interested family members you can contact.
- Ask the Residents' Council for help. Residents themselves can talk to their families and you may be able to connect with some family members who are attending the Residents' Council.



Talk to the Administration and Staff at the Long-Term Care Home

As noted in Chapter 2, the *Long-Term Care Homes Act* permits Long-Term Care Homes to have Family Councils. Plus, Homes **MUST** assist in the establishment of a Council within 30 days of receiving a request from a family member of a resident or a person of importance to a resident. If a Family Council requests staff assistance from the Home, the Home must appoint a staff person who is acceptable to the Council to assist.

Start off on the right foot in engaging in this new partnership:

- Talk to the Home's administrator about assigning a staff person to help you get started.
- Help educate Home staff about the positive role a Family Council can play.
- Think about how staff can help develop the Family Council and spread the word by telling families about the Council.

One Way to Get Started: Form a Planning Team

Once there is a small group of people interested in forming a Family Council (say two or three people that are interested in working with you), it is a good idea to form a small planning team. You might prefer to call the group a steering committee or some other name.

We are suggesting that the structure and goals remain flexible in these early stages, when things are just getting started because it will be important to tap into others' ideas and give them a sense of ownership too as you bring people on board.

Some of these preliminary goals should include ideas for introducing the concept to all families of residents of the Home.

The First Planning Team Meeting

The first planning team meeting should emphasize getting to know each other – perhaps over dinner or some other relaxed setting for conversation. Although the meeting is relaxed there should still be an agenda that will stimulate conversation and make participants feel that they have accomplished something.

Set an Agenda

An agenda for the first few meetings might include:

- Sharing information about yourselves and your interests in improving the quality of life of residents in the Home
- The role of Family Councils
- The role of Home staff
- Designating an acting chair or temporary lead meeting volunteer to facilitate meetings
- Discussing values and how you think these values should guide the Council's work
- Developing a road map that will guide at least in the short term – some next steps. These should include:
 - Targeting a date for a first informal meeting open to all family members to discuss the purpose of the Council and assess their interest in becoming involved with the Family Council
 - Identifying individuals to organize this meeting with the help of Home staff
 - Generating ideas for a Code of Conduct and preliminary goals – some of the things that ultimately you will want to include in a formal Terms of Reference. (See Chapter 4 for more about developing a Terms of Reference.)
 - Identifying planning team member skills and interests
 - Discussing how you will share the work and ultimately assigning tasks as necessary to achieve your goals. (Note: this is where the informal structure begins to move to a more formal structure.)



Tips for Effective Planning

- Whatever your agenda, be sure to set a next meeting time, date, location and a tentative agenda.
- Keep notes of who has agreed to do what.
- Send out a follow-up e-mail or make follow-up calls reminding people of what they have agreed to do and the next meeting date.

Becoming a Family Council

The planning team may move naturally into a Family Council – or not. Perhaps, the emerging group will have to hold an election of officers to signal the shift from the planning team to an established Family Council. (See the discussion of when a group is a Family Council under FAQs, below.) Or, the Council may choose a committee or shared leadership model and decide who will perform which role as part of transitioning from a planning team to a Family Council.

Every Family Council develops in its own way based on the unique needs and interests of the individuals involved. You may quickly gather a critical mass of interested individuals allowing you to form a Family Council within a short period of time. In other cases, it may take time to bring people on board.



Q: When is a group a Family Council?

A: A Family Council is a specific kind of group, not just a collection of people. To become this kind of group, some conditions must be met. There must be a collection of people with all of the following characteristics:

- Come together regularly
- Interact with one another
- Share a sense of belonging or purpose
- Have common goals and objectives that include improving the quality of life of all residents in the Long-Term Care Home, supporting families and friends of residents, and giving families a voice in decisions that affect them and their loved ones in the Home
- Have some structure, rules and methods of operation.



See more about Family Councils as groups in “Chapter 4: Maintaining Your Family Council.”

Plan an Introductory Open Meeting

The Importance of an Introductory Open Meeting

Whether you are staff, or family member, or a small group of individuals functioning as a planning team or even a newly minted Family Council, when starting a Family Council, it is most important to hold a meeting to which all friends and families of residents are invited. An open session allows you to orient family members generally and generate interest in the Family Council. It signals an open and inclusive approach, laying a positive foundation that will support more formal, ongoing recruitment and Council operations.



See more about developing a recruitment plan under “Ongoing Recruitment” in “Chapter 4: Maintaining Your Family Council.”

This section is written assuming that your small planning team engages in some initial outreach using an open introductory information session. ***If your Council is at a later stage of development, but you have not held an open meeting, you will still want to review this material.***

Basic Objectives of an Introductory Meeting

There are four basic objectives that you will want to achieve by holding an introductory meeting for families and friends of residents:

1. Explain the concept of Family Councils.
2. Establish people's interest in having a Family Council.
3. Begin organizing a Family Council, if there is sufficient interest.
4. Make sure people feel included and have a positive experience (this could be the beginning of a long relationship).



See a sample flyer for promoting an introductory meeting at the end of this chapter.

Use a Family Survey to Help Plan the Details

In order to determine how best to achieve these objectives, you may want to use a family survey. We have included a family interest survey later in this section.

- Start with a survey that can be given to family members and close friends of residents (what the *Long-Term Care Homes Act* calls "persons of importance to residents"). This will give you a sense of whether there is general interest in a Family Council in advance of the open meeting.
 - Based on the survey findings, consider:
 - How can families best be encouraged to participate?
 - How can families best be introduced to the idea of a Family Council?
- After the information session, how will we ensure that new staff and new families know we exist? These are important questions to consider in preparing for any information session – even after you have formed a Council - to introduce new families to the Family Council and recruit new Council members.

Notify People about the Introductory Meeting

- In your notices about the information session, provide a brief description of what a Family Council is and the roles that Councils have played. People will not attend something if they don't know what it is or if they are welcome to attend. Make sure that your notice indicates that all family members and friends of residents are welcome to attend. Be brief. Be clear. Use everyday language.
- Make sure to advertise the session and use a number of different strategies to get your message across. Remember, the staff person assigned can help you with this process:
 - Let all Home staff know about the session so that they can pass on information to families and friends who come to visit residents.
 - Request that the Home insert flyers into mailings/billings. (Homes are usually willing to send invitations to families on their mailing list.)
 - Post flyers in the Home on bulletin boards. (All family members and friends may not be on the Home mailing list.)
 - Make personal phone calls to families to invite them if possible.
 - Place notices in the Home's newsletter, in local newsletters or community newspapers.

Design the Introductory Meeting to be Welcoming and Informative

- The information session should be planned for a time when people are most likely to attend. Avoid summer when families are likely to be on vacation.
- Ask the Home to provide a room where the meeting can be held.
- Make the environment relaxed by allowing time for attendees to mingle with each other.
- Be sure to ask family members how a Family Council could help them and listen to their needs.
- Serve some food/dinner/refreshments.
- Make the session attractive by inviting guest speakers to speak to topics of interest that were identified in your survey – for example:
 - Invite a family member who knows about Family Councils to speak at the session. This will be well received.
 - If you don't have a family member at your Home that is able to do this, network with neighbouring Homes that have an operating Family Council and invite one of their members to attend and speak.
 - Find out what other Councils are doing and when orienting your Council members to the concept, present these examples.
- Do set an agenda (see below), but don't make it heavy. Give everyone just enough information to trigger their interest and enthusiasm.
- Build on the interest that you generate in this meeting and encourage participants to sign up for the next meeting to learn more about starting a Family Council. Follow-up with these people with a personal phone call.



Create a sign in sheet where people provide their contact information. The contact sheet should include an agreement to release the contact information to Planning Team/Family Council members and Family Councils Ontario, and confirm their interest in receiving mailings or calls about upcoming meetings, etc. Contact Family Councils Ontario for a sign-in sheet template.

- Once you have a group for your next meeting you can carry on with the work of the planning team or form a Family Council.

Follow a Basic Agenda that Establishes Interest in a Family Council

Regardless of the details, the introductory meeting should include the following components aimed at establishing interest in a Family Council:

1. **Welcome participants**
Start with a warm welcome and express appreciation to participants for coming.
2. **Describe what Family Councils are about.**
Next discuss the purposes, importance and structure of Family Councils.
3. **Determine people's interest in forming a Council**
Be sure to allow adequate time for family members to ask questions and discuss their ideas about a Council. Do not assume that everyone will be in favour of the Council. You may want to distribute a Family Interest Survey to those who have not already completed a survey (see below).
Ask for people to indicate their interest at this point (e.g., show of hands) from people who would be willing to attend future meetings, etc. You may want to assure people that this does not constitute a firm commitment.
Plan for the next meeting
Identify the meeting place, time, and date to accommodate as many families/friends as possible.



This might be enough for your first introductory meeting. Assuming you have generated some interest, plan to take the next step in forming a Council at a second meeting. The agenda in this case would include:

- **Welcome participants**
You may find that some additional or different people attend a second meeting
- **Review outcome of previous meeting, confirming level of interest**
- **Select temporary lead volunteers**
Councils usually begin with temporary lead volunteers in the role of chair, vice-chair and secretary who serve until a leadership structure is chosen by the Council or regular elections are held. It is possible that those who were involved in planning the introductory meeting may be willing to lead the Council temporarily.



See Chapter 4 for more information about Council leadership options.

- **Decide on the structure of future meetings**
If the group is small, the Council usually invites all families to each meeting.
If the group is large, task groups or committees may be needed to plan and make decisions.



See Chapter 4 for more information about possible committees.

- **Determine role of staff**

The Council should decide to what degree, if any, staff should be involved. Often family members are reluctant to express concerns in front of staff. Even with a staff assistant assigned by the Home, family members may choose to meet in private occasionally, or spend a portion of each meeting without staff present.



See more about the role of staff in Chapter 5.

- **Plan for the next meetings**

At this point, you may want to set regular meeting times (most Family Councils meet monthly), once again ensuring that they accommodate as many interested in participating as possible.



It is a good idea to meet at the same time each month to promote continuity.

You may be able to accomplish everything on these lists in one meeting instead of two or perhaps you will need three meetings to take things this far in establishing a Council. It all depends on the level of interest and people's current capacity to commit time to the Council.



Q: In addition to assigning a staff person, how can the Long-Term Care Home assist in organizing a Family Council?

A: In addition to providing a staff person to assist, here are some ways that a Long-Term Care Home can help family members and friends of residents to organize a Family Council:

- Provide meeting space and donate refreshments.
- Educate staff and encourage them to help generate interest in the Family Council.
- Send out notices (e.g., in the Home's own mailings to family members, etc.).
- Dedicate a bulletin board to the Family Council.
- Accept that sometimes family members may choose to meet in private without staff present. Suggest this to them if they have not thought about it or requested it.

Anticipate Challenges and Be Prepared to Address Them

The following information appeared in the Family Council Handbook published by the Advocates for Care Reform in British Columbia. We have made minor modifications in light of the Ontario context.

Family members may face some challenges when trying to organize a Family Council. It is helpful to anticipate and expect these, so as to be prepared to address and deal with them.

The following challenges may arise:

- **Family members don't feel they have the time.**

Family members have jobs and children, and visiting also takes up their time.

A couple of hours once a month is all the time commitment needed to contribute to a successful Family Council. (Note: Holding an office/executive position/lead volunteer position, being involved in committee work and undertaking projects take more time, but participants can choose what roles they want to play and this may change over time depending on other commitments.)

Try to schedule meetings so that families don't need to make a separate trip to the Home to attend the meeting. For example, schedule the meeting for immediately after dinner so they can share a meal with their loved one and then go directly to the meeting.

- **Family members fear retaliation.**

Unfortunately, a common fear among some family members is that if they complain, staff at the Home will take it out on their loved one.

A Family Council provides a safe environment for families to voice their concerns and opinions. The Family Council is also much more than a complaint mechanism – it is an opportunity for family members to meet, share and exchange information, learn and support each other.

It is important to keep in mind that the most effective Family Councils emphasize collaboration with the Home and actively and purposefully encourage and support dialogue, i.e. two-way communication with the Home. Family Councils are beneficial for Homes too – through the Family Council, the Home has access to family members to provide them with important information, feedback and observations on issues and concerns.

- **Family members feel discouraged.**

Family members may be discouraged because they have tried to voice their concerns and nothing has been done.

The Family Council provides representation for family members as a group, and therefore facilitates the collective support and strength of the group as a whole.

- **Family members and Home staff lack information and understanding about Family Councils.**

Sometimes challenges arise because family members and Home staff are not informed and lack understanding about the role and benefits of a Family Council.

Family Councils Ontario can provide information and resources to help families and staff members understand and recognize the important role a Family Council can play in improving the quality of the care environment.

Not all administrations welcome input from families and there may be resistance from the Home to setting up a Family Council. Such resistance is often because the purpose and intention of the Family Council is not understood. It is important to work collaboratively with the Home in setting up the Family Council and to make sure that the Home has a clear understanding of the role and benefit of the Council in supporting and educating families.

These are just a few of the challenges that you may encounter in the early stages of forming a Family Council or even when the players change – for example, Home administration changes, new family members join the Council. Other challenges are described in “Chapter 4: Maintaining your Family Council.”



Anticipate Challenges

What are some of the challenges that we may experience?

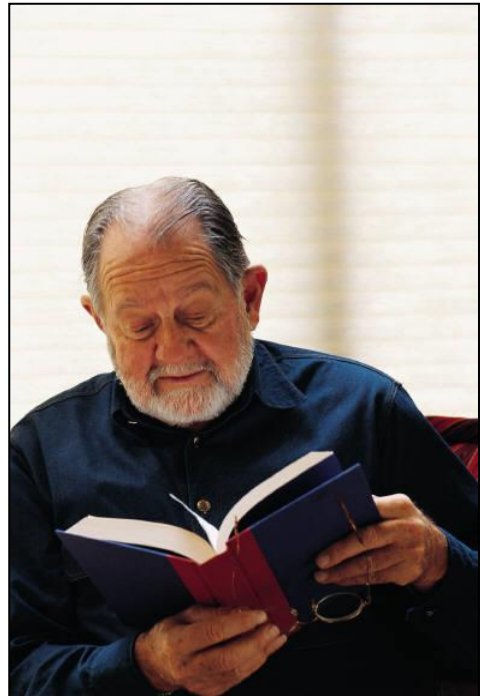
Make a list of the possible challenges that you may face.

What can we do to address each challenge?

Brainstorm what you can do if faced with a certain challenge.
Make a checklist of things to do.

What resources can we prepare to help us deal with each challenge?

Brainstorm who you can call on for help in dealing with an unexpected challenge.
Now that you have considered some of the possible challenges, you are well prepared to face the unknown.



Samples

Sample Meeting Invitation (1)

YOU ARE INVITED TO OUR FAMILY COUNCIL MEETING

Learn About Family Councils

For staff, family and friends interested in Family Councils

Monday March 22nd

7-9:30 pm

Meadows of Fairmont

523 Kalarand St

Niagara Falls

Topics include:

***Overview of Family Councils and What They Do**

***Strategies on Maintaining a Family Council**

***Recruitment Ideas**

Presenters are:

Mary Smith, Family Council Facilitator, and

Megan Doe, Family Councils Ontario

To reserve a spot or find out more information,
please call Joan Doe at 555-555-1234

Refreshments will be served!

