

EMPOWERMENT

Resident Empowerment is an important part of making residents feel like they are at home and have a voice in what they do.

This section focuses on resident and family councils, making each successful, sample by-laws, best practices, and more. The information may be used by councils as a guide to creating a council in a facility, or making an existing one more effective.

The 1987 Nursing Home Reform Act guarantees nursing home residents and their families numerous important rights that not only enhance the nursing home experience, but improve facility-wide services and conditions. According to section 483.15(c), residents and family members have the right to hold private meetings as a group, known as family or resident councils. Federal law references “families” of residents may participate in a family council but this can also include close friends of residents.

Federal law states the following:

- *A resident has the right to organize and participate in resident groups in the facility;*
- *A resident’s family has the right to meet in the facility with the families of other residents in the facility;*
- *The facility must provide a resident or family group, if one exists, with private space;*
- *Staff or visitors may attend meetings at the group’s invitation;*
- *The facility must provide a designated staff person responsible for providing assistance and responding to written requests that result from group meetings;*
- *When a resident or family group exists, the facility must listen to the views and act upon the grievances and recommendations of residents and families concerning proposed policy and operational decisions affecting resident care and life in the facility.*

While nursing homes do not have to agree with, or meet all of the group’s recommendations, they do have to consider the recommendations made by a resident or family council and try to accommodate for the recommendations.

Resident and family councils meet to discuss problems or concerns within the facility, but they also provide support to one another, plan activities for residents and families, or may invite speakers present to their group on a variety of topics.

RESIDENT EMPOWERMENT

By Sharon McIntyre, Executive Director
Resident Councils of Washington

What picture comes to mind when you see yourself in a nursing home or assisted living? Do you see a life of purpose, independence and meaning or do you see a life of mere existence and a loss of identity? Those of us that work in a long-term care facility want to believe, in our hearts, that we are doing the best we can to provide a homelike environment, great care and are creatively providing activity programs that incorporate the beliefs, experience, education and passions of our residents.

The Resident Councils of Washington is a partnership of people living in long-term care facilities family members and friends, healthcare professionals and educators who believe that disability and/or chronic illness does not mean inability. In our 22 years we have been learning what empowerment means to residents and how we can ensure that they have the tools necessary to continue with their journey of life. Residents have taught us through our strategic planning, marketing, legislative and education committees what is important to them. At the top of their lists are the following: continuing education, access to resources, outlets for independence, extended social opportunities inside and outside of their home, decision making opportunities, a voice or opportunity to represent themselves publicly, public support and respect for their abilities and passions, but most of all residents and those entering long term fear isolation, loss of identity and purpose.

As staff, volunteers and advocates we have an obligation to our growing long-term care residents to equip them with the resources to be as involved as possible in their lives. Residents who wanted to make a difference in the care of their friends founded the Resident Councils of Washington. Empowerment means giving residents the opportunity for education, networking, discussion, regulatory and legislative decision making. Without an organization like RCW in your community you can start in your own community involving residents in meaningful decision-making. Most facilities have resident councils the next step is to network with fellow residents from other facilities even if it is only a handful of homes.

Why? Residents will:

- Obtain information and learn from the experiences of others
- Increase their sense of purpose and fulfillment in life
- Learn to exercise rights and pursue personal choices
- Participate as movers and shakers in forums and conferences

Testimonials:

Listen to your resident and family members. Check out the following testimonials:

"I am truly thankful to serve my fellow residents statewide through this wonderful organization. It is an honor and privilege to work with such generous and dedicated people. It gives me a very fulfilling life" Louise Clark, resident

“As a participant in such a diverse organization as RCW, it pleases me to assist my fellow residents to make a difference in their lives.” Sara Lanniciello, resident

“RCW helps boost morale and gives dignity back to residents after traumatic events have changed their lives. Residents become active participants in events that affect their daily lives and feel safe in expressing themselves.” Holly Farthingale, family member

How to Quick Tips:

Staff, Ombudsman or Volunteers: Begin by making a commitment to have one community event for and by residents in your community.

Pull together the regional ombudsman, members of the activity association in your area, a social worker, marketing and management staff for a meeting.

Outline your purpose: i.e. to have a resident conference in your community.

Identify resident leaders just as you would to begin a resident council in your facility.

At the first meeting get acquainted, learn about the purpose and benefits of the resident conference concept and begin to identify the pieces that fit into the puzzle. The conferences are educational, social and inspiring to all who attend.

Plan date, place, time. Prepare an invitation, mail and follow-up with a personal telephone call sharing that the group would be privileged to have Mr. or Mrs. _____ in attendance. Find a facility who will sponsor the first meeting in a private room, good ventilation, lighting and sound system (even for just a few representatives)

Plan and publish an agenda. The agenda should include:

- I. Welcome and Introduction
- II. Purpose of Meeting and mental picture of what a resident conference is:
We have copies of our brochures on the resident council website www.residentcouncil.org.
Success stories of other conferences (can use RCW as an example)
Sell the idea as an opportunity to socialize, learn and network from others.
- III. When and Where – Allow 6 months of planning time before event
- IV. Needs
 - Site
 - Accommodations for how many? Good traffic flow
 - Well ventilated, good acoustics
 - Space for a minimum of 2 breakout sessions
 - Adequate parking, on the bus line, centrally located or participants
 - Food – sponsor?
 - Cost? Rent, food, equipment?
- V. What?
 - Conference Content
The agenda for a conference may look like the following:
9:30 a.m. Registration, health snack, background Harpist

10:00 a.m. Welcome and short keynote or motivational speech including a resident and staff or volunteer partnership
10:30 a.m. Break out sessions
Determine 2 – 3 subjects or pick one and have divide the group.
11:45 a.m. Wrap up groups (representatives share highlights from their group with the entire group)
12:30 p.m. Lunch
1:15 p.m. Resident Rights Skit and closing

Hint: Have the group, in particular residents, brainstorm on topics they would like to learn about. Soon you will find a pattern in their thought process that will allow the facilitator to categorize their thoughts and develop break out sessions. Go around the room to make certain all participants have input as to their needs and interests. You will be surprised at the participation.