Sample Meeting Invitation (2)

You are Cordially Invited To Attend:

Family Council Meeting



Wine & Cheese Party

Wednesday November 10th

7:00pm-8:00pm

❖ Meet Department Heads ❖

Get Information on Current Nursing
Home Issues/Happenings

❖ Assist Staff to
Problem Solve ❖
Voice Concerns, Give
Feedback & Make
Suggestions for Improvement



❖ Get Involved with Care Teams ❖
Let's Support Each Other to Provide Resident
Focused Care

Please RSVP to:

Sample Family Interest Survey (1)

FAMILY INTEREST SURVEY

1. Do you have a good understanding of what a Family Council is?

- ☐ Yes ☐ Somewhat
☐ Not at all

2. Have you attended Family Council meetings?

- ☐ No ☐ Once
☐ Occasionally ☐ Regularly

3. If you have not attended or do not attend regularly, why?

- ☐ No information on the Council ☐ Not interested
☐ Meeting day or time is not convenient ☐ Too busy

4. What is your preferred meeting time?

- ☐ Weekday ☐ Weekend
☐ Day meeting ☐ Evening meeting

5. Check topics or projects that interest you.

- ☐ *Learning about the long-term health care system including:*
☐ Standards and Regulations ☐ Legislative Issues
☐ Compliance System ☐ Funding
☐ Home Inspection or Survey
☐ Other _____

Learning more about the operation of the Home including:

- ☐ Administration ☐ Policies and Procedures
☐ Nursing care ☐ Dietary and food service
☐ Physician services ☐ Social Service
☐ Pharmacy services ☐ Security
☐ Activities ☐ Rates of Care
☐ Other _____

Providing special activities or services for residents including:

- ☐ Visiting residents without families
☐ Joint resident and family activities and events

- ☐ Opportunities to share concerns and ideas with other families
- ☐ Working with other families to give input on policies, procedures, problems and solutions
- ☐ Participating in a welcoming committee that supports the families of new residents
- ☐ Other _____

6. Are there any improvements or changes that you would like to see in this Home? If yes, please list the improvement(s) or change(s) you would like to see.

- ☐ Yes ☐ No

Family Council Membership

If you would like to be a member of the Family Council, please provide your name and telephone number and/or email address. A Family Council member will contact you!

Name: _____

Telephone Number _____

Email Address (if applicable) _____

Please give this completed Interest Survey to the Family Council Staff Assistant _____.

Sample Family Interest Survey (2)

INTEREST SURVEY

1. Do you have a good idea of what a Family Council is?
 - ☐ Yes
 - ☐ Somewhat
 - ☐ Not at all
2. Have you attended Family Council meetings?
 - ☐ No
 - ☐ Once
 - ☐ Occasionally
 - ☐ Regularly
3. If you have not attended or do not attend regularly, why?
 - ☐ No information on the Council
 - ☐ Not interested
 - ☐ Meeting day or time not convenient
 - ☐ Too busy
 - ☐ Other: _____
4. What is your preferred meeting time?
 - ☐ Weekday
 - ☐ Weekend
 - ☐ Day Meeting
 - ☐ Evening Meeting
5. Check topics or projects that interest you
 - A. Learning about the Long-Term Care system
 - ☐ Standards and regulations
 - ☐ Legislative issues
 - ☐ Compliance system
 - ☐ Funding
 - ☐ Home inspection or survey
 - ☐ Other
 - B. Learning more about the operation of the Home
 - ☐ Administration
 - ☐ Policies and procedures
 - ☐ Nursing care
 - ☐ Dietary and food service
 - ☐ Physician's services

- ☐ Social services
- ☐ Pharmacy services
- ☐ Security
- ☐ Activities
- ☐ Rates of care
- ☐ Other

C. Providing special activities or services for residents

- ☐ Visiting residents without families
- ☐ Joint resident and family activities and events
- ☐ Opportunities to share concerns and ideas with other families
- ☐ Working with other families to give input on policies, procedures, problems and solutions
- ☐ Participating in a Welcoming Committee that supports the families of new residents
- ☐ Other

6. Are there any improvements or changes that you would like to see in this Home? If yes, please list the improvement(s) or change(s) you would like to see.

- ☐ Yes ☐ No

7. Please think about what you see and what happens when you or family members visit your family member or a resident at [name of Long-Term Care Home]?

a. What are the things staff do that you like?

b. What are things that you wish staff would do?

Chapter 4: Maintaining Your Family Council



Introduction

This chapter discusses moving from an informal structure (your initial planning group) to a more formal one (a full-fledged Family Council – no matter what size) and what you need to consider in order to maintain your Family Council over time. Major sections focus on:

- Family Councils as groups, with group dynamics
- That first official meeting as a Family Council
- Developing a formal Terms of Reference and a Code of Conduct
- The roles and responsibilities of various Council members
- Running effective meetings
- Recruitment – the ongoing process of renewing your Council
- Promoting diversity
- Overall effectiveness in processing concerns and in making sure the Council runs smoothly
- Regional networking meetings

A Family Council is a Group

Maintaining the Group is Primary

As noted in "Chapter 3: Getting Started," a Family Council is a group with some specific characteristics. These are repeated in the text box, right, for reference.

A Family Council is a family-led peer support/mutual aid group. A peer support/mutual aid group has a few special characteristics:

- Members share a common situation or experience.
- The group is self-governing and self-supporting.
- There is strong emphasis on solidarity and equality.
- The group emphasizes fellowship and face to face contact.
- Members encourage and support one another.
- The process of maintaining the group is primary.

A Family Council is a Group

A Family Council is a collection of people with all of the following characteristics:

- Come together regularly
- Interact with one another
- Share a sense of belonging or purpose
- Have common goals and objectives that include improving the quality of life of all residents in the Long-Term Care Home and giving families a voice in decisions that affect them and their loved ones in the Home
- Have some structure, rules and methods of operation.





Being aware of the stages that a group will experience is important to maintaining the group.

Stages of a Group

Stage 1: Forming

Characteristics: High numbers, nervous leaders, silent members, people leaving early, people who come once and then not again.

Consider: Be clear about your goals and guidelines. Keep Calm. Don't push.

Stage 2: Storming

Characteristics: Fewer people, members not quite ready to make a full commitment, conflict, power struggles.

Consider: Make sure everyone has a chance to speak. Stick to the agenda. Set time aside to discuss tensions/conflicts.

Stage 3: Norming

Characteristics: Fewer people, members coming regularly, more commitment, readiness to volunteer, lots of talk, sense of trust, ease, lots of laughter.

Consider: Share the work. Do an evaluation. Congratulate yourselves!

Stage 4: Performing

Characteristics: The group is working well together, demonstrates effective problem-solving and decision-making skills, flexibility in roles and good resolution of conflicts.

Consider: Set realistic goals. Do not take on too much work. Take time to celebrate accomplishments.

Stage 5: Recycling

Characteristics: Some members may leave because of the loss of their loved on or they may rethink their commitment to the process.

Consider: Keep calm. This is an inevitable and natural stage and, as members leave, it is important that the Council has an ongoing recruitment plan in place. Have a discussion about what it feels like. Celebrate what you have gained. Breathe. Say goodbye... you are about to reinvent yourselves.

This information about group process was provided by the Self-Help Resource Centre, <http://www.selfhelp.on.ca>, (416) 487-4355, toll-free 1-888-283-8806.

A Family Council is an Organization

A Family Council is not just any group. It is a group of volunteers organized in a particular way. While recognizing that there are many variations among Family Councils, there are some common organizing elements that we suggest are important for all Councils. How many elements pertain to your Family Council?

✓ A Collective Identity Rooted in a Common Focus

Do Council members have a sense of a common identity?

Everyone in a specific Family Council has a loved one who has been living in the same Long-Term Care Home. All members are focused on improving the well being of their loved ones and supporting each other. This is what brings members together to agree on collective activities and actions. In this way, Family Council members have a collective identity that is rooted in a shared experience and a common focus.

✓ A Mission or Purpose Statement

Does your Council have a written purpose statement that captures this collective identity and common focus? Have members agreed on the statement and set up a system to ensure that they will review it periodically?

✓ Common Goals

Have family members agreed on specific actions that they want to take – actions (or projects) that they feel can make a difference in the quality of life for their loved ones, or support families or staff in the Home?

✓ Ways to Communicate and Share Information

Do new family members know about the Family Council? Do they know who they can call or contact about upcoming meetings and Council projects? Members can communicate with each other and other families/friends of residents through the Home's newsletter, a Council newsletter and posted minutes.

✓ Structures and Processes Support Continuity

Does your Council have a written Terms of Reference that makes it clear:

- who can be a Council member
- how long people can be Council members (e.g., whether people can stay involved after their relative in Home moves on or dies)?

Do you have a recruitment process and plans that will assure continuity when members leave?



See more about recruitment later in this chapter.

Things to Think About at Your First Family Council Meeting

You are now past the “getting started” stage discussed in Chapter 3. It’s time for your first official Family Council meeting. Here are some ideas for what to include on your agenda.

- Have a ‘meet and greet’ (e.g. ice-breakers). Get to know each other and learn about the family members’ loved ones in the Home.
- Discuss the ultimate purpose/goals of the Family Council- why do you need a Family Council, what do you want the Family Council to accomplish?
- Discuss developing a Terms of Reference and provide samples.
- Discuss the type of structure that the family members want for the Family Council (role of staff, roles and responsibilities for Family Council members, leadership, representatives for each Home’s area).
- Think about how the Family Council will communicate with others who are not able to attend the meetings- newsletters, bulletin board, word of mouth, welcome tea, etc.
- Discuss who will develop the agendas and ensure that every agenda is multifaceted in order to promote positive meetings.
- Identify who will produce a summary or minutes of the meetings and post or distribute the summaries to families who could not attend the meeting.
- Review activities that the Family Council would like to work on and choose a project to concentrate your efforts on over the course of the next few meetings.
- Discuss times that work well or not for holding meetings.



Developing a Formal Terms of Reference

What is a “Terms of Reference?”

A Terms of Reference typically describes the basic purpose of a Family Council, its structure and operating procedures.

Why is a Terms of Reference important?

A Terms of Reference is a way of communicating what a Council does:

- To its members
- To people outside the Council who may have an interest in its activities (e.g., the Home’s resident’s Council, Long-Term Care Home administration and staff)

Family Council Membership

A Family Council is a self-led, autonomous, group. A Family Council develops its own Terms of Reference, including who may be a member. The Council may set provisions within its Terms of Reference for continuing the membership of a Family Council member who no longer has a family member/friend who is a resident in that home.

A Terms of Reference helps a Council ensure fairness and accountability. For example:

- Specifying who may join a Council and how membership works
- Establishing how a Council selects its leaders ("officers" or lead volunteers)
- Describing how often elections of officers/lead volunteers will be held. Without this, some officers/lead volunteers may end up serving indefinitely without the support of the full Council.

Research on the development of Family Councils indicates that one of the most important aspects of a successful Council is structure and direction. This is what a Terms of Reference provides. A Council that lacks structure and direction often fails despite the good intentions of everyone involved.

When is it Best to Develop a Terms of Reference?

Once you have a small group of people who want to be involved in a Family Council, you need to have a Terms of Reference to help bring organization to the group.

You may hammer out a preliminary Terms of Reference among your initial planning team (see "Chapter 3: Getting Started"). However, you will want to ensure that others who join the Council in its early stages are involved in the process and that everyone has some ownership of the Terms of Reference. This will help you build the best foundation for moving forward.

Ultimately, your group should vote on the Terms of Reference as a way of signalling that you have agreed on a common purpose and how you are going to work together.

A Terms of Reference can be amended as the needs of the Family Council change. In fact it is a good idea to review your Terms of Reference on an annual basis.

Sections in a Terms of Reference

Typical headings in a Terms of Reference are:

- Purpose or mission
- Goals
- Membership
- Officers/lead volunteers and their duties (e.g. chairing the meeting, taking notes etc...)
- Elections
- Meetings
- Amendments

As noted in "Chapter 2: What is a Family Council?", the main purpose of a Family Council is to improve the quality of life of residents and to give families and friends a forum for sharing their experiences, supporting each other, learning and exchanging information.

This means that, while the wording of specific Family Council mission or purpose statements may vary, many tend to be similar in focus. For example, regardless of the type of Home, its location or size, most Family Council mission statements identify all family members and friends as members, address the difficulties that many families encounter in the Long-Term Care environment, and are committed to monitoring and increasing the well-being of the residents.

Developing a Code of Conduct

What is a Code of Conduct?

Establishing group rules can be important to making sure that groups run smoothly and ensuring that conflict is minimized.

Individual actions and behaviours of Family Council members can reflect on the Council as a whole. A "Code of Conduct" can help a Council determine how members, collectively and individually, wish to act and be represented in the Home.



A Code of Conduct outlines the criteria for an effective Family Council member and what types of behaviour are/are not conducive. For example, issues such as respect for residents, staff, visitors and volunteers and confidentiality may be included. A Code of Conduct may describe when Family Council members should advocate on behalf of residents. Avoiding gossip may be addressed in the Code of Conduct. In addition, a Code of Conduct may extend to how meetings operate and what types of behaviours/actions are expected at meetings.

Drafting a Code of Conduct

It is recommended that the Code of Conduct be a collaborative effort and reviewed on a regular basis, or when Council needs change. A variety of items can be included. As each Council is unique, Codes of Conduct will vary.

We suggest that each Council member be provided with the Code of Conduct. This will help to ensure that the Council as a whole and all members abide by the Code.



See sample Codes of Conduct the end of this chapter.





Tips and Ideas

Confidentiality in Peer Support (Self-Help) Support Groups

Adapted from A Fact Sheet from the Self-Help Resource Centre – www.selfhelp.on.ca

Here is what some people have said about confidentiality in groups:

- “Generally speaking, confidentiality means never discussing, without direct consent, the circumstances of another group member.”
- (Self-Help Mutual Aid Facilitator Training, Ministry of Social Services, Government of B. C.)
- “What you see here, what you hear here, when you leave here, let it stay here!”
(Dreamcatchers peer support group pamphlet)

What is confidentiality?

Technically speaking, confidentiality means we do not share any information or stories with others. However, many groups decide that members may talk about what they heard or learned in the group, as long as no identifying information is shared. This means nothing about name, family members, address, etc. is shared.

It is very important that each group member respects general agreements about confidentiality and anonymity. Confidence is defined in the dictionary as “a state of trust.”

Why is confidentiality so important?

Personal sharing is important to peer support/mutual aid. An environment of trust and safety allows group members to share more deeply with others.

People must feel that information will be kept confidential before they can safely share their stories. Some groups describe confidentiality as the anchor of mutual support.

By creating and maintaining trust with each other, we can share and support more deeply.

Two exceptions you should know about:

There are two exceptions where you must report information by law. You should make sure that group members understand these exceptions.

1. If you suspect that a child is or may be in need of protection.
2. If someone declares a plan to harm him/herself or another adult.

Besides the two exceptions, the only time you can change a commitment to confidentiality is if you ask and talk directly with the person concerned.

What does my group need to do about confidentiality?

Confidentiality is both a commitment and a skill. To gain people's commitment, discuss the specific needs of each group member. Then decide on shared rules for your group.

To be sure everyone is clear, (especially newcomers) you can:

- Read out a statement at the beginning of each meeting
- Ask people if they have questions or concerns about the group's current confidentiality agreements.
- Give examples of a common situation where confidentiality needs to be practiced (e.g. meeting a group member at a public event)
- Use rituals which remind members about their commitment

To support group member's skills in practicing confidentiality you can:

- Talk about case studies or group members' experiences
- Try role playing difficult situations

Developing Realistic Goals

Well-organized groups are able to offer potential members a “road map” of where they are going, why they should make the trip and who will help them get there.

A Family Council cannot maintain itself until it has its own “road map” in place.

Just as many Family Councils have similar mission statements, many have similar goals. We have identified four common goals below:

Support

Support is broadly defined by Family Councils. While some Family Councils place greater emphasis than others on the supportive function of their Council, many Family Councils support their members, the residents and the staff. Others may focus on projects or activities to benefit the residents, family members or staff. It is important to choose projects that are achievable and not to take on too many projects at one time. Often, families will state that they feel supported merely by seeing another family member sitting across from them at the Council meeting.

Examples:

A Family Council welcomes new families to the Home.

A Family Council sends sympathy cards to families whose residents have died.

A Family Council organizes staff appreciation events to recognize staff on all shifts.

A Family Council asks the Residents' Council what the residents need.

Communication

A Family Council assists in facilitating and enhancing communication between families, staff and residents.

Examples:

Family Councils can invite management to their meetings to explain their role and how they address problems.

Family Councils can develop a newsletter where they explain their function, projects they are working on etc.

A Family Council member sits on the dietary committee in order to relay residents' dietary needs.

Education

The Family Council provides a forum for discussing relevant issues. Family Councils receive information directly from the administration, staff and guest speakers. Council members also learn from each other.

Examples:

A Family Council and its staff assistant work effectively together, sharing information and providing assistance as needed.

A Family Council invites the Ministry of Health and Long-Term Care compliance advisor assigned to the Home to its Family Council meeting to talk about issues in Long-Term Care.

A Family Council invites the Home's new director of care (DOC) to its meeting for introductions and to familiarize the director with the Council's mission.

Advocacy

According to Webster's Dictionary, an advocate is “one who pleads another's cause.” Family Councils advocate on behalf of ALL residents.

Examples:

A Family Council addressed the issue of staff food being left at nursing stations. This was a safety hazard for residents with cognitive impairments who are on special diets and for those who are in danger of choking.

A Family Council informed and worked with the staff to reduce the number of bedpans and urinals being left out in residents' rooms.

Residents with hearing impairments were limited in activities and sensory stimulation. A Family Council successfully advocated for the installation of closed captioned television services for these residents.

Council Leadership: Roles and Responsibilities

Family led Councils are important to the effective operation of Family Councils. Councils that are not Family led are missing a major opportunity to become self-determining. As mentioned before, many family members will not speak freely in staff-run meetings. Surveys and experience have shown that staff-run Councils are, on the whole, less active and less attended than family-run Councils; as well, staff-run Councils deny families direct responsibility for the work of their Councils.

In the case of a new Council, you may want to consider various leadership models including shared leadership, leadership by committee and elected positions. If you choose to elect Council leaders, elections should be held regularly thereafter, as specified in the Council's Terms of Reference.

Leadership Models

A Family Council can function in a democratic way without electing officers, if it prefers another system of leadership. Some Councils choose leadership by committee.

Volunteers

In many newly-organized or small Councils, the choices of willing leaders are limited. Members with more experience may volunteer to be officers until all members know each other well enough to choose a leadership model.

Shared Offices

Sometimes Council members are hesitant to accept particular roles, but may be willing to share the role with another member.

Two Council members may choose to share the role of Chair and share the responsibility of facilitating meetings, coordinating activities and communicating with the Home's Administrator or staff assistant. Or for example, in one Family Council, a mother and daughter share the office of secretary and take turns performing the duties involved.

Leadership by Committee/Shared Council Leadership

Many Councils choose this plan. Often Councils have difficulty recruiting leaders because members fear that too much work will be involved. A committee or shared leadership model can be used to share responsibilities in creative ways, thereby easing members' fears and distributing work more widely. The following are examples of shared Council leadership positions. They can be adapted to the needs of each individual Council. In a small Council, each member might be given a role in the leadership structure.

| Example of Shared Council Leadership | | |
|--------------------------------------|---|---|
| Position | Duties During Meetings | Duties Between Meetings |
| Meeting Volunteer | Leads meeting according to the planned agenda. Facilitates discussion so all have a chance to be heard. Ensures Council procedures are followed (voting on decisions, etc.). Recognizes the efforts of others. | Draws up the next meeting agenda. Communicates with the staff assistant and other Long-Term Care Home staff as needed. Coordinates the work of other members by seeing that needed tasks are being done and making suggestions when problems arise. |
| Records Volunteer | Takes notes or tapes the meeting for minutes. Reads the minutes from the previous meeting. | Writes or types minutes from notes or tapes. Handles Council correspondence. |
| Communications Volunteer | Reports on any news from the Home, other Councils, Family Councils Ontario, the legislature, the Advocacy Center, etc. Distributes printed information on matters of importance to members. | Posts or distributes minutes and notices of future meetings. Maintains the Council bulletin board and/or newsletter column. |
| Welcoming Volunteer | Introduces new families and anyone attending a first meeting. Reports on welcoming/orientation efforts. | Obtains information on new residents or families from the Home (if possible). Chairs the welcoming or orientation committee. |
| Program Volunteer | Reports on future meetings (dates, times, speakers, etc.). | Arranges for speakers, films, etc., on topics chosen by the Council. |
| Outreach Volunteer | Presents concerns and suggestions from members not present. Reports on progress made in dealing with past concerns. | Coordinates efforts to increase participation in the Council. Responds to concerns/ requests for information on the Council. |

Traditional Officer Positions

Some Family Councils hesitate to elect leaders/officers. Many family members are reluctant to serve as officers because of their lack of experience or time. Having a clear understanding of the duties included in various officer positions can help alleviate these concerns. Your Council may choose to adopt the roles and duties as laid out below, alter them to suit the needs of the Council or choose another leadership model.

Chairperson/President

Presides over Family Council meetings. This includes:

- Setting up the agenda in advance of each meeting and seeing that it is followed. Agendas are discussed in detail in Part Three, Chapter Sixteen.
- Possessing knowledge of the Council's Terms of Reference and Code of Conduct, and seeing that they are followed.

- Keeping control of meetings by maintaining order, discouraging repetitious discussion, and moving ahead with the business of the meeting when momentum lags.
- Maintaining impartiality. It is the chairperson's duty to see that all sides of an issue receive a fair hearing. His/her influence should not be used to promote personal opinions.

Coordinates Council activities and programs

- Coordination is necessary if a Council is to function as an effective, smooth-running whole. A wise chairperson will direct his/her efforts toward getting as many members as possible involved in the work of the Council and keeping in touch with members who have accepted tasks to determine if the work is being done. It is a mistake for leaders to do everything themselves.

Maintains communication with staff/administration

The chairperson and other leaders represent all families and should maintain open communication with administration and staff in order to convey the interests of family members.

Vice-Chairperson

The traditional duty of a vice-chairperson is to fill in for the chairperson. If your Council elects a vice-chairperson, you may wish to determine what duties the office will entail.

Secretary

The secretary is usually responsible for taking notes at meetings, recording and maintaining a file of meeting minutes, maintaining Council correspondence, and having the Terms of Reference and Code of Conduct handy in case of questions. The secretary may also conduct meetings in the absence of the chairperson and the vice-chairperson.

In some Councils, the secretary is responsible for notifying families of upcoming meetings. However, other members could be assigned this task.

The secretary may also write thank-you notes to speakers, financial supporters and others who donate their services to the Council.

Holding an Election

Elections should be well planned. The process usually takes more than one meeting as several steps are involved.

Families should receive advance notice of the upcoming nominations and election. The notices should clearly state how a family member can participate in the process. If possible, all families – not just active Council members – should be notified.

A **nominating committee** can be used to gather and present nominations to the Council. If a committee is used, Council members should be told how to present their nominations to the committee. If a committee is not used, part of a Council meeting can be set aside for receiving nominations. This should be done at least a month before elections are held.

If possible, the list of nominees should be distributed to Council members before the election, so they can consider the choices.

Elections should be by secret ballot at a meeting of the full Council.



There should be an orderly system for transferring leadership from old to new officers. The contributions of outgoing officers should be recognized.

Electing officers at regular intervals is a way to rotate leadership positions among members and to prevent leaders from becoming burned out.



Some Final Tips for Developing a Terms of Reference

- ✓ Each Family Council is unique and Terms of Reference should be tailored to fit the individual Council. If you are starting from a sample Terms of Reference, include only those items that are appropriate for your Council and consider if you need to add any items.
- ✓ Give all current members an opportunity to be involved in developing the Terms of Reference (e.g., group brainstorming) to promote ownership among all Council members.
- ✓ Keep the language clear and simple. Terms of Reference are of little use if Council members do not understand them.
- ✓ Each section or item in the Terms of Reference should be concerned with only one idea – e.g., membership, officers/lead volunteer roles, Council member conduct.
- ✓ When considering the appropriate structure for your Family Council (i.e., number of officers and committees if any), think about the size, style and needs of the families and their residents living in the Home. Think about the goals you have set and the projects that you want to undertake.
- ✓ Include how often the Terms of Reference should be revisited by the Council e.g. annually, bi-annually. It is important to review the Terms of Reference on a regular basis in order to ensure that it reflects the current needs and structure of the Family Council.
- ✓ Always include instructions for making future amendments to the Terms of Reference: The Terms of Reference should indicate who can originate proposed amendments, how it is done, what kind of approval is needed for ratification (majority of members, two-thirds, etc.) and the effective date of new amendments (immediately, one month, etc.).
- ✓ After the Terms of Reference are drafted, give members plenty of time to review the draft and suggest amendments before finalizing it and voting on it.



See sample Terms of Reference at the end of this chapter.

Who Needs to See our Terms of Reference?

Each member should receive a copy. Post them if you can.

New members should be given a copy. Ideally, you should give new members an opportunity to review the Terms of Reference with another experienced Council member so that they can ask questions and clarify anything that is confusing before they attend a Council meeting.

The Terms of Reference should also be given to the Home's administrator and the Council's staff assistant. This is important to maintaining a positive working relationship between the Council and the Home.

Running Effective Meetings

Well-planned and well-run meetings will go a long way towards the success of your Family Council! If meetings are not run effectively, members may not continue to attend. Plus, it may be difficult to recruit new members if meetings are viewed as a "waste of time."

Each Council is different and has different needs, but these tips can help you to successfully plan, execute and follow up on your meetings.

Planning for the Meeting

1. Determine the objective of the meeting. Every meeting should have a clear purpose, for example learning about funding for Long-Term Care Homes or discussing concerns about food choices. Meetings that are vague and that have no clear purpose will be frustrating to members and will discourage attendance. Keep in mind that part of the purpose of the meeting will usually include new business and new concerns.
2. Prepare the agenda for the meeting. An agenda will provide the chair/meeting volunteer and members with a structure and time limits for the meeting, and it will help the group to focus on the important issues. Consistently well planned agendas will increase attendance at meetings. Post or otherwise share the agenda at the Home/with the members a week before the meeting, where possible.

Ideas for creating good agendas:

- Highlight special events, such as guest speakers or educational presentations.
- Organize topics in terms of new and old business. Old business may include follow-up on previous concerns, projects, ideas and successes, whereas new business may include new concerns, projects, and ideas.
- For each item on the agenda, indicate the person responsible (where necessary) and the time to be allotted.
- Don't use the exact same agenda for every meeting — make it specific to each meeting so that the content to be discussed is clearly reflected.
- Put the most important information in the middle of the agenda since that's when most people will be at the meeting.
- The last item on the agenda should be positive so that the meeting will end on a high note. Success stories or inspirational quotes work well.
- Allow some time for free conversation. This will allow people to voice concerns, gain support and share information — set a specific time limit for this session in order to keep the meeting on track and maintain structure. For example:
 - Use a flip chart to write down ideas and then refer back to them for discussion

- Hand out index cards and ask people to list up to three main areas of concern or interest and then compile a group list
 - Set a time limit for each person
3. Review minutes from the previous meeting; these will serve as a guide for planning the meeting. Minutes remind you what items were postponed from the last meeting and what work should have been accomplished between meetings and should be reported on. Make sure to follow up on any items that were postponed or any questions that were not answered.

Setting Up the Meeting

1. Set the time, date and place of the meeting. If possible, standardize the time and place so that members can establish a routine. Try to keep the meeting time limited to 1 to 2 hours.
2. Get people to come to the meeting. Ways to do this include:
 - Talk to people directly: The most effective way to increase attendance is through face-to-face contact.
 - Talk about Council meetings to other families. Pass along stories of success, accomplishments and the support gained through the Family Council.
 - Hand out flyers announcing your next meeting when you visit.
 - Ask each member to bring another family to the next meeting.
 - Make reminder phone calls or send e-mail messages to people who attended previous meetings.
 - Send a mailing, and post flyers at the Home.
 - Try to make flyers as eye-catching as possible, and list the specific issues to be addressed or guest speakers that will be attending.
3. Reserve a meeting room
 - Discuss the amount of meeting space needed.
 - Choose space that meets the needs of the group.
 - Arrange for appropriate equipment – e.g., a podium for speakers, a TV or DVD player, a projector, etc.
 - Arrange chairs in the meeting room so that everyone will be able to see, hear and pick up materials.
4. Make copies of the agenda and any other materials for distribution at the meeting. Designate a person to hand out material and provide direction to latecomers so there is minimal disruption to the meeting.
5. Prepare a sign-in sheet. Get names, addresses, phone numbers, and email addresses (if applicable). Sign-in sheets are helpful in establishing quorum and for looking at trends that can help signal recruitment needs.



See a sample meeting sign-in sheet at the end of this chapter.

6. Arrange for refreshments (including water for speakers).
 - People will be more likely to stay after the meeting to socialize if there are refreshments available.
 - Time to socialize is an important way for members to get to know each other and develop a sense of commitment to the group.
7. Assign roles and tasks for the meeting; for example facilitator, minute taker, sign-in person, material hand-out person, time keeper etc. These roles can be static or rotated among members.

A Note About Meeting Minutes

Taking minutes should not be an unpleasant task. Many people make it harder than it is. The minute taker should simply summarize each important point in one or two sentences, rather than recording all the details of the discussion. Make sure to include topics discussed, questions raised, actions taken/to be taken and any decisions made. Minutes should keep the Council on track in terms of what has been done and what needs to be done.

Good minutes will:

- Give information about each issue/topic discussed and what actions were proposed
- Track resolved and unresolved business
- Document accountability (who agreed to do what by when)
- Fill in members who missed meetings
- Provide a guide for future agendas

Caution: Maintaining Confidentiality is Important

Your Council will likely want to circulate meeting minutes to Council members and Home staff. Ensure that the minutes do not detail who said what. Be aware of confidentiality issues.

Options for dealing with this issue are:

- Omit the names of Council members attending, indicating the number of members attending only.
- Identify the officers of the Council by name and then indicate that other members attended to make up quorum.
- Maintain two separate sets of minutes (this can be challenging!): one for Family Council members that identify assignments, etc. and one for broader circulation.

Some Councils do use sign in sheets and these are kept only for Council purposes. (See the discussion of sign-in sheets earlier in this chapter and a sample sign-in sheet at the end of this chapter).



Also take a look at the Fact Sheet on Confidentiality in Peer Support Groups prepared by the Self-Help Resource Centre at <http://www.selfhelp.on.ca/resource/factsheetonconfidentiality.pdf>. This has been included as a resource related to “Developing a Code of Conduct,” which appears later in this chapter.

Role of the Facilitator/Chair/Meeting Volunteer

Keeping the Group on Task:

- Start and end the meeting on time if possible. Don't start the meeting more than 10 minutes late.
- Be firm about sticking to the agenda. Members will appreciate a meeting that stays on task and doesn't waste their time. When members raise issues not on the agenda, address it during time allotted for new business or, if not possible, assure them that their concern will be addressed at a future meeting.
- Periodically do a time check to remind members how much time is left and what still needs to be covered.
- Stick to time frames estimated on the agenda but don't be a tyrant. If a discussion takes longer than anticipated, the group can vote to postpone other items on the agenda until the next meeting or go past the allotted time.