- VI. Marketing
 - Date, place, title of conference out as soon as possible]
 - Coordinate with local advocates, facilities, organization, volunteers, Ombudsmen
 - Prepare a data base for mailing

- VI. Determine costs and Fund Development
 - What are your community resources for sponsorship?
 - Do you need to charge?
 - Could you incorporate a fundraiser into your program? Raffles?
 - Could facilities sponsor tables?

Meet monthly until your conference is planned in detail. Remember long-range planning, resident ownership or participation determines the success of your first conference. You are on your way to a successful conference and the beginning of what could be a regional resident council.

"In the end it is not the years in your life that count; it is the life in your years"
Abraham Lincoln

References:

- The Resident Council of Washington Website www.residentcouncil.org
- The Resident Council Handbook

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Email: rcwexec@residentcouncil.org

Example of Resident Empowerment

Concerned Resident Advocates of Schuylkill County /
End of Life Care Task Force,
Pottsville, Schuylkill County, Pennsylvania

Since October 2001, presidents of resident councils in Schuylkill County, Pennsylvania have been meeting to discuss common issues and concerns with the help of the local LTC Ombudsman. The opportunity to dialogue and travel to each other's home was new and refreshing, which help them re-energize, be empowered and the chance to meet continuously. From the initial luncheon, *Concerned Resident Advocates of Schuylkill County* (CRA) was formed. This organization has been meeting on a quarterly basis and has tackled a variety of consumer issues. Some examples include the allowed Personal Needs Allowance for Medicaid NH residents; access to absentee ballot applications; dietary policies and procedures; and the most recent, the end-of-life care.

The issues related to end-of-life care were particularly troublesome for the CRA membership. After numerous discussions and individual attempts to impact the status quo, the *End of Life Care Task Force* was formed. In October 2004, the CRA members met with facility staff, health care professionals, hospice professionals, clergy, and ombudsmen. The task force met several times before creating a *Position Statement* (see below). A CRA member and a volunteer LTCO jointly chair the Task Force. The program is coordinated and supported by the local ombudsman.

Since it's inception, the CRA group has become affiliated with the PEER program in conjunction with the PA State LTC Ombudsman Office. [The PA PEER Program trains residents as advocates]. As evident in the *position statement (below)*, this determined group of residents is attempting to impact the way end of life care is being provided to long-term care consumers in Schuylkill County.

Through the PEER program affiliation, members of CRA learned that they were not alone in their dissatisfaction and concerns regarding the provision of end of life care. Since the program's inception, other PEER groups throughout the Commonwealth of PA have joined the CRA GROUP.

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The CRA End of Life Care Task Force Position Statement:

Concerned Resident Advocates of Schuylkill County *End of Life Care – A Position Statement*

Introduction

The Concerned Resident Advocates (CRA) is an organization comprised of LTC consumers residing in nursing homes and personal care facilities in Schuylkill County, PA. They meet regularly throughout the year to address issues of concern for LTC consumers. The purpose of the organization is to identify issues; strategize possible solutions; and facilitate positive change. The organization has been in existence since October 10, 2001, and in their four-year history, they have made an immeasurable contribution to the quality of life and quality of care provided both locally and across the Commonwealth of Pennsylvania.

It is the consensus of the CRA membership that end-of-life care could, and should, be provided in a more respectful, dignified, resident-centered way. After much lengthy dialogue on this issue – peppered with personal experience and wisdom – the CRA membership offers the following recommendations to facilities, health care providers, and direct care workers. The CRA membership hopes that these entities will partner with them on the journey for improved end-of-life care here in Schuylkill County.

Background

It has been the general experience of the CRA membership that most facilities and providers approach death and dying from a “medical model” perspective. While realizing intentions were good, the members believe that the medical approach de-personalizes the process and results in a cold, almost “business like” response to death and dying. The residents cite experiences that prevented them from:

- Staying with a dying friend;
- Knowing that a friend has died; and
- Grieve and processing a loss.

Most members report that facilities typically shut all resident doors and secretively remove the remains of their friends and colleagues with little to no ceremony or recognition. The CRA members truly believe their facilities to be their homes; therefore, they would prefer that things be done differently in their homes.

Recommendations

The Concerned Resident Advocates of Schuylkill County hereby recommend that LTC facilities and their staff consider the following:

- Residents should be consulted (via resident council) as to our collective preferences for acknowledging the death of our roommates and friends. Facilities should make every effort to implement the changes recommended by the residents. Elders do not need to be shielded or “protected” from death. Death is something elders face every day. Elders have lived long lives and have experienced death many times over. Younger people can learn from us and we should be consulted about how death is handled in our homes.
- Residents who wish to stay with our ill or dying roommates should be able to do so—with the consent of the roommate.
- Residents should be afforded the opportunity to mourn our deceased friends in a formal setting (memorial services, worship services, etc.).
- Residents should be consulted regarding informing surviving residents when someone passes. (As one CRA member states: “We are not trash – to be taken out the back door in a bag”.) The passing of a resident should be communicated in a dignified, respectful manner. Surviving residents should be afforded an opportunity to express condolences and to accept condolences from staff.
- Residents should be consulted regarding ways to memorialize and remember friends who have passed.
- Facilities should evaluate (with resident input) the services that are available to assist residents with the numerous losses they experience as they age. Increased clergy support should be considered. CRA members comment that they watch staff console each other – but often they are not offered any comfort. At a time of their life where they feel an increased need for spiritual support, they have the least opportunities for accessing that.
- CRA members request that the chapel / worship areas of our homes be respected and be kept free from clutter – often they are used for meetings and storage of equipment, etc.
- Facilities should assist residents in attending funeral of friends and families in their communities.
- Staff should be sensitive to the fact that residents experience innumerable losses on a daily basis. This has an effect on mood. Often, we are almost fearful of emoting because of “consequences” – psych consults, etc. As one CRA member expressed – “Sometimes we need a good cry and we don’t need everyone panicking when we do”. Most residents are losing family and friends at an increased pace and not all are people that are living with us. Often, we are separated from those people we are losing and the separation makes the grieving more difficult for us.
- Facilities should support the efforts of the local end-of-life-care task force that resulted from the efforts of CRA and is co-chaired by CRA members and volunteer ombudsmen.

Signed by CRA membership: April, 2005

Shared By: Kimberly Shetler, Regional Ombudsman Coordinator, State of Pennsylvania

RESIDENT AND FAMILY COUNCIL RIGHTS IN NURSING HOMES

The 1987 Nursing Home Reform Act guarantees nursing home residents and their families numerous important rights that not only enhance the nursing home experience, but improve facility-wide services and conditions. According to section 483.15(c), residents and family members have the right to hold private meetings as a group, known as family or resident councils. Federal law references “families” of residents may participate in a family council but this can also include close friends of residents.

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For More Information...

For more information about Resident and Family Councils, please contact the National Citizen’s Coalition for Nursing Home Reform at 202-332-2275, or visit us on the web at <http://www.nursinghomeaction.org>.

Resident Councils

Resident councils are organizations within the nursing home or assisted living facility whose members are residents of the home. All residents of the home can participate just by the fact that they reside within the facility. Usually, residents who are able, speak up for those who cannot. Every resident council is different, due to differences in both the residents who participate and in the level of support and responsiveness from the facility.

Resident councils provide a vehicle for resident participation in decision-making and for residents to voice grievances and resolve differences. The Nursing Home Reform Law and federal regulations [§483.15(c)] give strong support and direction for staff in nursing homes to assist in the development and organization of resident councils. No comparable federal law exists for assisted living facilities.

The resident council has grown into a vital force where it has had support. Resident councils have made valuable contributions to decisions within facilities as well as at the state and national policy level. This is particularly true where coalitions of resident councils have helped individual facility councils to function more effectively and have provided a voice for residents on policy issues.

Importance of Resident Councils

Resident councils are important for many reasons. They have become more recognized by facility staff and residents for the important contribution that residents make when given the opportunity to speak for themselves. They provide a forum for residents to:

- Voice their concerns directly to staff.
- Hold the facility accountable.
- Identify problems and their solutions from the residents' perspective.
- Allow residents to recognize staff they feel deserving of recognition.
- Open up discussions on topics of interest to residents.
- Contribute to shaping their world.

In long-term care settings, whether they are large or small communities, resident councils can be a way to foster a feeling of connection to the community. They are a forum for sharing information and being a part of the world in which the resident lives. If the facility sees the value of residents participating in their own world, then the resident council can be a valuable vehicle—not just for improving life in the facility collectively, but also for assisting residents to feel alive individually and in relation to each other.

Excerpted from: ***Equipping Long-Term Care Ombudsmen for Effective Advocacy: A Basic Curriculum***, module on **Residents' Rights**. Developed by Sara S. Hunt for the National Ombudsman Resource Center, 2005. Available from the National Ombudsman Resource Center, www.ltombudsman.org; 202.332.2275.

Resident Council Resources

Resident Councils Resource Materials

The National Long-Term Care
Ombudsman Resource Center
The National Citizens' Coalition for Nursing
Home Reform
1828 L Street, Suite 801
Washington, DC 20036
202-332-2275; Fax: 202-332-2949
www.nursinghomeaction.org
www.ltombudsman.org

Elder Care Rights Alliance

2626 East 82nd Street
Suite 220
Bloomington MN 55425-1381
Phone: 952-854-7304; Fax: 952-854-8535
www.eldercarerights.org

Resident Councils of Washington

220 E. Canyon View Rd.
Belfair, WA 98528-9597
(360) 275-8000
www.residentcouncil.org

How to Organize and Direct an Effective Resident Council

Emmelene W. Kerr, March, 1992
Missouri Long-Term Care Ombudsman
Program
Missouri Division of Aging
P.O. Box 570
Jefferson City, MO 65102
1-800-309-3282; (573) 526-0727
www.dhss.mo.gov

Coalition for the Institutionalized Aged & Disabled

Brookdale Center on Aging
425 E. 25th Street, Room 818
New York, NY 10010
Phone: 212-481-4348; Fax: 212-481-5069
www.ciadny.org

Starting a Resident Council*

Most facilities have some kind of residents' group. Taking this into consideration, many will be looking for ways to make the group as effective as it can be. Regardless of whether you are starting a new council or improving an existing one, the same basic principles apply to making it successful.

A critical key to an effective residents' council is the attitude and philosophy of the caregivers. When the facility administrator recognizes the importance of providing self-governing groups, there will likely be little resistance to the establishment of the group. Additional support must come from other staff, including the nurse aides, who are convinced of the value of the council and committed to assisting residents in taking part.

It takes only one interested and committed person to get the ball rolling, but it takes many people working together to make the council successful.

When you have the support necessary to establish a council, working out the details and maintaining commitment from both the administration and the residents becomes the issue.

In developing an effective residents' council, it is important to look at who is trying to establish the council. Often it is a staff member who initiates the effort. If residents are not supportive of the idea, the effectiveness of the council will be limited. If however, the idea comes from residents, there will likely be more

support. Whatever the source of the inspiration for the group, it takes only one interested and committed person to get the ball rolling, but it takes many people working together to make the council successful.

As the facility staff and the residents work together to start or improve a council, the following steps should be taken:

1. Have a brainstorming session

Call a meeting of all persons interested in organizing a residents' council. This includes the administrator, staff, families, volunteers, and most importantly, all interested residents.

During the brainstorming session, the group needs to:

- Discuss the value of a residents' council to staff, residents, and the facility;
- Review the information in this packet and then consult your Local Long Term Care Ombudsman Program for further assistance;
- Explore and analyze possible staff resistance to a council and discuss potential staff roles and expectations;
- Secure both staff and administrative commitment to support a council;
- Identify potential resident leadership;

- Consider possible resident apathy or resistance and how to respond;
- Form a committee of four to six people to plan an exploratory meeting of all residents to discuss the establishment of a resident council.

2. Conduct an exploratory meeting

The committee should plan a meeting for all residents. A good strategy would be to schedule the meeting to coincide with a popular activity that a large number of residents would be expected to attend.

Unless there is a very capable resident, it may be necessary for a committed staff member to lead this meeting. The purpose of this meeting would be to:

- Inform residents of the purposes and benefits of a council;
- Share staff ideas and commitment to the project;
- Give examples of how councils are effective in other facilities. Invite a member of a residents' council from another facility to talk about his/her council;
- Lead a short discussion to identify the concerns of the residents and ways the council could address them;
- Take a vote to determine if there is interest in organizing a council; and
- If so, select a committee of four to six people (include residents, staff, and volunteers) to organize and plan the first meeting.

3. Conduct an organizational committee meeting

The work of this committee can probably be accomplished in two meetings. It is important for the administrator to show his/her support for the council at these meetings. This can be done either by a personal appearance or sending a letter to the committee. Once support is received, the organizational committee can establish some recommendations for basic structure fairly quickly. This includes:

- Establishing the purpose and function of the council;
- Establishing the organization-al structure and leadership;
- Establishing the role of facility staff in the council;
- Determining the resident needs and concerns that are appropriate for the council to address;
- Selecting special projects the council could be involved in;
- Determining when and how often to meet; and
- Planning a meeting where all residents are invited to hear and vote on the recommendations of the committee.

After this process the committee should have the basic components for writing by-laws by which the council will operate.

4. Implementing the plan

If residents vote to establish a residents' council based on the committee's recommendations, the only thing that remains is implementing the plans that have been made.

Creating and developing a residents' council takes time. Be patient and recognize council successes, even the small ones.

While "big projects" are important and residents gain a sense of satisfaction from involvement in such endeavors, building a cohesive group where people listen to each other with interest

and respect is important. This takes time, and may be difficult, but your efforts will pay off in the end.

It will help to get your council off to a good start if early in the life of a council you are able to point to successes that are meaningful to a large number of residents. Some areas where a council might be successful include: a change in serving procedures assuring residents get hot coffee; establishing a committee that sends cards and letters to residents in the hospital; or conducting a get acquainted activity for new residents.

*Taken from "How to Organize and Direct an Effective Resident Council," revised 2005, with permission of the Missouri State Long Term Care Ombudsman Program.

Key Components of Family Councils

Recruitment

- Conduct continual recruitment
- Include information about the council in resident admission packets
- Establish a “buddy system” where families from the family council are “assigned” to new family members to welcome them, answer any questions they may have from a family’s perspective, and invite them to participate in the family council
- Produce brochures or fliers that council members can give to other family members they see when they visit
- Provide a sign in sheet at meetings for names, telephone numbers and addresses of family members who attend in order to make future contacts and share reminders of meetings

Leadership

- Plan for the long-term stability of the group by putting structure in place, such as simple by-laws
- Work on leadership development so that if key members of the council stop participating in the council or leave the facility, the group will continue
- Invite family members of residents who die to continue to participate in the council

Relationship

- Communicate continually with facility staff and management to advise of any common concerns and suggestions, follow up on action to be taken, discuss family council activities, etc.
- To the extent possible, be part of the solution to problems or improvements to be made at the facility. When raising concerns, brainstorm for ideas about how the concern can be addressed.
- Establish contact with the long-term care ombudsman. The ombudsman can act as valuable resource.

Improvement

- Briefly evaluate meetings afterwards to see if that meeting accomplished its purpose (communicating a certain point, coming up with ideas for addressing an issue, getting a commitment from facility staff about action to be taken), and make note of things to improve upon
- Focus on common goals (identify and continuously assess progress)

- Follow procedures for conducting effective meetings, such as using agendas, starting and ending meetings on time, sticking to the topic scheduled for discussion, “assign” tasks for future activities to be accomplished before the next meeting
- Become educated about the laws and regulations that apply to nursing homes and particular issues affecting nursing home residents such as the provision of sufficient numbers of staff and staff training

Thoughtfulness

- Make sure that all activities and communication have purpose and will further progress toward the family council goals
- Remember that family councils may not produce immediate results but they can be effective if the council perseveres
- Active councils may consider acting as a resource for new family councils at other facilities
- Focus initially on “achievable” goals and projects