Setting a Positive Tone and Creating an Atmosphere of Respect:

- Model the kind of positive, involved attitude you want members to have.
- Project enthusiasm! Keep everyone in a productive, positive frame of mind "We have a great list of possible projects here, so let's move on to talk about priorities."
- Avoid expressing hopelessness, discouragement, or disappointment about attendance. Never start off by saying "Where is everyone?" Thank everyone for coming and celebrate your turnout, no matter how small or large.
- Refer to past successes the Council has had or to successes of other Councils as a way to establish a hopeful, excited tone. See Chapter 2 page 13 or the *Family Councils Ontario Newsletter* for ideas and stories to share.
- Members will only speak up if they believe they will be treated respectfully and their ideas will be given genuine consideration – it's everyone's job to create and maintain that atmosphere with the facilitator/chair/meeting volunteer taking the lead.
- Encourage members to speak to speak to each other with respect, and intervene when someone is disrespectful.
- Agree to disagree respectfully - "I don't agree with you Mr. X. Here's how I see it..."
- Eliciting Input from Members:
 - The job of the facilitator/chair/meeting volunteer is to draw as many people as possible into the discussion, not to monopolize the discussion or impose your ideas. Put personal feelings aside and function in the interests of the entire group.
 - Compliment people for good ideas; let them know their input is valued and desired.
 - Try to draw people in who are quiet, especially if they look like they have something they want to say. Ask for input from people who haven't spoken before getting second comments from those who have already spoken. "We'd like to hear from everyone. Would anyone who hasn't spoken yet like to comment?"
 - Make sure everyone has a chance to be heard. Set limits when someone is talking too much or taking up too much time.
 - Periodically summarize what's already been said and ask for additional input - "We have three ideas for involving new families. Does anyone have any others?"

Some More Ideas about Encouraging Input from Family Council Members

- ✓ Ask people to list three concerns on an index card and compile a group list.
- ✓ Use a flip chart to list shared concerns during brainstorming sessions.
- ✓ Appoint a time-keeper: ask each person to limit their comments to a certain number of minutes.

- Don't put anyone on the spot. Some people may prefer to listen to what the rest of the group has to say, and may contribute more over time. Calling on people by name when they have not indicated that they would like to speak can make people uncomfortable.
 - Make everyone welcome. For latecomers, make a brief summary to bring them up to date. "Welcome, thank you for joining us. We were just talking about..."
- Guiding the Group Toward Decision Making:
 - It's your job to help the group move towards accomplishing the objectives of the meeting. Keep everyone on track by following the agenda and setting time limits when necessary.
 - The process for making decisions should be formalized in the Terms of Reference to avoid confusion and controversy about proper procedure.
 - Make sure the issue is explained clearly, everyone has had the opportunity to express opinions, and members understand consequences before a decision is made.
 - Don't allow debate to continue endlessly; when it becomes repetitive seek closure and move to a vote.
- Encouraging Members to Take Action:
 - Turn complaints into action by breaking down issues into small, manageable tasks.
 - At each meeting have a list of tasks that need to be done. During the meeting assign tasks to people who have an interest in the issue. "Thanks for bringing that issue to light Mrs. X. Since you are concerned about residents receiving their snacks, could you gather more information about dietary needs and the current situation so that the Council can review it at the next meeting?"
 - Ask what skills individual members have and match up skills to needs of the Council.
 - Give people small tasks to complete and report back on at the next meeting. "Before the next meeting can everyone pass out 4 flyers for the next meeting?" People are more likely to attend meetings when they feel they have something to contribute.
 - Don't do it all yourself! In order to be an effective group, you have to draw on the skills and input of as many people as possible. Sometimes it may seem easier to "just do it all yourself" but in the long run that won't build an effective Family Council.



Evaluating the Meeting

- Evaluate group satisfaction:
 - Effective meetings that feel productive to members are essential for Family Council success. Do periodic formal evaluations (i.e. a survey).
 - Do ongoing, informal evaluations by asking for feedback from members. Ask how useful they think meetings are, ask for suggestions for improving meetings, and implement their suggestions.
 - Take complaints about meetings being "a waste of time" or "never seriously accomplishing anything" or "not dealing with the important issues" seriously. Never dismiss a complaint as unfounded until you have carefully considered it.

Tasks for After the Meeting

- Follow up after the meeting, for example by:
 - Sending thank you notes to appropriate person, i.e. speakers, meeting hosts, etc.
 - Following up discussions/decisions with any necessary letters and phone calls.
 - Preparing and distributing minutes.
 - Planning for the next meeting.

Ongoing Recruitment

Along with a written Terms of Reference (described above) and staff support (addressed in "Chapter 5: The Role of Staff"), a recruitment plan is essential to building a strong foundation for your Family Council.

Recruitment is an ongoing process and a specific recruitment activity/initiative should be scheduled on a regular basis.

Assemble a Team

A successful recruitment plan will require more than one person's time and talents. The team should include staff and family members who have time and energy to give to the project. The team's responsibilities:

- Help identify potential members
- Plan the recruiting meeting or event
- Carry out the publicity campaign
- Spread the message of the Family Council's potential to improve the quality of life for residents

Shape your Recruiting Efforts Around the Needs of the Targeted Audience

Do you want to attract new family members? Sponsor a newcomer's tea or social hour to introduce staff and Family Council members.

Do some family members live close to the Home but have chosen not to attend meetings? Try sponsoring a question and answer meeting with the administrator – something special that might attract this group.

Plan your Publicity Campaign

Articles in the Home's newsletter, brochures in the lobby, posters in several locations, invitations by mail, and reminder notices in the local newspaper are all possibilities for publicizing the Family Council and recruiting new members.

However, **nothing is more effective than a personal invitation**. Remember the number one reason people volunteer: They were asked! Try to get a commitment from each active member to invite at least one other person to the Council meeting.

A recruiting event is your opportunity to make people want to join the Family Council. Make sure everyone feels welcome and important. Start the meeting on time. The meeting agenda and program should give people a chance to learn and to share ideas and insights. End the meeting on time. Socialize! (A hint: The best times to recruit are in September and January.)

Planning for growth is a large task for any organization. Believing in the Family Council's potential to improve the quality of life for residents, and knowing what other Councils have accomplished will make every effort worthwhile.



Promotion and Recruitment Tips

Remember, people will avoid attending meetings because they don't know about them or they don't understand what a Family Council is so educate, educate, educate!

1. Offer topics that would interest new families:

Education and information topics will interest new families

For ideas on topics, brainstorm within your Family Council, ask local Family Councils or contact Family Councils Ontario

2. Prepare a welcoming letter to be included in information given to each new family. The letter could contain:

Welcoming section

Definition of a Family Council

Benefits of a Family Council

Activities the Family Council is working on

Name and phone number of a Family Council member who can be contacted for help or more information

The website or e-mail address for the Family Council

An offer to accompany the new family to the first meeting

Provide a context for people to understand the need for Family Councils by making reference to demographic statistics that emphasize the aging population and the need for families to advocate for their family members who reside in Long-Term Care Homes

Describe the purpose of a Family Council and the roles they play in a Long-Term Care Home

Identify issues that are important to family members and how Family Councils address those various issues

Emphasize that Family Councils understand the concerns that families have and can help them by providing education and mutual support

Include details on how they can become involved with the Family Council (attend family nights, welcome teas, contact current members)

3. Invite new members to your meeting in ways that would make them feel most welcome:

Mention new members in your promotional materials. For example, "New members are always welcome. Please join us at our next meeting!"

Give personal invitations by phone, in person, or by letter. (Staff can ask family members for written permission to give their phone number to the Family Council for follow-up. Ask Family Councils Ontario for more information about developing contact forms.)

Establish a "designated host" system

Sponsor a new family tea or social hour

Give newcomers a meal ticket for a free meal

Host a welcome tea to introduce new members to the Family Council and to have both staff and family present

Ensure that the first introduction to Family Councils includes time for people to socialize and network

At the introductory meeting, be sure to introduce the family members that are on the Family Council

Make sure to advertise through various media (newsletters, phone calls, local cable television, flyers, etc.)

Follow-up with interested family members at other family nights or social events

4. Make sure that your meetings run smoothly and are worthwhile:

Start and end meetings on time
Use agendas
Train your leaders
Use a concern form to process complaints
Have a Terms of Reference and Code of Conduct
Adopt projects that make expenditure of time worthwhile
Ensure that the meetings are well organized
Prepare an agenda in advance
If your Family Council has a Chair, ensure that he/she has good leadership qualities and follows the agenda
Choose people for your executive or as lead volunteers that are motivated, innovative and talented
Establish guidelines or a Terms of Reference that your Family Council will adhere to
Maintain confidentiality
Set time limits for the meeting and ensure that the meetings start begin on time and finish on time
Nominate a secretary or recording volunteer to take minutes

5. Ask others to help you recruit:

Ask the social worker, activation coordinator and other staff to assist your Family Council with recruitment by suggesting names of family members that they think would be interested in a Family Council, and by helping to promote the Family Council
Ensure that current Family Council members are aware of recruitment issues and have them assist with the promotion of the Family Council
Design business cards for your Family Council and have members carry those cards with them to assist with recruitment and promotion
Residents can speak to their families and friends and encourage them to attend a meeting and find out more about the Council

6. Publicize your Council:

Advertise, advertise, advertise!
Create a Family Council bulletin board and post your minutes and other items of interest (Be careful to ensure confidentiality – for example, by identifying only the officers by name and the number of other Council members with no names unless agreed to)
Use elevators, bulletin boards, or walls to post flyers and other printed material advertising the Family Council and upcoming meetings
When holding your first meeting, personally call families (if possible) to invite them and continue to do so once your Council has formed
Design a website to post information on Family Councils and on upcoming meetings
Create an email address for your Family Council and send messages and updates
Put a flyer or brochure in mailings on a consistent basis and leave copies in the Home where they can be picked up (e.g., at the front desk)
Produce business cards for the members to distribute to other interested family members
Use a suggestion box. Locate the box in the lobby along with a poster that invites families to share their thoughts. Council members can review the contents of the box at Council meetings
If you have a newsletter, reserve a section for Family Council updates. If you don't ask for space in any other Home newsletter or publication
Ideally, if you don't have a newsletter -make one!
People will volunteer if they think that someone they love will benefit from the organization's activities. Collect testimonials and use them in your promotional materials.
Have an information table on Family Councils set up at social events located in the Home or events that target family members

Give Council members name tags to wear so that others can identify them as Council members. People who are interested in the Family Council can ask them questions
Have guest speakers at Family Council meetings that speak on topics that are of interest to family members (dementia, funding mechanisms for Long-Term Care Homes, the Long-Term Care system, changes related to aging etc...)
Educate all staff about the Council so they can refer people to the meetings
Ask staff to identify families that they think would be good Council members. Tell them that you will follow up with them in two weeks... and follow up.

7. Be patient!

Promoting Diversity

The Government of Ontario's Diversity in Action Toolkit (see "Chapter 6: Resources and Supports") defines diversity as follows:

Diversity: means differences among individuals or groups.

Diversity is a strength that should be valued and promoted. Diversity is about gender, gender identity, ability, culture, race, size, spiritual or religious choices, language, age, lifestyle and perspectives and interests.

Promoting diversity is important to Ontario's Long-Term Care sector including the work of Family Councils.



Review the Family Councils Ontario values in "Chapter 1: Introduction." FCO supports inclusive practices.

Promoting diversity needs to be part of your thinking

- As you are getting started
- As you are recruiting new members
- As you are thinking about how to support the quality of life of residents and the interests of their friends and families



Also check out Chapter 6 which includes additional resources to support diversity.





Tips for Promoting Diversity

- **Ensure diversity is addressed in your Terms of Reference:**
Include a statement about diversity in your Terms of Reference.
- **Make diversity a priority.**
Create a plan to recruit members from diverse groups.
Include in your advocacy agenda issues that are of special interest to residents with diverse needs.
Make special efforts to include immigrant families who may face barriers attending Family Council meetings, perhaps because of language or cultural differences, hearing or vision impairments, etc.
- **Make your meetings and materials as accessible as possible.**
Translate flyers, letters, minutes and newsletters into the languages represented in your Home.
Have bilingual families translate meetings and materials.
Ask bilingual staff if you have trouble recruiting families who speak different languages.
- **Create an environment that does not tolerate bias.**
Do not tolerate biased or insensitive remarks.
Discuss the fact that discrimination is illegal, destructive and unacceptable.
Include respect for diversity in your Code of Conduct
Create a safe place for all people to participate.
- **Educate residents, families and staff about the different cultures in your Home.**
Encourage the Home to plan activities and events that give staff, residents and families an opportunity to share and celebrate differences – e.g., international potluck meals, opportunities to share photos, stories, or in cultural or artistic activities that promote diversity
Seek diversity awareness training for your Family Council when they are considering decisions, plans and activities and involve staff if possible
Encourage the Home to provide residents with opportunities to examine their own prejudices.
Encourage the Home to provide regular in-service training on diversity issues including cultural sensitivity, cross-cultural communication, and interpretation training.
- **Evaluate how well you are doing.**
Ask Family Council members directly as part of your evaluation process.
Contact family members who do not attend and find out if there are barriers.

Being an Effective Voice: Processing Concerns

Benefits to Residents and Family Members

A Family Council provides family members with an opportunity to have a collective voice in decisions that can affect the care of their loved ones and family members themselves. For this reason, it is important for Councils to spend time identifying and processing concerns in a group. An individual may find that others share the same experience. This alone may help reduce individual anxiety. Plus, the time and energy required to address a matter or problem can be shared by the group rather than borne by individuals separately. Ultimately, the Family Council is a collective voice and a true partner in ensuring the well-being of residents along with the Long-Term Care Home.

Benefits to Long-Term Care Homes

In addition, a Family Council offers the administrator and staff in the Home an opportunity to:

- Hear the constructive input of families;
- Keep families informed of changes and issues affecting the Home;
- Address small concerns before they become major problems; and
- Seek family support on issues affecting both the Home and its residents.

Ontario's *Long-Term Care Homes Act* also provides for Family Councils to advise the administrator of the Home formally regarding any concerns or recommendations the Council has about the operation of the Home. In this situation, the Home has a duty to respond to the Council in writing within 10 days of receiving notice of any concerns or recommendations.

The Council may also report these concerns and recommendations to the "Director" (that is a person appointed by the Minister of Health and Long-Term Care).

We are suggesting that Councils adopt the following the steps listed below to make sure that concerns can be fully shared, discussed and ultimately resolved as effectively as possible.



Steps to Processing Concerns in the Family Council

1. Allow the member to fully explain a concern.
2. Determine if other members share the concern. If the concern affects only one resident, the family member should discuss the concern with the appropriate staff or Council member for direction.
3. If members feel there is an issue that they wish to pursue, they will have to determine if they have the information and time to do so at the meeting, or if they wish to wait until a future meeting to pursue the matter.

4. In some cases, additional information may be needed and can be provided by the administrator or other staff person who might be invited to speak to the group. Also, an outside speaker might be called in to offer needed insight and information on a topic. Make sure you understand all applicable regulations and requirements.

5. Seek creative suggestions from Council members for problems and concerns.

6. Using a concerns form, formally present your concerns to the administrator and appropriate staff including:

- the concern
- to whom it is addressed
- suggestions for possible solutions
- date of expected response

Although this is the recommended system for processing a concern, each Family Council should set up a system that is most effective and one that meets the needs of the Council and the Home.

Whatever your system, we suggest you put your concerns in writing and keep written notes that allow you to track the concern: when you presented it, the person to whom you addressed it, any initial response and the time of that response, what you did next and when, etc.

7. Allow adequate time for replies and action from the Home. Refrain from unreasonable demands.

8. Discuss the response from staff members at the Family Council meeting. If the Council is satisfied, the Council reports its satisfaction to the department head. If unsatisfied, initiate a new complaints form to the administrator, communicating its dissatisfaction with the staff's response to the original concern.

If the Family Council remains unsatisfied, it should set up a meeting with the administrator and the compliance advisor, if necessary. It may be helpful to contact Family Councils Ontario.