Ways for Families to Overcome Obstacles to Family Council Development

OBSTACLE	POSSIBLE SOLUTIONS
<p>Family members lack time</p>	<ul style="list-style-type: none"> ● Begin and end meetings on time. If family members see that meetings are efficient and purposeful, they will be more likely to come to future meetings ● Share leadership responsibilities and delegate small tasks to members so that the time commitment for individual members is not too substantial ● Make use of agendas to keep meeting on track ● Schedule meetings at times that are convenient for family members
<p>Family members lack interest</p>	<ul style="list-style-type: none"> ● Introduce yourself to other family members on your loved one's unit. Ask them about how they've felt about the care provided to their loved one and any ideas they have about needed improvements. Family members will respond to a personal invitation more readily than a letter or flier. ● Explain the rights of family councils to other family members and the potential that family councils can have to promote improvements at the home. ● Introduce the concept of a family council in a positive way. Family councils can be useful for advocacy as well as information sharing and support. All nursing homes have room for improvement and new ideas.
<p>Family members fear retaliation</p>	<ul style="list-style-type: none"> ● If family members are reluctant to be seen at family council meetings, discuss the possibility of meeting off-site so that family members will feel more comfortable coming to meetings. ● Explain that family council members give each other support and strength. Also point out that issues or concerns will be presented to the facility administration as a group, not an individual, concern. ● Present the family council positively to both family members and nursing home personnel.

<p>Council members get discouraged easily</p>	<ul style="list-style-type: none"> ● Pick both short and long-term “achievable” goals so that the council can see concrete progress. Make sure that council goals are firmly rooted in the common concerns and interests of the members. ● Meet at least once a month to assure continuity and ability to identify goals and work toward them.
<p>Family members lack information and education</p>	<ul style="list-style-type: none"> ● Contact NCCNHR with questions or need for guidance ● Use the ombudsman program as a resource ● Ask the facility to arrange for speakers of interest
<p>The family council experiences resistance from the nursing home</p>	<ul style="list-style-type: none"> ● Have a few leaders meet with nursing home management separately to introduce the council and its purpose in a positive manner. ● Communicate constantly and try to respond positively to concerns the facility may have. ● Know the rights guaranteed to family councils by federal regulations. ● Seek the assistance of outside agencies if necessary. ● Discuss and come to clear agreements with facility personnel about what can be accomplished and expect that personnel will follow through on those commitments. Follow up on verbal communication with communication in writing to prevent misunderstandings.
<p>Difficulty getting names of other family members</p>	<ul style="list-style-type: none"> ● See above for suggestions on how to work with the facility ● Start a “buddy system” where council members greet new families and invite them to council meetings ● Keep a sign in sheet for each meeting and gather contact information

For more information, contact:

National Citizens’ Coalition for Nursing Home Reform, 1828 L Street, NW, Suite 801, Washington, DC, 20036, 202.332.2275,
<http://www.nccnhr.org>.

Membership

Membership in the Family Council is limited to relatives, legal guardians and designated friends of current and former RG residents. To become a member, please complete the form on the back of this brochure. We welcome new members and encourage all qualified individuals to join us in advocating for residents and providing support for family members.

Meetings

Family Council meetings are normally held at 7:00 p.m. on the first Wednesday of each month in the Garden Room.

The meetings are informative and participatory. They usually last for about 75 minutes and are open only to Family Council members and guests invited by the Family Council Chair.

Seminars

The Family Council I sponsors informational seminars on the third Wednesday of most months. Guest speakers discuss a topic of interest and respond to your questions.

The seminars are held in the Garden Room and begin at 7:00 p.m. They usually last for about 60 minutes and are open to the entire Riderwood community.

Concerns

The Family Council brings a united voice and a united effort in resolving common concerns. Family Council concerns are forwarded to the administration for resolution. A public file of this correspondence, as well as responses from the administration, is available for review at the receptionist desk.

Consultations

The officers of the Family Council are available to consult with a resident or a family member on any issue or concern. Upon request, an officer will attend a meeting with staff members in order to provide you with informed support. Also, upon request, the Family Council will provide a "buddy" to help orient you to RG.

Officers

Jim P., Chair
Phone
Email Address

Bob G., Vice Chair
Phone
Email Address

Val K. Vice Chair
Phone
Email Address

Welcome

Welcome to Renaissance Gardens (RG), the health care neighborhood in the Riderwood community. We hope that your experience at RG will meet or exceed your expectations.

The Family Council is a volunteer membership organization focused on the care received by RG residents and the quality of life they enjoy. Please feel free to draw on our experience with respect to any issues that you may have.

Mission

The mission of the Family Council is to provide a structure for families, as a consumer group, to (1) discuss and take actions related to improving the care, well-being and happiness of all RG residents and (2) provide support for family members and a forum for them to learn more about RG, Erickson Communities, the long-term care system and concerns of other family members.

Join

PRINT CAPITAL LETTERS
Date
Your Name
Your Mailing Address
Your Telephone Number
Your E-Mail Address
Resident's Name
Resident's Room Number
Resident's Relationship to You

Please give the completed form to the RG receptionist; mail it to Family Council, 3160 Gracefield Rd, Silver Spring, MD 20904-1986; or email the requested information to pattonjl@hotmail.com. Thank you!

Revised March 2006

Renaissance Gardens
at
Riderwood

Family Council



The Family Council is independent of the management and staff of Riderwood, an Erickson Continuing Care Retirement Community in Montgomery/Prince George's County, Maryland.

Promoting Participation in Family Councils

One challenge faced by many family councils in nursing homes is recruiting and maintaining members. Frequent changes in residents and, therefore, family members, can cause levels of participation to fluctuate and have an impact on the stability and continuity of a family council.

Below are suggestions for family councils on how to contact families of new residents and create strategies for ongoing recruitment.

Points to Remember about Promoting Family Council Participation

- Do not get discouraged. Even a small group can be effective. Many family councils have active participation by only about 10% of the families of the residents in the facility.
- Efforts to notify families and friends concerning family council meetings, events, and accomplishments must be ongoing due to frequent changes in residents/families.

Supporting New Families

- Participate in new family orientations at the facility to provide information about family council activities.
- Visit a new resident and their family members shortly after their arrival to share information about the council.
- Sponsor social events to meet new families and residents.

Personal Contacts

- Personal contact (i.e. personal invitations, introductions, etc.) is essential for promoting participation in family councils. Each participant should make a point of inviting other family members to participate between meetings.
- Consider having family members volunteer to be "greeters" in the lobby of the nursing home to introduce themselves and to tell families about the benefits of a family council.

Building A Network

- ◆ Provide a sign-in sheet at meetings for names, phone numbers, and addresses of families who attend in order to make future contacts and share reminders of meetings.
- ◆ Appoint or elect family members to act as floor/unit representatives to recruit new members and advertise meetings.
- ◆ Include in the admissions packets a permission slip to allow the release of the new families' phone numbers to the council.
- ◆ Provide ongoing support to one another during and between council meetings.

Develop Written Materials

- Produce brochures, fliers, and newsletters so that families have visual reminders.
- Ask the nursing home to put information about the family council in their newsletter to families.
- Place a bulletin board in the lobby to share the mission statement and successes of the family council, information about meetings and other items of interest to family members.

Tips for Making Resident/Family Council Meetings Meaningful

One of the challenges in starting a family council is promoting participation in the council. One important way to do this is to conduct efficient and meaningful meetings for those who participate. Some tips for having successful family council meetings are below:

Use Structure

Agenda. Use an agenda -- even if it contains just a few simple items. You may even want to assign suggested time limits to agenda items to keep the meeting moving and give participants an idea of what to expect from the beginning.

Meeting Length. If at all possible, try to limit the length of meetings to between 1 hour and 1.5 hours. Because family members' time is limited, people may hesitate to come to meetings if they are too lengthy.

Regular meeting time. Try setting a regular meeting time (Ex. the 3rd Thursday of each month) so that family members can plan to attend family council meetings ahead of time even if they do not receive announcements or see fliers.

Meeting Procedures. Try using parliamentary procedure, Roberts Rules of Order, or some other agreed-upon structure to keep meetings moving in an orderly and efficient manner.

Make Time for Shared Input

Input/Setting Group Goals. In order for family members to be committed to and active in the family council, they must feel that they have input into group decisions and priorities and that council activities will have an impact on the care their loved one receives. The council should schedule time for family members to have discussion and brainstorming without facility staff present. This private discussion will allow family members to voice any concerns freely and allow the council to decide on group issues and goals. When facility staff are present for these discussions, the discussion can become a "complaint session" rather than an honest, proactive discussion of concerns and actions the family council can take to bring about improvements.

Structure for Input. In order to make this input constructive for the activities of the family council, it is important to facilitate this process with some kind of structure. Some suggestions for ways to keep the discussion moving are:

- Use a flip chart to compile a list of shared concerns/interests during brainstorming sessions.
- For large groups, appoint a time keeper who will remind the group to move on if discussion gets stuck on a particular agenda item,

- Hand out index cards and ask people to list top three areas of concern or interest and then compile a group list,
- Introduce discussion by asking each person to limit their comments to a certain number of minutes,
- You can use an egg timer with a bell to help remind the group when it is the next person's turn to speak,
- Ask each person in the group to verbally list their top three areas of interest or concern.

Focus on Action and Efficiency

Next Steps. Before the end of each meeting, always plot out next steps, review action items and delegate tasks to be accomplished before the next meeting.

Business vs. Pleasure. Try rotating responsibility among members for bringing refreshments. This will enable family members to get to know each other, socialize and support each other informally after the meeting.

Formulate Solutions/Recommendations. Brainstorm with the council for ideas for solutions to concerns raised. Formulate a specific request for how a concern should be addressed.

RESIDENT/FAMILY COUNCIL MEETING AGENDA

Date: _____

- I. Welcome and Introductions
- II. Read and approve minutes of last meeting
- III. Officer/Committee/Representative Reports
- IV. Old Business (i.e., review of business that was unfinished at last meeting)
- V. New Business
- VI. Guest Speakers (if invited) or Special Issue
- VII. Resident Concerns
- VIII. Adjournment
- IX. Social Time
Note: Many councils plan for refreshments and a social activity following the meetings.

RESIDENT COUNCIL BY-LAWS

I. Name

The name of our resident council shall be _____.
(name of council)

II. Purpose

The purpose of the resident council is to:

- Give residents greater participation in affairs within their own home
- Suggest improvements and assist administration in providing better programs, surroundings, and services
- Promote friendship and understanding among residents; and
- Provide and receive necessary information for the benefit of all residents.

III. Membership

Every resident of _____ is a member of the
(name of facility)
resident council. Every member shall be given the opportunity to vote.

(Note: Some councils have representative council members from each wing, building or floor who make up the council. This structure needs to be developed before by-laws are written.)

IV. Officers and Their Duties

Officers of the council shall be:

- President (Chair) – shall preside over all meetings
- Vice President (Vice Chair) – presides in the absence of the president
- Secretary – records and maintains minutes of each meeting;
- Treasurer – responsible for all financial business of the council.

Officers of the council shall be elected every _____ in
(period of time, such as every year, or every six months)
_____(month).

In the event that an officer is/becomes unable to fulfill his or her duties; a special election will be held at the next regularly scheduled council meeting.