9. When the issue is resolved, tell the residents and families of your success through a mention in the minutes, an entry on the Council's' bulletin board, or an item in the Homes newsletter etc.

10. Show appreciation when things go well.

Evaluating How Your Family Council is Working

Family Council members sometimes don't see the importance of evaluating their meetings. An evaluation can help determine if your Council is effective and if the time and effort spent on your Council is worthwhile.

Why?

- To ensure we are on track meeting our mission statement and goals and that they meet members' needs
- To reassess our organization including Terms of Reference
- To learn what will help make our Council more effective based on past experience
- To celebrate and recognize the strengths/resources within the Council

When?

- On a regular basis or whenever the need to evaluate is expressed
- If membership is down and there are concerns about the Council continuing

What?

- Council organization
- Member participation
- Administration and staff participation
- Constructive Council involvement

How?

- Complete the Family Council Self-Evaluation Questionnaire (see "WHEN?" above)
- Use a Kleenex box, or other container, for anonymous suggestions that are read out on a regular basis
- Pair and share, then report to the whole Council
- Use a flipchart to record feedback
- Review previous evaluations when the next evaluation is done to see how the feedback has been incorporated the feedback

*Remember:

There is no perfect model for all Family Councils. The needs of each Home and each Council are unique. However, there are characteristics that successful Councils share that can be measured to help analyze your Council's strengths and weaknesses. The most important measure of your Council's success is how you feel about your Family Council!



A sample evaluation questionnaire is included at the end of this chapter.

Other Ways of Improving Your Council's Effectiveness: Dealing with Difficult Behaviours

The following has been adapted from Energetic Meetings: Enhancing Personal and Group Energy and Handling Difficult Behavior by Jeanie Marshall, used with permission from the publisher, Marshall House. <http://www.mhmail.com>.

Some Councils have members whose behaviours disrupt Council order, create disputes, and dampen the spirit and enthusiasm of the Council. Such behaviour does not make an individual a 'bad' person. Some Council members may be experiencing and trying to cope with an overwhelming amount of stress or change which can impact their behaviour. Therefore, it is essential that we focus on the behaviour rather than labels or personalities.

The following are a few examples of behaviours that can negatively impact the functioning of a Family Council. Possible motivations and actions for each behaviour are also provided. You may see that most of us slip into such behaviours on occasion.

Behaviours that May Pose Problems within the Council

Dominates

- Talks a lot
- Takes control of the Council
- Speaks over others

Possible Motivations Possible Actions for Leader and/or Others

- Is eager
- Enjoys being the centre of attention
- Is exceptionally well informed and anxious to share information
- Displays enthusiasm by talking
- Likes showing off

Standard Procedures/Prevention Strategies

- Arrange for everyone to contribute, it may also be a good idea to appoint a "time keeper."
- Develop Terms of Reference or Code of Conduct; remind the Council of existing Terms of Reference or Code of Conduct.

Options for Current Situation

- Ask the group to respond to the one who is dominating, "What do some of you think or feel about what _____ has just said?"
- Interrupt, emphasizing task and time (time keeper).
- Give this individual a task such as taking minutes as they will need to listen to others in order to do so.
- Say, "That's an interesting point. Let's see what others in the Council think about it."

Clashes with Others/Anger

- Conflicts with other members of the Council
- While some conflict may facilitate creativity, too much can keep members from contributing

Possible Motivations Possible Actions for Leaders and/or Others

- May not like one or more Council members
- May be a personality conflict
- May not like the way things are progressing; they may feel that others are getting more attention, talking time, etc.

Standard procedures/prevention strategies

- Focus on Council goal or problem to be solved, not on personalities.
- Emphasize points of agreement not points of disagreement.

Options for Current Situation

- Allow clashing members to share feelings with one another or with the whole group.
- Request that member(s) stop arguing.
- Give an "I" message, e.g., "I feel very disappointed when I hear such bitter remarks."
- Ask that personal differences be kept from the group, or say that the arguing is inappropriate within the setting.
- If the anger is directed towards you, acknowledge it and ask whether the member has specific concerns about the Council or feels that some of their needs are not being met. Do not get into defending yourself as a facilitator or as a person.

Refuses to Budge from Position

- Exhibits stubborn behaviour, related to the group or individuals or with respect to the issues under consideration.
- Won't see others' points of view.

| Possible Motivations | Possible Actions for Leaders and/or Others |
|----------------------|--|
|----------------------|--|

- | | |
|---|---|
| <ul style="list-style-type: none"> • Does not want to change a prejudgment • May have personal interest in believing what they do • Misunderstands or did not hear others • Is frustrated • Does not feel part of the Council • Does not feel heard | <p>Standard procedures/prevention strategies</p> <ul style="list-style-type: none"> • Before deciding on a response, feel sure that the individual is wrong in their facts. <p>Options for Current Situation</p> <ul style="list-style-type: none"> • Be certain that the individual is heard • Do not argue • If the member seems adamant they are right, decide whether the issue is worth the concern. Validate their feelings, "I can see how you feel" and move on. • If the member seems simply misinformed, validate what they said and try and tell them the facts: <ul style="list-style-type: none"> • "I can see how you would believe that to be true..." • "That is one way of looking at it, and some others believe..." • Ask the individual to accept the Council's viewpoint for the moment: later, there may be time to explore his or her viewpoint more fully. |
|---|---|

Rambles

- Talks at random, drifting and straying, usually over several different topics.

| Possible Motivations | Possible Actions for Leaders and/or Others |
|----------------------|--|
|----------------------|--|

- | | |
|---|---|
| <ul style="list-style-type: none"> • Is preoccupied with own interest • Needs time to get to the point • Is unaware or uninterested in Council goals • Likes to talk! | <p>Standard procedures/prevention strategies</p> <ul style="list-style-type: none"> • Develop a mission statement and goals; restate them at the beginning of each meeting to keep everyone on target, especially the individual(s) who ramble. • Set a standard of limiting comments (for example to two minutes) and appoint a time keeper to assist in keeping meetings on track. <p>Options for Current Situation</p> <ul style="list-style-type: none"> • Thank individual and focus attention by restating relevant points. Move on to another individual. • Question the one who is rambling, directing her or him to the subject and task. • Emphasize time, task, and structure. • Acknowledge valid points so that the person knows he or she is heard. |
|---|---|

Discusses Wrong Topic

- Talks about a subject other than the one on which the group is scheduled to be focused on.

| Possible Motivations | Possible Actions for Leaders and/or Others |
|----------------------|--|
|----------------------|--|

- | | |
|--|---|
| <ul style="list-style-type: none">• Did not hear the agenda item• Is not paying attention• Is enthusiastic or preoccupied with another topic | <p>Standard procedures/prevention strategies</p> <ul style="list-style-type: none">• Provide agenda at the beginning of meeting. <p>Options for Current Situation</p> <ul style="list-style-type: none">• Remind individual or group as a whole as to which topic on the agenda is being discussed.• Accept responsibility: "Something I said must have led us off the topic; let's return to ____."• Use humour that acknowledges topic is incorrect without "putting down" the individual.• Interrupt and clarify the topic. |
|--|---|

Asks Frequent or Irrelevant Questions

- Asks questions that seem to be off the subject and/or asks questions more often than seems normal.

| Possible Motivations | Possible Actions for Leaders and/or Others |
|----------------------|--|
|----------------------|--|

- | | |
|---|--|
| <ul style="list-style-type: none">• Is afraid of not understanding• Is curious• Is not paying attention• Wants to be the centre of attention | <p>Standard procedures/prevention strategies</p> <ul style="list-style-type: none">• Ask the Council to please hold questions until the allotted time. <p>Options for Current Situation</p> <ul style="list-style-type: none">• Thank the individual who persistently asks questions and then ask if others have questions.• Give the individual a job (e.g. taking minutes)• Say, "I'd like to hear from some of you who have not yet spoken."• Ask if others have questions.• Say directly to the individual, "when you ask so many (or such) questions, I wonder if you're listening to what we've already said." |
|---|--|

Holds Side Conversations

- Talks with one or more persons during the meeting distracting and drawing the attention of one or more members.

| Possible Motivations | Possible Actions for Leaders and/or Others |
|----------------------|--|
|----------------------|--|

- | | |
|--|---|
| <ul style="list-style-type: none">• Finds meeting unresponsive to personal needs | <p>Standard procedures/prevention strategies</p> <ul style="list-style-type: none">• Suggest that members write notes to each other so conversations will not distract others. |
|--|---|

- Is uncomfortable talking to the entire Council
- Wants to catch up on other information
- Needs to inform someone about an important matter
- Is bored
- Establish a member-agreed rule (could be included in Terms of Reference or Code of Conduct) that only one person talk at a time when the group is in session.

Options for Current Situation

- Comment that you find it more satisfactory if only one person talks at a time.
- Stop talking. Side-talkers will feel exposed. When they stop their conversation, continue.
- Call on side-talker by name, asking an easy question. Avoid embarrassing the offenders.

Complains

- Expresses negative feelings, especially of dissatisfaction or resentment.

Possible Motivations

- Is frustrated
- Is unhappy about something unrelated to the current situation
- Has a legitimate complaint

Possible Actions for Leaders and/or Others

Standard procedures/prevention strategies

- Listen to what Council members have to say so they feel heard.
- Be solution-oriented.

Options for Current Situation

- Let the individual(s) know that the gripe has been heard and direct the Council forward.
- Check with other Council members to determine if they relate to the complaint. If the complaint relates only to that individual and pertains to the Home, direct them to the appropriate staff member or resource (this could be done immediately or right after the meeting). If the complaint relates only to the individual and is directed towards the Family Council, it could be discussed with the Council as a whole (if time permitting) or it could be discussed in private after the meeting. If other Council members can relate to the complaint it could be dealt with immediately or it can be added to the next agenda.

Says Little or Nothing

- Does not speak freely or openly.
- Uncommunicative, shy, or quiet.

Possible Motivations

- Is naturally quiet
- Is timid
- Feels shy, unsure, or uncomfortable with the Council
- Prefers to listen

Possible Actions for Leaders and/or Others

Standard Procedures/Prevention Strategies

- Create a climate that is conducive for all group participants to express themselves. Also, value contributions of all members.

- Needs time to process information
- May use silence to avoid getting too involved with the Council.

Options for Current Situation

- Ask, "Is there anyone who wishes to speak who has not had the opportunity?"
- Encourage, but do not insist, that the person speak. Everyone has a right to participate silently.
- Watch the individual. If he or she tries to speak but gets cut off, make an opening for them to speak by calling him or her by name.
- Accept that some persons are naturally quiet.
- Give encouragement when silent members do talk and communicate interest in hearing from them. Attempt to include them in discussions, "Sarah, I wonder if you have some thoughts/feelings about this subject?" (Do not overuse this technique).

Above All, Stay Positive

In Chapter 3, we discussed the need to anticipate challenges that you would encounter in starting your Council. Challenges occur all the time.

Some Councils struggle when Council members move on and participation drops. Others struggle when new members join – members who want to change the way things are done.

A Family Council is always a work in progress. A Family Council that adapts to these changes, that reinvents itself and keeps going – no matter what its size: 5 or 50 – has the potential to improve the lives of residents in Long-Term Care Homes and give their families and friends a more effective voice in their care. **Stay positive.**



Tips and Ideas

Keep that Council Positive!

Once a Family Council has been started it must be maintained. Keeping your Council running effectively over time must be an ongoing priority. It requires a plan that encourages present members to stay and new members to join. A Council that is positive, well organized, respectful of its members and Home staff, and has a vision that is accepted by its members will have a good chance of continuing for a long time. The following are some points to consider when developing a maintenance plan:

- ✓ Keep your Family Council positive by controlling gripe sessions and using a concerns/recommendations form to process concerns
- ✓ Keep communication positive between Family Council members and Home staff
- ✓ Acknowledge and thank existing leaders
- ✓ Celebrate accomplishments
- ✓ Acknowledge the efforts of both members and staff i.e. staff appreciation activities
- ✓ Educate your members so that they will continue to be empowered
- ✓ Educate all Home staff about the Council so that you gain and maintain their support
- ✓ Implement a Family Council evaluation survey at least annually to solicit feedback from your members about the Council
- ✓ Implement a Home survey to all family members to help obtain feedback that will assist with your recruitment plan
- ✓ Keep active as members will not continue to come to a Council that wastes their time once a month
- ✓ Research your community for other Homes that may have a Family Council to gain resources that may be of benefit
- ✓ Let others know the activities the Council has been involved with through newsletters, minutes, mailings, Family Council bulletin boards etc.
- ✓ Run your meetings effectively and efficiently by seeking training.

Networking Meetings

Members of Ontario Family Councils gather several times per year for education about issues concerning Long-Term Care, to share experiences, exchange information and explore issues of common concern. Family Councils Ontario uses the Local Health Integrated Network (LHIN) boundaries to organize Family Councils into 14 regions across Ontario. Networking meetings are held across the province giving Family Councils across the province a chance to attend without having to travel too far to participate.

Family Councils Ontario may assist the volunteer planning committees to make meeting arrangements, find guest speakers and, when appropriate, facilitate networking sessions.

Feedback has told us how helpful it is for Family Councils to have opportunities to network with other Councils. Participants report that they leave the meeting feeling supported and renewed. To find out about a regional networking meeting in your area or if you are interested in hosting a meeting, contact Family Councils Ontario.

You can locate the region for the home you are associated with by using the LHIN locator at the following link: <http://www.lhins.on.ca/>

Review: Ingredients of a Successful Family Council

- Sound organization including a Terms of Reference, Code of Conduct, agendas, and meeting minutes. The Terms of Reference should be reviewed at least annually and may be read aloud at the beginning of each meeting.
- Well-run regular meetings:
 - Meetings planned and led by members (family and friends).
 - Meetings of reasonable length that begin and end on time.
 - Meetings conducted in such a way that members feel free and safe to express their concerns.
- A variety of activities, rather than focusing on just one or two efforts that may not appeal to everyone.
- Involvement in activities that really address the needs, concerns, and interests of families and residents.
- Ongoing efforts to recruit and inform all families and friends about Council meetings, events, and accomplishments, with special effort to reach out to families of new residents.
- Promotes diversity; uses inclusive practices
- Self-evaluates so that the Council can learn and improve.
- A supportive staff assistant that understands and promotes Council independence.
- Realistic, effective efforts to resolve concerns rather than just “complaining.” This often hinges on a Council’s ability to differentiate between individual and group concerns and the willingness of members to identify and focus on the concerns of the group rather than on personal dissatisfactions.
- Opportunities for Family Council members to gain needed information about the Home and the Long-Term Care system in general.
- Commitment, support and involvement of staff and administration.
- Open communication and mutual respect between the Council, administration and staff. This means regular opportunities for Council members to inform staff and administration of their concerns and ideas as well as a means for staff and administration to keep the Council informed of updates, changes, and issues in the Home.
- Input from the Family Council into decisions that are being made in the Home.
- Celebration of accomplishments.
- Appreciation, by staff, of the accomplishments of the Family Council.
- Recognition of members’ individual efforts and contributions on behalf of the Council
- Acknowledgment of staff efforts – i.e., staff appreciation activities.

Samples

Sample Terms of Reference (1)

St. Andrew's Home for the Aged Terms of Reference

1. Name

The name of the organization shall be the St. Andrew's Family Council

2. Mission Statement

The St. Andrew's Family Council's mission is to:

“Improve the quality of life and quality of care for all residents by promoting an atmosphere of sensitivity, caring and support among staff, friends and family members of the residents of St. Andrew's.”

3. Goals

- To inform and educate families
- To share ideas for the purpose of problem solving
- To maintain two-way communication between families, residents and the Home
- To advocate on behalf of all residents and families
- To provide mutual support for family and friends of residents including those that are new to the Home

4. Membership

Members of the St. Andrew's Family Council shall be:

A friend or relative of a resident of St. Andrew's. Relatives and friends of a deceased resident are encouraged to continue their active membership.

5. Officers and Their Duties

Officers of the organization shall be the Chairperson, Co-chairperson, Secretary and Treasurer.

- The Chairperson shall preside over all meetings. In the event of his/her absence, the Co-Chairperson shall preside.
- The Secretary shall record the minutes of each meeting and maintain the minutes as a permanent record.
- The Secretary shall also be responsible for completing designated forms relating to requests for Home administrative action.
- The Treasurer shall collect monies for the organization, disburse funds with the approval of the group and maintain the financial books as a permanent record.
- If an officer can no longer perform his/her duties, the Executive Committee shall appoint a member to serve out the remainder of the term.
- An Executive Committee shall consist of Family Council Officers.
- Committees may be set up as needed by the Executive Committee and may include welcoming, grievance, activities etc.

6. Elections

Elections shall be held every year in March.

A Nominating Chairperson shall be selected by the Executive Committee, who in turn selects his/her committee to make a selection of candidates to present to the membership for election.

Members are encouraged to volunteer on their own initiative to be considered for office.

7. Meetings

Meetings will be held on the first Wednesday of every month from 7:00-8:30 p.m.

Subcommittee meetings shall be held as deemed necessary by Council members

8. Amendments

Amendments may be made to these Terms of Reference at any regular meeting of the Council, by a 2/3 vote providing the suggested changes have been read at the previous meeting.

Sample Terms of Reference (2)

I. Name:

The name of the organization shall be the Sunnyplace Home Family Council.

II. Purpose

The purpose of the Sunnyplace Home Family Council is to:

1. Comfort, inform and motivate friends and relatives of Long-Term Care Home residents.
2. Improve the quality of life, well-being and happiness of all residents of the Home.
3. Provide input on Long-Term Care Home decisions and act on shared concerns and problems.
4. Promote positive attitudes toward aging and the role of Long-Term Care Homes in Long-Term Care.

III. Membership and Attendance

- A friend or relative of a resident may become a member of the Sunnyplace Home Family Council.
- Residents of the Sunnyplace Home may not attend Sunnyplace Home Family Council meetings, unless invited.
- Members of deceased residents are encouraged to continue their active membership.

IV. Leadership by Committee

- The Sunnyplace Family Council shall be led by a committee including a Meeting Volunteer, Records Volunteer, Communications Volunteer, Welcoming Volunteer, Program Volunteer and Outreach Volunteer.
- The Meeting Volunteer shall preside over all meetings. In the event of his/her absence, the Outreach Volunteer shall preside. In the event of the Meeting Volunteer and Outreach Volunteer's absence, the Welcoming Volunteer shall preside.
- The Records Volunteer shall record the minutes of each meeting and maintain the minutes as a permanent record. In the absence of the Records Volunteer, the Communications Volunteer shall fulfill the duties of the Records Volunteer.
- Sub-committees may be set up by the Council Program and Outreach Volunteers and may include Activities, Welcoming, Grievance, etc.

V. Meetings

- Meetings of the Sunnyplace Home Family Council shall be held monthly, alternating between the fourth Tuesday of one month and the fourth Sunday of the next month.
- Sub-committee meetings shall be held as deemed necessary by the sub-committee.
- Meetings may be changed with a majority vote of the membership attending a meeting, should the need arise due to holidays, etc.

VI. Amendments

- All proposed amendments shall be mailed to all Council Members prior to a meeting. Amendments may be made by these Bylaws at any regular or special meeting of the Council by a majority vote. Amendments go into effect immediately.

VII. Code of Conduct

- Individual actions of Family Council members reflect on the Family Council as a whole. All members should ensure that their actions maintain the high regard of the Council. Effective Family Council members:
 - ⊗ Show respect, sensitivity and consideration for all persons in our Long-Term Care Home.
 - ⊗ Respect the privacy and confidentiality of all residents, family/friends of residents, staff and visitors of our Home.
 - ⊗ Avoid making judgments about any situation in the absence of all facts and information.
 - ⊗ Follow the chain of command when addressing concerns.
 - ⊗ Do not intervene in any resident's care before consulting the staff member(s) responsible for their care.

Sample Terms of Reference (3)

1. Name

The name of the organization shall be the Cheeryplace Long-Term Care Home Family Council.

2. Purpose

Our mission is to provide sensitive and caring support for families and friends of new and long term residents. We want to ease the stress of admissions and transfers, create friendship bonds and provide a safe and knowledgeable forum for concerned families.

3. Council Members

All members of the Family Council shall have or have had a friend or relative as a resident of Cheeryplace Long-Term Care Home.

The Family Council Board shall consist of no more than 17 voting members who are selected by the Family Council. The officers will be the following:

- ⊗ Chairperson
- ⊗ Vice-Chairperson
- ⊗ Secretary
- ⊗ Treasurer
- ⊗ A staff member from Cheeryplace Long-Term Care Home shall act in an advisory capacity as a non-voting member.

4. Elections

Elections for the above officers shall be held in June and the selected people shall serve for one year starting on July 1st.

5. Meetings

Meetings of the Family Council shall be held at the discretion of the Family Council Board.

Meetings of the Family Council Board shall be held monthly at the discretion of the Family Council Board.

6. Amendments

Amendments may be made to these bylaws at any regular or special meeting of the Board with a majority vote. The suggested changes are to be read at the meeting preceding the one at which voting takes place. Amendments go into effect immediately.

Sample Meeting Sign-in Sheet

| MEETING SIGN-IN SHEET | |
|------------------------|---------------------------------------|
| Family Council Meeting | Meeting Date: Thurs., June 25th 2009 |
| Secretary: Jane Doe | Place/Room: Sunnypace Home Auditorium |

In signing this document I will honour the confidentiality & Code of Conduct of the "Terms of Reference" of Sunnypace Home.

***Please indicate if you agree to have your contact information shared with Family Councils Ontario and other members of the Sunnypace Home Family Council. The information will be used for Family Council purposes only (i.e. for communication, record keeping and statistical purposes) and will not be sold or shared outside of the Sunnypace Home Family Council and Family Councils Ontario.*

***Optional due to privacy laws**

| Resident | Family Member | Family/ Staff | New member? | Phone* | E-Mail* | Can this information be shared? ** |
|----------|---------------|------------------|----------------|--------|---------|---|
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Sample Code of Conduct

Code of Conduct for Family Council Members

“This is HOME to your LOVED ONE”

(And all residents here)

Preamble: Individual actions of Family Council members reflect on Family Council as a whole, therefore the actions of all members should ensure that Family Council maintains its high regard. The reputation and image of the Family Council should be considered in each member’s communications and actions. **The wearing of a Family Council “Name Tag” is a sign of service and support, and indicates personal commitment to our Mission Statement.**

CRITERIA FOR AN EFFECTIVE FAMILY COUNCIL MEMBER:

- ⚙ Show respect, sensitivity and consideration for all persons you meet in our Long Term Care Home (residents, staff, visitors and volunteers).
- ⚙ Respect resident privacy and confidentiality (Resident Bill of Rights).
- ⚙ Respect the sensitivity and confidentiality of information discussed at Family Council meetings.
- ⚙ Avoid making judgments about any situation in the absence of all of the facts and information.
- ⚙ Recognize that all persons are unique individuals and be sensitive to this.
- ⚙ Respect that each resident and family member has the opportunity to advocate on their own behalf. Family Council members should only advocate on the behalf of a resident and/or their family members if a) there is a barrier they cannot remove or overcome and b) with their consent.
- ⚙ The intent of advocacy is to remove barriers that cannot be removed or overcome by the resident or their family alone.
- ⚙ Follow the chain of command when addressing concerns.
- ⚙ Do not intervene in any resident’s care before consulting the staff member(s) responsible for their care.
- ⚙ Recognize that idle, sensational or groundless talk (gossip) about any person is harmful and hurtful.
- ⚙ Have a clear understanding of abuse (financial, physical, emotional) and report any abuse immediately to the supervisor on duty.
- ⚙ Know and follow all the rules of our Long Term Care Home. Lead by example.

I _____ agree to this Code of Conduct.

Sample Self-Evaluation Questionnaire

Family Council Self-Evaluation Questionnaire

Check “yes” or “no” to the question that reflects your most honest opinion. For best results, a group of Family Council members should take the test. A Council meeting may be a good time to have members take the test and discuss the results. For each “yes” the group can discuss their success and for each “no” answered that question should be discussed and decisions/suggestions can be made as to how improvements can be made.

A. How is your Council organized?

| | | |
|---|------------------------------|-----------------------------|
| Does your Council meet regularly? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| Does your Council meet monthly? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| Does your Council have officers/lead volunteers who are family or friends of residents? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| Does your Council have a written Terms of Reference? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| Do meetings have a planned agenda and do all meeting participants know what is on the agenda? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| Are minutes (or notes) kept of meetings and retained for future reference? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| Do you post minutes or news of Council meetings in the Home or publish them in a newsletter? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |

B. How do families and friends of residents participate in the Council?

| | | |
|---|------------------------------|-----------------------------|
| Are most families and friends aware of the Council and its purpose? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| Are Council meetings planned and led by families and friends and not by staff? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| Is your Council financially independent of the Home? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| Is information about your Council readily available to families who are new to the Home? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| Is there a core group of families and friends who attend most meetings and seem interested? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| Do you think that most Council members feel they can speak honestly at meetings without fear? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| Does the Council have the opportunity to meet without staff or administration present when requested? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| Are Council projects and tasks somewhat divided evenly among Council members? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |

C. How do Long-Term Care Home staff participate in the Council?

| | | |
|--|------------------------------|-----------------------------|
| Do you think most of the Home’s staff are aware of the existence and purpose of the Council? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
|--|------------------------------|-----------------------------|

| | | |
|---|------------------------------|-----------------------------|
| Is information about the Council included in staff orientations, in-service training, or staff meetings? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| Has a specific staff person been chosen to work with the Council? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| If the staff person working with the Council were to change, would the Council continue to function at its present level? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |

D. How does the administration participate in the Council?

| | | |
|--|------------------------------|-----------------------------|
| Do you think the administration is supportive of the Council? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| Is there a regular means by which administration keeps informed of Council meetings and activities? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| Does administration keep the Council informed of the Home's news and changes in policies and regulations? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| Does administration seek the Council's opinion on policies, procedures, and other issues? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| Do you feel that administration hears the Council's concerns and recommendations, and gives them serious considerations? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |

E. How does your Council become constructively involved?

| | | |
|--|------------------------------|-----------------------------|
| Is the Council involved in welcoming or orientation of new family members of residents? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| Is the Council informed about the duties, functions and responsibilities of the various departments of the Home? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| Does the Council provide opportunities for members to gain needed information on the Long-Term Care system? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| Has your Council been involved in sponsoring a special event or activity for families and/or residents? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |

Chapter 5: The Role of Staff



The Role of Staff

The Relationship Between the Council and the Home Administration

The relationship between the Council and Home staff and administrator is important to a successful Family Council. A strong, positive relationship helps to ensure good communication and successful initiatives and activities of the Council.

Also, when invited, representative(s) of a Home must meet with a Council.

Why Promote a Family-run Council?

Members are more likely to feel responsible for the success or failure of their Council. They will either be proud of their success or work to turn it around.

They are likely to pursue the issues and activities that interest them rather than what staff feel that they “should do.”

Tasks are likely to get done when duties are spread among several members instead of upon one staff person.

The Importance of a Staff Assistant

Good staff support can have a significant positive impact on the success of a Family Council.

The decision as to whether or not the Council wants a staff assistant should be made by members during its first few meetings, and if so, what the assistant's role will be. Ontario's *Long-Term Care Homes Act (LTCHA)* uses the term “Family Council Assistant.”

Staff assistants who are dedicated to the importance of family involvement can be great assets.



What the LTCHA says about “Family Council Assistants”

The Long-Term Care Homes Act uses the term “Family Council Assistant.”

Under the Act, a Family Council may request a Home to appoint a Family Council Assistant to assist the Council.

The LTCHA requires a Home to work cooperatively with a Family Council and to appoint a “Family Council Assistant” to work with a Council, where a Council makes this request. The person in this role takes direction from the Family Council, attending meetings and maintaining confidentiality as required by the Council.

The staff assistant is usually appointed by the Home's administrator and often is the one to initiate the development of a Family Council and later assist with the ongoing recruitment and maintenance of the Council.

It is important to maintain a strong and positive relationship between the staff assistant and the Council. If there are tensions or conflict, it is important to deal with these quickly before they become worse. Maybe the issue is meeting times. Maybe some Council members are uncomfortable discussing their concerns in front of staff. The Council should discuss its concerns – among its own members and ultimately with the staff assistant. If the matter cannot be resolved, Council should discuss its concerns with the Home administrator.



In addition, the full text of the *Long-Term Care Homes Act (LTCHA)* is available through [Service Ontario kiosks](#), and on-line at the [Government of Ontario's e-laws site](#).

The Appropriate Role of a Family Council Assistant

- The appropriate role of the staff assistant is to assist or facilitate the work of the Council - to make things easier or to help. A staff assistant should make it easier for Family Council members to achieve their goals.
- Council members must request staff help. Some Councils choose to meet without staff of the Home present or invite staff only to certain meetings. For a Council to be truly self-determining, these options must be possible.

Assistance that a Staff Assistant may Provide

- Helping to tell families of new residents about the Family Council and encouraging them to attend
- Advising families on changes within the Home (e.g., dietary changes, new policies, new staff)
- Explaining the Home's policies and procedures
- Making other staff aware of the Council and its importance
- Helping the Council communicate its questions and ideas to, and receive responses from, appropriate staff and administration
- Bolstering Council members' self-confidence and enthusiasm
- Seeing that members receive recognition for their efforts
- Helping members learn the skills needed to achieve their goals
- Training Council members to run effective meetings
- Facilitating the development of an action plan for processing concerns including:
 - Encouraging individual members to take specific concerns to the appropriate staff
 - Encouraging the Council as a whole address collective concerns to the administration or appropriate staff person in a Home
- Helping to book guest speakers
- Facilitating communication with outside stakeholders (without speaking for the Council) – e.g., the Ministry of Health and Long-Term Care's compliance advisor
- Sharing information with the Residents' Council (without speaking for the Family Council) when Family Council members are unable to attend

Activities that a Staff Assistant Should Leave to Council Members

- Performing any task that members are able to do
- Taking meeting minutes
- Planning and running meetings
- Speaking on behalf of the Council
- Selecting meeting times and dates, topics of interest, projects and activities

Q. My Home does not currently have a Family Council? What can I do?

A. When a Home does not have a Family Council, it may be up to a staff member to start the process. Start by talking to family members who are visiting the Home, by distributing a Family Interest Survey (see page 33 for a sample) or organizing an information session and inviting all the family members and friends of all the residents of the Home. It is important to get the word out! Posters, flyers and brochures can be posted on bulletin boards, left at display tables, by the front door, distributed with the monthly mailings and handed out to families and friends visiting the Home.

Q. Sometimes I feel like if I don't run the Council, it won't accomplish anything.

A. Many well-meaning staff assistants take on tasks that Council members are not doing. For example, if no Council members seem to want to take meeting minutes or organize guest speakers then staff take on this role. However, there are many reasons why family-led Councils are more effective. When the Family Council is led by family members, they are more likely to feel responsible for the success of the Council. If there are problems, then members are more willing to work to solve them. Family-run Councils are likely to be more engaging and successful because they pursue the ideas and issues that interest them. Finally, staff assistants have a variety of other responsibilities and cannot accomplish alone what an entire Family Council can. A staff assistant who provides assistance and support without running the Council is actually encouraging the Council to accomplish its goals and be successful!