V. Committees

Executive Committee:

The council shall have an Executive Committee whose purpose is to give direction and organization to the council.

The Executive Committee will include:

(Note: The Executive Committee is generally made up of the Officers, and if the council so chooses, the Committee Chairs).

Standing Committees:

The Council shall also have the following standing committees as needed:

Welcoming – to greet new members and orient them to the facility;

Sunshine – to prepare greeting cards for residents in the hospital, and those who have birthdays. They may send cards to families who have lost a loved one.

Food – to serve as a liaison between dietary services and the residents for suggestions and improvements.

Activities – to serve as a liaison with the activities staff to plan and set up recreational programs.

Grievance – to listen to concerns and provide an opportunity for discussion before the full council meets; to follow up on complaints with the administrator or ombudsman.

Each standing committee will select a chairperson who will serve for _____.
(period of time)
Temporary committees can be established by appointment on an as needed basis.

VI. Elections

Elections of officers/representatives shall be held every _____.
(month of elections)

The elections will be conducted using written ballots listing nominations for each office. Nominations will be made at the meeting prior to the election.

VII. Meetings

General meetings of the Council will be held every _____

(be specific, day, time, location)

Note: If you have executive meetings or committee meetings, list date, day, time and location for those as well.

VIII. Amendments

Amendments may be made to the bylaws at any regular or special meeting of the council by a 2/3 vote, providing suggested changes have been read at the previous meeting. Amendments will go into effect immediately.

IX. Rules of Order

Each general meeting will be conducted according to a written agenda. Robert's Rules of Order will be followed unless the council wishes to change or add to the rules based on the determination of the group.

Sources:

How to Organize and Direct an Effective Resident Council: A Technical Assistance Manual of the Missouri Long-Term Care Ombudsman Program, April 2005. 800.309.3282. <http://www.dhss.mo.gov/Ombudsman>

Resident Council Handbook: Creating Opportunities for Meaningful Decision-making. Resident Councils of Washington, 2001. 360.275.8000. www.residentcouncil.org.

The Resource to Effective Nursing Home Councils. ElderCare Rights Alliance, 2005. 952.854.7304. www.eldercarerights.org.

**RENAISSANCE GARDENS AT RIDERWOOD
FAMILY COUNCIL**

BYLAWS

I. Applicability

These Bylaws provide for the governance and operation of the Renaissance Gardens at Riderwood Family Council (hereinafter referred to as "Council"). Renaissance Gardens at Riderwood is an assisted living, skilled nursing and rehabilitation facility located in Prince George's County, Maryland on the campus of Riderwood Village, an Erickson Continuing Care Retirement Community. The Council is an organization of family members and other individuals associated with residents of Renaissance Gardens at Riderwood. The right to form and hold a family council independent of the management and staff of a nursing home is provided by the 1987 Federal Nursing Home Reform Act.

II. Purpose

The purpose of the Council is to provide a structure for families, as a consumer group, to (a) discuss and take actions related to improving the care, well-being, and happiness of all residents of Renaissance Gardens at Riderwood and (b) provide a forum for families to learn more about Riderwood Village, Renaissance Gardens at Riderwood, the long-term health care system, and concerns of other families.

III. Membership

Council membership shall be restricted to qualified individuals. Qualified individuals include: (a) relatives of a resident; (b) the legal guardian of a resident; and (c) individuals appointed by a resident, or if the individual is incapable of appointing an individual, individuals appointed by a relative of a resident. A qualified individual shall immediately become a member of the Council (hereinafter referred to as "Member") by submitting a membership application. Membership shall remain in force until terminated by the Member.

IV. Officers

There shall be three officers of the Council: (a) Chair and (b) two Vice Chairs. Each officer shall be a Member and serve without compensation.

Officers shall be nominated and elected during the December Council meeting for a term of one year. A vacancy in any office shall be filled by election for the remainder of the term. Newly-elected officers shall take office immediately upon election. An elected officer may be removed from office by the Council.

Unless there is only one candidate for an office the election of officers shall be by ballot vote. If no candidate gets a majority on the first ballot, the candidate getting the least number of votes shall be eliminated. The voting shall continue until one candidate gets a majority.

V. Meetings

Council meetings shall be held in the Rose Court Garden Room at Renaissance Gardens at 7:00 p.m. on the first Wednesday of each month or at such other time or place designated by the Chair. Notice shall be given to each Member by electronic or regular mail at least seven days prior to a Council meeting. The notice shall include an agenda.

Council meetings shall be open to (a) Members and (b) non-members who have been invited by the Chair. The presence of Members associated with ten or more residents shall constitute a quorum. A quorum shall be required to conduct business.

Robert's Rules of Order Newly Revised shall be the parliamentary procedure at Council meetings. The votes of a simple majority of the Members present and voting in person, subject to the limitation that only one indivisible vote may be cast with respect to each resident, shall decide any question.

VI. Amendments

These Bylaws may be amended by the Council, subject to the requirement that the text of a proposed amendment shall be (a) introduced by a Member at the previous Council meeting and (b) included with the agenda of the Council meeting during which the amendment is to be considered.

Family Councils

Family councils are groups that meet regularly and whose membership includes family and friends of residents. Like resident councils, there is language in federal law that mandates that the facility provide support and assistance to family councils. [§483.10] However, even with the federal nursing home law supporting family councils, the reality is that few facilities have active family councils. This may be changing. More facilities are seeking Joint Commission on Accreditation of Healthcare Organization accreditation, which requires more active support and encouragement of family councils from the facility.

Family councils provide a needed link to the world outside of the facility for residents. They are especially valuable in the small, assisted living facilities where residents may be hesitant to voice concerns. They can be a buffer for residents having problems with the homes' administration and can provide an oversight from the community that is invaluable.