Q. I want the Family Council to be independent and family-led, but members seem unwilling to take responsibility. How can I help the Family Council become self-led and self-determining?

A. If members attend Family Council meetings, but do not accept leadership roles or tasks, several things may be going on.

If staff have run the Council in the past, members may be hesitant to take control. This is true even if good relations exist between the Council and the staff assistant. Family members may not be confident that they can successfully run the Family Council or feel that they lack the necessary skills. A staff assistant can help the Council members by encouraging them to look at their strengths and see what role or task they would be suited for. For example, if one of the Council members is very organized and has good computer skills, they may be interested in taking notes. Or, if one of the Council members is outgoing and enjoys talking to new residents and family members, then she/he may be interested in being a welcoming volunteer, which involves introducing new families and anyone attending a first meeting, reporting on welcoming/ orientation effort, and chairing the welcoming or orientation committee. A staff assistant may also help the Council become self-led and self-determining by providing members with support and training to lead meetings, take minutes, organize guest speakers and refreshments etc... if needed. Try brainstorming with the Council to identify the strengths of all the members and then look at what 'gaps' exist and work together on ways to support members so that they can take on roles and activities necessary to have a successful Council. Since each Council is unique, the strengths and needs will differ.

Some members may be reluctant to make a commitment by taking on roles or tasks. They may feel that they have many other responsibilities and do not have the time to take on anything else, even if they may wish to do so. Staff assistant can encourage and support members by discussing

the time requirement for tasks or roles, discussing how roles or tasks could be shared amongst members (e.g. chairperson or secretary role) and emphasizing that any level of participation or involvement is both welcome and appreciated!

Family Council members may want reassurance that when they are self-led and self-determining that the staff assistant will continue to provide support and assistance when required. Whether a Family Council starts as family-led or transitions from staff-led to family-led, staff continue to fulfill a supportive role. Even the best family-led Councils need support from staff.

Even the most skilled and supportive staff assistant cannot replace family members who accept responsibility for their Council. However, both Council members and staff can promote Family Council independence and success. It may be a gradual process of building Council members' confidence and finding roles they are suited for. Eventually, a much stronger Family Council will result!

Transition From a Staff-led to Family-led Council

There are four basic steps to transitioning from a staff-led to family-led Council. These steps provide a guideline for the transition process and may vary depending on the strengths and needs of the Council and its members.

Step 1 - Education

- Define what transitioning means to the Council
- Identify why transitioning is taking place
- Contact other Family Councils (over the phone, at networking meetings...)
- Read resource materials e.g. Family Councils Ontario newsletter, factsheets and sample items
- Contact Family Councils Ontario
- Ask yourself:
 - When I step down as chair of the Family Council
 - I am afraid that... the Council will disband, not be successful etc...
 - I think members may fear... that they will not be successful, that they will face challenges etc...

Step 2 - Beginning the Transition

Here are some tips to help you start to begin the transition process:

- Start as soon as possible.
- Identify that the goal for the Council is to be self-led and self-determining and ensure that there is continued open communication with the Council as to the goal of being family-led.
- Identify leaders and/or those who can take on Council roles and tasks
- Be direct about what the transition process entails and what it means for a Council to be family-led
- Depending on the experience of Council members, staff may support the group and their leaders by providing training and general support
- Openly discuss with Council members the things that might go wrong
- If Council members are reluctant to transition it is usually because they:
 1. **Fear that too much will be expected of them. Possible solutions:**
 - Adopt the shared leadership model
 - Make a list of roles i.e. chair, co-chair, time-keeper, promoter, etc.
 - Make a list of tasks that need to be done and then distribute them fairly so that not only a few people are carrying the whole work load

2. Lack clarity on what is expected. Possible solutions:

- Make people aware of what is expected with each role and task in advance
- Clarify how long they are expected to do the task and discuss time commitments and ways of sharing the work

These steps may also be helpful to Councils that experience a transition in leadership roles within the Council.

3. Fear that they are unqualified to perform certain tasks. Possible solutions:

- Provide training and contacts for additional support
- If you are a staff member, reassure them that you will not be leaving your supportive role in the Council
- Assess the Council's overall situation and staff involvement
- Decide which tasks members can genuinely not perform, which ones they may need assistance on and which ones they can perform with no assistance
- Be fair with your expectations
- As a staff person, decide which tasks you could do more easily or cheaply
- Don't insist that members take responsibility for things such as photocopying, mailing, refreshment etc.
- Don't delegate to the point that you are no longer a support to the Council
- Remember that every Council needs some assistance!

Step 3 - Letting Go

Transitioning to a family-led Council structure

- Usually takes about two meetings
- Highlight the Council's achievements
- Brainstorm with members about how they want to say celebrate the transition e.g. have a party, barbeque etc.

The last meeting

- Acknowledge the work done in the transition process and the participants
- Do a group evaluation
- Group vision and goals
- Suggest some activities for the Council to work on
- Ensure that a recruitment plan is in place

Step 4 - After the Change in Leadership

- Determine how you can help support the Council after you step down as Council leader
- Connect the Council with external support such as:
 - Other Family Councils (e.g. Regional networking meetings)
 - Relevant community and provincial organizations
 - Resources e.g. Family Councils Ontario tip sheets, DVD
- Connect them with internal supports such as the names of relevant staff members i.e. managers of different departments and Administration
- Continue to communicate with Family Council members! Your support and encouragement will go a long way to supporting their activities and success!



Tips for Staff Assistants: Promoting Member Responsibility

- ✓ Be clear in your mind about your role in facilitating the work of the Council and discuss this with members in the early meetings of the new Council.
- ✓ If a staff assistant tries to do the work of a Council until it is better organized, members may be unwilling or unaccustomed to doing these tasks. Avoid this from the beginning! Listen and facilitate, rather than direct Council activities.
- ✓ Encourage members to distribute tasks fairly among themselves to avoid the fear that too much will be expected of one person.
- ✓ Help Council members keep track of what they have agreed to do and who is doing what: put tasks in writing and clearly state what is required and how long a member is expected to do the task.
- ✓ Seek ways to make tasks easier or more interesting. Try to match members' interests and skills to tasks.
- ✓ Resources, advice and help are available from the Home and from Family Councils Ontario. Call on these sources of support when you need them.



Chapter 6: Resources and Supports



Resources and Supports

The following information includes links and contact information to assist you in obtaining resources and supports that may help you in starting and maintaining your Family Council.



Self-Help Resource Centre

The Self Help Resource Centre (SHRC) strengthens communities across Ontario by promoting peer support groups that facilitate positive outcomes for people who are facing diverse life transitions and challenges. SHRC does this in collaboration with dedicated staff, volunteers, partners and community members through outreach, networking, capacity building, consultation, resource development, and knowledge exchange.

40 St. Clair Ave East Suite 307
Toronto, Ontario, M4T 1M9
Tel: 416-487-7355
Tel: 1-888-283-8806
<http://www.selfhelp.on.ca>



Concerned Friends of Ontario Citizens in Care Facilities

Concerned Friends is a volunteer group that works with residents of Long-Term Care Homes and their families. The organization works to address the issues of quality care (physical, social, emotional) and the general conditions that residents face in Long-Term Care Homes.

140 Merton Street, 2nd Floor
Toronto, Ontario, M4S 1A1
Tel: 416-489-0146
<http://www.concernedfriends.ca>

Other Organizations

(Listed in alphabetical order)

Advocacy Centre for the Elderly (ACE)

ACE is a community-based legal clinic for low income senior citizens. The organization provides direct legal services, public legal education, and advocacy.

2 Carlton St, Suite 701

Toronto, ON M5B 1J3

Tel: 416-598-2656

www.ancelaw.ca

ALS Society of Ontario

ALS stands for "Amyotrophic Lateral Sclerosis" (also known as Lou Gehrig's disease). The ALS Society helps to facilitate access to support, care and treatment for those living with ALS through its equipment program, support groups, and community information and referral. The ALS society engages in advocacy, raising awareness and education.

3100 Steeles Ave E, Suite 402

Markham, ON L3R 8T3

Tel: 1-866-611-8545

www.alsont.ca

Alzheimer Society

The Alzheimer Society provides support, information and education to people with Alzheimer's disease, families, physicians and health-care providers. Examples of the types of support that are available include: helping people find programs and services they need such as support groups, day and respite programs, home support, and help with the transition to Long-Term Care. The organization also offers a wide range of information in print, videos and audiotapes as well as information meetings and workshops.

20 Eglinton Ave. W., Suite. 1600

Toronto, ON M4R 1K8

Tel: 1-800-616-8816

www.alzheimer.ca

Aphasia Institute

As a teaching and learning centre, the Aphasia Institute provides direct service to people with aphasia and their families in the Greater Toronto Area through the Pat Arato Aphasia Centre. The Institute also works to inspire people, both locally and further afield, through advocacy and awareness, education and training, and applied research and resource development.

73 Scarsdale Rd.

Toronto, ON M3B 2R2

Tel: 416-226-3636

www.aphasia.ca

Arthritis Society of Canada

The Arthritis Society of Canada is a not-for-profit organization devoted to funding and promoting arthritis research, programs and patient care.

Ontario Division
393 University Avenue, Suite 1700
Toronto, ON M5G 1E6
Tel: 1-800-321-1433
www.arthritis.ca

Association of Advocates for Care Reform (ACR), British Columbia

ACR is a non-profit organization comprised of concerned citizen volunteers whose focus is to improve the quality of life and care for people living in long-term, residential care in British Columbia. The Association's web site features a variety of resources and links.

3348 West Broadway
Vancouver, BC V6R 2B2
Tel: 604-732-7734
www.acrbc.ca

Canadian Cancer Society

The Canadian Cancer Society funds research on all types of cancer, offers information (e.g., pain management, nutrition, managing side effects), treatment and risk reduction, and provides support for people living with cancer through peer support groups, and transportation to and from cancer related care.

Ontario Division
55 St. Clair Ave W., Suite 500
Toronto, ON M4V 2Y7
Tel: 1-800-268-8874
www.ontario.cancer.ca

Canadian Diabetes Association

The Canadian Diabetes Association plays a leading role in supporting Canadians who are directly affected by diabetes, and their loved ones, through research, education, service and advocacy.

522 University Ave., Suite 1400
Toronto ON M5G 2R5
Tel: 1-800-226-8464
www.diabetes.ca

Canadian Hearing Society

The Canadian Hearing Society provides services that enhance the independence of deaf, deafened and hard of hearing people, and encourage prevention of hearing loss. The organization provides a wide range of services including: Audiology, Hearing Aid Program (dispensing and fitting), Technical Devices, Ontario Interpreter Services, Hearing Help Classes, Hearing Care, Counselling and General Social Services.

Canadian Hearing Society
271 Spadina Rd.
Toronto, ON M5R 2V3
Tel: 416-928 2504
TTY: 416-964 0023
www.chs.ca

Canadian Mental Health Association (CMHA)

CMHA promotes the mental health of all individuals across Ontario and is the primary source of information about mental health and mental illness. The organization is involved in distributing information to local CMHA branches, consumers/survivors and family members, policy makers, business leaders and the media.

Canadian Mental Health Association, Ontario
180 Dundas St W., Suite 2301
Toronto, ON M5G 1Z8
Tel: 1-800-875-6213
www.ontario.cmha.ca

Canadian National Institute for the Blind (CNIB)

The Canadian National Institute for the Blind (CNIB) provides rehabilitation services at no cost to people who are blind, visually impaired and both deaf and blind to enhance their independence.

1929 Bayview Ave.
Toronto, ON M4G 3E8
Tel: 1-800-563-2642
www.cnib.ca

College of Nurses of Ontario (CNO)

The CNO is the governing body for Registered Nurses (RNs) and Registered Practical Nurses (RPNs) in Ontario. The College regulates nursing to protect the public interest and sets requirements to enter the profession, establishes and enforces standards of nursing practice, and assures the quality of practice of the profession and the continuing competence of nurses.

101 Davenport Rd
Toronto, ON M5R 3P1
Tel: 1-800-387-5526
www.cno.org

Community Care Access Centres (CCACs)

CCACs are local organizations that can help people access government-funded home care and Long-Term Care services. Funded and regulated by the Ministry of Health and Long-Term Care, CCACs coordinate a variety of health services to maintain an individuals' health, independence and quality of life. Specific services relating to Long-Term Care include:

- providing information about Long-Term Care Homes
- determine suitability and eligibility for placement
- provide assistance in the application process

Examples of specialized services geared to specific health needs include: Convalescent Care (short-term care in Long-Term Care Homes), Acquired Brain Injury Services and Palliative Care.

To find your local CCAC, contact the Ontario Association at the phone number listed below or visit the Association's website and use the CCAC locator.

Tel: 416-750-1720

www.oaccac.on.ca

Elder Abuse Ontario

Elder Abuse Ontario is dedicated to raising awareness of elder abuse and neglect through public education, professional training, advocacy and service coordination.

2 Billingham Road, Suite # 306

Toronto ON M9B 6E1

Tel: 416-916-6728

<http://www.elderabuseontario.com>

Hospice Association of Ontario

The Hospice Association of Ontario provides information about a wide range of hospice palliative care services and resources such as:

- hospice palliative care programs
- hospice palliative care units
- community-based services
- pain and symptom management
- bereavement support services
- palliative care education

2 Carlton St., Suite 707

Toronto, ON M5B 1J3

Tel: 1-800-349-3111

www.hospicelifeline.com

Ministry of Health and Long-Term Care Information Line

The Ministry INFOline is available to provide general information about the Ministry of Health and Long-Term Care programs and services. The information is about government services only. INFOline does not provide medical advice or counseling. Hours of operation are Monday to Friday, 8:30 am – 5:00 pm.

Tel: 1-866-532-3161

TTY: 1-800-387-5559

Multiple Sclerosis (MS) Society of Canada

The Multiple Sclerosis Society of Canada is a national volunteer organization that supports MS research, services for people with MS and their families, MS clinics, social action and public education.

National Office
175 Bloor St E., Suite 700, North Tower
Toronto, ON M4W 3R8
Tel: 1-800-268-7582
www.mssociety.ca

Office of the Public Guardian and Trustee

The Office of the Public Guardian and Trustee (OPGT) helps to protect the rights and interests of mentally incapable adults who have no one else to act on their behalf. The services available include:

- property guardianship
- personal care guardianship
- decisions about treatment and admission to Long-Term Care
- guardianship investigations
- appointment of private guardians of property
- acting as litigation guardian
- estates administration

Power of Attorney Kit

The office of the Public Guardian Trustee also offers many useful information brochures which are available on their website.

595 Bay St. Suite 800
Toronto, ON M5G 2M6
Tel: 1-800-366-0335
www.attorneygeneral.jus.gov.on.ca/english/family/pgt

Ontario Association of Residents' Councils (OARC)

The objectives of OARC are to:

- encourage the formation of Residents' Councils in all Ontario Long-Term Care Homes
- encourage residents in Long-Term Care Homes to participate in the management of their Home
- identify key issues facing residents
- speak with one voice to the provincial government
- promote legislation which improves the lifestyle and safeguards the welfare of residents
- assist and advise individual Residents' Councils

80 Fulton Way, Suite 201
Richmond Hill, ON L4B 1J5
Tel: 1-800-532-0201
<http://www.ontarc.com/>

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

OANHSS is a provincial, non-profit organization representing Long-Term Care Homes, seniors housing, and community agencies that provide care and services on a not-for-profit basis.

7050 Weston Rd., Suite 700
Woodbridge, ON L4L 8G7
Tel: 905-851-8821
www.oanhss.org

Ontario Long-Term Care Association (OLTCA)

OLTCA is a Long-Term Care provider association in Ontario that represents a mix of operators including private, not-for-profit, charitable and municipal.

425 University Avenue, Suite 500
Toronto, Ontario M5G 1T6
Tel: 647-256-3490
www.oltca.com

Ontario Seniors' Secretariat

The Ontario Seniors' Secretariat influences and supports policy development across all government activities on behalf of Ontario seniors. It works with other ministries and other levels of government to identify areas where policy development and coordination can result in improved services for seniors. The Secretariat identifies issues and trends among Ontario's senior population through research, demographic projections and regular dialogue with key seniors' groups.

Examples of initiatives include:

- Seniors' Info (first multi-jurisdictional Seniors' Portal in Canada www.seniorsinfo.ca)
- Elder Abuse Strategy
- Ontario's Strategy for Alzheimer Disease and Related Dementia
- A Guide to Programs and Services for Seniors in Ontario
- A Guide to Advance Care Planning
- Ontario Seniors' Seminars
- Seniors' Month

The Seniors' Secretariat is responsible for: Diversity in Action: A Toolkit for Residential Settings for Seniors. Government of Ontario, 2008.

http://www.culture.gov.on.ca/seniors/docs/DiversityInAction_ENG_Web.pdf

This was developed as a result of Concerned Friend's Diversity initiative "Creating Welcoming Communities in Long-Term Care Homes."

777 Bay St, Suite 601C
Toronto, ON M7A 2J4
Tel: 1-888-910-1999
www.ontarioseniors.ca

Osteoporosis Society of Canada

The Osteoporosis Society of Canada is a national organization serving people who have, or are at risk for osteoporosis. Services to individuals with osteoporosis and the public include free publications, a bilingual toll-free information line, educational programs and referrals to self-help groups and community resources.

1090 Don Mills Rd., Suite 301
Toronto, ON M3C 3R6
Tel: 1-800-463-6842 (English)
Tel: 1-800-977-1778 (French)
www.osteoporosis.ca

Parkinson Society of Canada

Parkinson Society of Canada is a national, not-for-profit, volunteer based charity with more than 100 chapters and many support groups working nationwide. Its purpose is to ease the burden and find a cure through research, education, advocacy and support services.

4211 Yonge St., Suite 316
Toronto, ON M2P 2A9
Tel: 1-800-565-3000
www.parkinson.ca

Regional Geriatric Programs of Ontario (RGPs)

RGPs offer a range of specialized geriatric services that assess and treat functional, medical and psychosocial aspects of illness and disability in older adults who have multiple and complex needs. The RGP services five regional areas – Toronto, Kingston, Hamilton, Ottawa and London. For information about cognitive assessments, care planning, services for seniors, contact:

Toronto: 416-480-6026
Kingston: 613-548-5567 ext. 5439
Ottawa: 613-798-5555
Hamilton: 905-777-3837 ext. 12436
London: 519-685-4292
www.rgps.on.ca

Toronto Long-Term Care Homes and Services

Toronto Long-Term Care Homes and Services has developed a tool kit to help guide Homes in developing cultural competencies in providing care and services for lesbian, gay, bisexual and transgendered (LGBT) residents, partners and their friends. The tool kit is titled Diversity Our Strength: LGBT Tool Kit For Creating Lesbian, Gay, Bisexual and Transgendered Culturally Competent Care at Toronto Long-Term Care Homes and Services, Toronto Long-Term Care Homes & Services, December 2008. It is fully downloadable in PDF format at the Toronto Long-Term Care Homes and Services web site:

www.toronto.ca/ltc/pdf/lgbt_toolkit_2008.pdf

Veterans Affairs Canada

Veterans Affairs Canada (VAC) provides client-centred services and benefits that respond to the needs of veterans and their families, in recognition of their services to Canada; and to keep the memory of their achievements and sacrifices alive for all Canadians. VAC provides pensions for disability or death, economic support in the form of allowances, health care benefits and services to:

- members of the Canadian Forces and Merchant Navy veterans who served in the First World War, the Second World War or the Korean War
- certain civilians who are entitled to benefits because of their wartime service
- former members of the Canadian Forces (including those who serviced in Special Duty Areas) and the Royal Canadian Mounted Police
- survivors and dependents of military and civilian personnel

Ontario Region
145 Government Rd. W.
Kirkland Lake, ON P2N 2E8

Mailing Address:
Bag Service 4000
Kirkland Lake, ON P2N 3P4
General Inquiries: 1-866-522-2122 (English)
1-866-522-2022 (French)
www.vac-acc.gc.ca

Glossary of Terms



Glossary of Terms and Abbreviations

Activities of Daily Living (ADL)

A term which includes all the routines in which a resident engages to meet his/her basic daily needs (e.g., walking, eating, use of toilet, bathing, dressing, and grooming).

Accreditation

A process that organizations volunteer to participate in to evaluate their services and to improve the quality of their services. For more information on the accreditation process used in Long-Term Care Homes, contact Accreditation Canada.

1-800-814-7769

www.accreditation.ca

Administrator/Executive Director/CEO

A person who has the overall responsibility for the day-to-day operations of a Long-Term Care Home, and is accountable to the Long-Term Care Home operator, board of directors or municipal council.

Advance Directive

A document in which a capable person describes his or her wishes relating to future health care.

Advocacy

The activity of speaking on behalf of an individual or group to ensure that their rights are respected and their needs are met.

Assistive Devices

Equipment which assists a resident to maintain or increase independence and safety in activities of daily living (e.g., walker, hearing aide, or cane).

Care Conference (Team Conference)

A meeting between a resident (if capable), family members or the person with Power of Attorney for Personal Care, the Home's nursing and staff representatives from other departments to review and further develop the written care plan. The first care conference usually occurs about six weeks after the resident has been living in a Long-Term Care Home, and then annually thereafter.

Care Plan

A written document that outlines the types and frequencies of the Long-Term Care services that a resident is to receive in order to meet his/her needs. A care plan should include what nursing and other interventions are to be undertaken, the health outcomes to be achieved, and specified regular interviews for the review of care.

Capable (mentally)

Defined in legislation as having the ability to understand information relevant to making decisions and the ability to appreciate the reasonably foreseeable consequences of a decision or lack of a decision.

Comfort Allowance

Comfort allowance is defined in the *Long-Term Care Subsidization Act* as the allowance granted to persons deemed to be "in need" by the Ministry of Health and Long-Term Care to an applicant living in a nursing home for the purchase of items relating to recreation and comfort.

Community Care Access Centre (CCAC)

CCACs are agencies funded by the Ministry of Health and Long-Term Care that assist people in need of home and community care services, including admission into Long-Term Care Homes. CCAC case managers/placement coordinators authorize all placements in a Long-Term Care Home for both permanent and short-stay admissions and arrange home care services.

Complex Continuing Care

Also referred to as “clinically complex care.” Governed by the *Public Hospitals Act*, these facilities offer hospital-based care required by persons whose conditions are medically unstable (i.e., fluctuates through periods of exacerbation) and/or require skilled technology-based continuing or intermittent care. Patients who have been classified as “clinically complex” (based on MDS/RUGS 111 methodology) have one or more of the following conditions or care requirements and are likely most appropriately cared for in a chronic hospital or unit: internal bleeding, parenteral/IV feeding, stage four ulcers, chemotherapy, acute medical conditions, suctioning, transfusions, lung aspirations, tube feeding, burns dialysis, radiation, tracheotomy care, ventilator, or residents meeting the criteria for the Extensive Services or Special Care categories.

Concern

“Concern” is the term used throughout this guide to identify matters of interest or importance (major or minor) that can affect resident care and/or the ways in which family members themselves engage with their loved one and with the Long-term Care Home. The *Long-Term Care Homes Act* uses a number of terms including “concern,” “complaint,” “advice” and “recommendations when speaking to issues that Family Councils may bring forward to operators of Long-Term Care Homes or Ministry of Health and Long-Term Care officials.

Do-Not-Attempt Resuscitation (DNAR) Order

A “Do-Not-Attempt-Resuscitation” (DNAR) order is a written instruction that tells health care professionals not to perform CPR. CPR (Cardiopulmonary Resuscitation) is a complex process that is used when a person’s heart and breathing stops. CPR may include chest compressions, intravenous drugs, electrical shock to the heart (defibrillation), insertion of a breathing tube down the throat (intubation), connection to a breathing machine (ventilator), and/or admission to an Intensive Care Unit. People who are terminally ill often feel their quality of life is already diminished or unacceptable. In these cases, some patients might prefer to be cared for without aggressive efforts at resuscitating them.

Informed Consent

For information about consent to treatment including capacity to consent, visit the Office of the Public Guardian and Trustee (OPGT) web site for more resources. (The office is part of Ontario’s Ministry of the Attorney General.)

www.attorneygeneral.jus.gov.on.ca/english/family/pgt/

Inter-Disciplinary Team

A group of people with different kinds of training and experience working together, usually on an ongoing basis. Professionals often use the word “discipline” to mean a field of study. Therefore, an inter-disciplinary team might include a physiotherapist, a social worker, nurse, recreational therapist, chaplain, etc.

Licensee

“Licensee” means the holder of a licence issued under the *Long-Term Care Homes Act*, and includes the municipality or municipalities or board of management that maintains a municipal Home, joint Home or First Nations Home approved under Part VIII of the *Act*.

Living Will

For information about powers of attorney and living wills, visit the Office of the Public Guardian and Trustee (OPGT) web site for more resources. (The office is part of Ontario's Ministry of the Attorney General.)

www.attorneygeneral.jus.gov.on.ca/english/family/pgt/

Local Health Integration Networks (LHINs)

LHINs are regional entities designed to plan, integrate and fund local health services, including hospitals, community care access centres, home care, Long-Term Care and mental health within their specific geographic area. There are 14 LHINs in Ontario. They reflect the reality that a community's health needs and priorities are best understood by people familiar with the needs of that community and the people who live there. They are mandated to engage the public in the planning and integration process. For more information, refer to www.lhins.on.ca.

Long-Term Care

Long-Term Care represents a range of services that address the health, social and personal care needs of persons who, for one reason or another, have never developed or have lost some capacity for self-care. Services may be continuous or intermittent, but it is generally presumed that they will be delivered for the "long-term" (that is, indefinitely) to persons who have demonstrated need, usually by some index of functional incapacity.

Long-Term Care Home

Under the *Long-Term Care Homes Act, 2007*, Long-Term Care Home means a place that is licensed as a Long-Term Care Home under the Act, and includes a municipal Home, joint Home or First Nations Home approved under Part VII of the Act.

Long-Term Care Homes Act

The *Long-Term Care Homes Act, 2007* is the Ontario statute that regulates all Ontario Long-Term Care Homes. For more information visit: www.e-laws.gov.on.ca or www.health.gov.on.ca/english/public/legislation/ltc_homes/ltc_homes.html.

Palliative Care

Palliative care addresses the physical and psychological aspects of end of life. It involves:

- pain and other symptom management
- social, psychological, cultural, emotional and spiritual support
- caregiver support
- bereavement support.

Whether palliative care is offered through a formal palliative care program or through a variety of other avenues, the focus of the care is on achieving comfort and respect for the person nearing death and maximizing quality of life for the patient, family and loved ones.

Person or Persons of Importance

This is a term used in *Ontario's Long-Term Care Homes Act* to identify someone who is a friend or in a close relationship with a resident of a Long-Term Care Home. Persons of importance may be members of a Family Council.

Personal Support Worker (PSW)

Personal Support Workers are front line workers who play a key role in community, group living and facility-based settings. Services provided by a PSW include personal care, such as hygiene, mobility and other routine activities. PSWs are not regulated. PSWs are certified on completion of an education program offered by private vocational institutes, community colleges, boards of education and the Ontario Community Support Association.

Power of Attorney (POA)

A legal document that gives someone the right to act on another person's behalf. In Ontario there are 3 kinds of Power of Attorney: Continuing Power of Attorney for Property, Power of Attorney for Personal Care, and Non-Continuing Power of Attorney. For more information contact the Ministry of the Attorney General at 1-800-518-7901.

www.attorneygeneral.jus.gov.on.ca).

Psychotropic Drug

A chemical that alters brain function, resulting in temporary changes in perception, mood, consciousness, or behaviour. Often used for treating neurological and psychological illness.

Public Guardian and Trustee (PGT)

The Public Guardian and Trustee refers to a person as well as to a corporation created under the Public Guardian Trustee Act. The office of the PGT is charged with various duties and responsibilities under several pieces of legislation. Under the *Substitute Decisions Act*, the PGT may become a court appointed guardian for persons incapable of property or personal care decisions, and may become the statutory guardian of a person. The PGT may also be required to investigate allegations that a person is mentally incapable and as a result is in danger of losing property, their health, or their liberty or security. Under the *Health Care Consent Act*, the PGT is the substitute decision maker of last resort for health care treatment decisions, decisions regarding admission to a Long-Term Care Home, and personal assistance services and decisions.

RAI-MDS

The RAI-MDS (which stands for Resident Assessment Instrument – Minimum Data Set) is a set of computerized care management tools. These tools help health professionals in Long-Term Care to assess and monitor the care needs of their residents. The RAI-MDS 2.0 is the version chosen for use in Long-Term, Care Homes across Ontario.

Registered Nurse (RN) AND Registered Practical Nurse (RPN)

RNs and RPNs study from the same body of knowledge, however RNs study in greater depth and over a longer period of time. It takes four years to complete an RN degree, versus only two years to complete an RPN diploma. The longer period of study in the RN program allows the RN to gain a greater depth of nursing knowledge in clinical practice, decision making, critical thinking, leadership and management, research utilization, health care delivery systems, and resource management.

RNs and RPNs provide care to clients who are individuals or groups of individuals, including family members and significant others. Both provide care in situations in which a client's condition is less complex and the outcomes are predictable. RNs also provide care in situations in which a client's condition is more complex and the outcomes of care are not predictable. When RPNs provide aspects of care in these more complex situations, they do so in collaboration with RNs and with other members of the health care team. For more information contact the College of Nurses of Ontario 1-800-387-5526.

www.cno.org.

Regulated Health Professional

A person belonging to one of the health professions that is regulated under the *Regulated Health Professions Act*.

For more information visit: www.health.gov.on.ca/english/public/program/pro/pro_mn.html.

Residents' Bill of Rights

A list of the rights of residents of all Long-Term Care Homes as set out in legislation governing Long-Term Care Homes in Ontario. These rights are deemed by legislation to be a contract between the Long-Term Care Home and each resident. For more information on the Residents' Bill of Rights, visit: www.cleo.on.ca/english/pub/onpub/subject/seniors.htm.

Restraints

Anything intentionally used to limit the movement or behaviour of a resident of a Long-Term Care Home and over which the resident has no control. This may include:

Chemical Restraint: A pharmaceutical given with the specific purpose of inhibiting or controlling behaviour or movement.

Physical Restraint: An appliance or apparatus that inhibits general movement. Included in this definition are:

- jackets and vest restraints
- geriatric chairs or wheelchairs with tabletops in place
- roller bars on wheelchairs
- lap belts if they are applied in such a fashion that the seat belt opening is placed at the back of the chair and the seat belt cannot be undone by the resident.

Environmental Restraint: A barrier which confines a resident to a specific space, such as locked doors and locked units.

Restorative Care

Restorative care is an interdisciplinary philosophy of care approach to care provision designed to guide care and services to support a resident maximizing his/her remaining strengths and abilities in order to attain/maintain the maximum level of functioning possible and/or desired by the resident.

Substitute Decision Maker (SDM)

The person who has the legal authority to make decisions relating to personal care issues and/or property matters on behalf of an individual who is not capable of making and understanding the consequences of his or her decisions.

We Welcome Your Suggestions

Please help us to develop and improve resources for you and others by providing us with your feedback!

Family Councils Ontario

Your Guide to Starting and Maintaining a Family Council

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