One of the reasons that family councils do not develop is that family members and friends have limited time and may not be able to both visit their loved one and attend a family council meeting. Unless there is a pressing need, many family members and friends understandably would rather spend their time visiting.

Importance of Family Councils

Family councils can be a vehicle for breaking the isolation of residents and family members. Additionally, they can provide needed validation for family members and residents. Sometimes family members feel as though they are "causing trouble" if they bring forward a complaint. In isolation, a family member may believe that they are the only family experiencing problems.

There is strength in numbers when voicing complaints or concerns to facility management.

Complaints are far less likely to be brushed aside or blamed on the resident when brought forth by a family council. It is easy to ignore a complaint when the administrator hears from a lone family member; but when the concern is brought forth in a group setting, there is the public relations need, if nothing else, that will propel the concern forward to resolution. It is true that there is "strength in numbers".

Some facilities hold information-sharing sessions or support groups such as an Alzheimer's support group and label them as a family council. Although they may be very helpful to family members, they are not what is meant by a family council. Family councils are regular meetings run by family and friends of residents with the support of facility staff. Family councils can be very powerful. Some are completely run by family and friends of residents. Staff can come to their meetings by invitation only!

One family council member felt that the greatest benefit to her was the fact that through the council she had developed friendships with other family members. When she could not visit with her mom, she could call another family member and ask them to look in on her mom. This shared “looking out” for each other contributes to her feeling that her mother is all right even on the rare evening she cannot visit.

Joint Family Councils

Sometimes family members may want to join together with family members from another facility because there are too few family members from just one facility. At other times, family councils join together because some problems are too large for one family council to tackle. Ombudsmen have knowledge of the concerns of not only one home but of others in the area. If s/he hears the same concerns voiced by family members from different homes, it most likely surrounds an issue that needs to be addressed at a higher level. The ombudsman program can be instrumental in bringing people together. S/he can let people know that they are not alone, that others have voiced similar concerns. The ombudsman can ask them if they have any interest in getting together with others who are concerned and, with their permission, can share their name with others. The ombudsman program can also hold open forums where people can come together to voice concerns.

*Ombudsmen
help bring
people together.*

As effective as a family council in a given home can be, joint family councils can be a powerful voice for change. They can affect change in large ways, such as impacting the legislative process to address concerns systemically, or to change policy in the Medicaid office. For example, perhaps a number of family councils are concerned about under-staffing. They can each address this problem at their own facility. But they may also want to bring the problem of under-staffing throughout the area to the attention of state officials. They might want to become engaged in an effort to increase the minimum staffing level in facilities. Another big concern for many residents and families is the need for privacy. This, too, would need to be tackled on a system level. Perhaps a coalition of family groups would want to advocate for passage of a law requiring all newly-built facilities to have more single rooms.

Joint family groups can become even more powerful by joining other citizen action groups to form coalitions that support needed change. A few excellent resources on family councils follow.

Family Council Resources

Family Education & Outreach: Final Report

The National Citizens' Coalition for
Nursing Home Reform
1828 L Street, Suite 801
Washington, DC 20036
Phone: 202-332-2275; Fax: 202-332-2949
www.nursinghomeaction.org

Long Term Care Ombudsman Guide To Developing And Supporting Family Councils and the Family Guide To Effective Family Councils

Robyn Grant, Consultant
The Legal Assistance Foundation of
Metropolitan Chicago
111 W. Jackson Boulevard, 3rd Floor
Chicago, IL 60604
Phone: 312-341-1071, ext. 8341;
Fax: 312-612-1441
www.lafchicago.org

Nursing Home Family Council Manual

Texas Advocates for Nursing Home
Residents
P.O. Box 68
DeSoto, TX 75123
Phone: 972-572-6330; Fax: 972-572-7954
www.tanhr.org

Elder Care Rights Alliance

2626 East 82nd Street, Suite 220
Bloomington MN 55425-1381
Phone: 952-854-7304; Fax: 952-854-8535
www.eldercarerights.org

Friends & Relatives of the Institutionalized Aged, Inc.

18 John Street, Suite 905
New York, NY 10038
Phone: 212-732-4455; Fax: 212-732-6945
www.fria.org

STORIES

EMPOWERMENT

Long-term care ombudsmen, activities professionals, and others submitted the following stories and others related to residents exercising choice.

A Long Term Care Ombudsman had a 96-year-old resident at a facility in central Illinois. This resident was in a wheelchair and determined to return home. The resident talked to the LTCO about how beautiful her house was, and how she needed to get home to take care of it. The resident was alert and once again determined to go home. The Ombudsman talked with the resident help at home, and the resident made it clear to the Ombudsman that she would not need help. She talked about the wonderful neighbors that she was 'blessed' with. When the Ombudsman asked about cleaning and scrubbing the floor, and that maybe the resident could have someone come in once a week to assist with cleaning, she graciously declined help stating that should would put a wet rag on the floor and move it with her feet. After many conversations with the resident, and the resident and the facility, a cab was called and the resident returned home. She called the facility the next day to let them know everything was fine and she was happy to be home. The resident was able to live her final days (6 months) the way she wanted, in her own home. This case taught the Ombudsman to ask the question: just because a person is over the age of 80 or 90 why do people assume they can no longer make decisions for themselves?

A resident, Mary needed dental treatment and a full set of dentures. The MCHHS was able to provide her with a dental exam and dentures through our Senior Voucher Program run by the Senior Dental Program. Mary was aware of the lack of dental treatment in nursing facilities and she was very appreciative of the care given to her by our program. She was asked and graciously accepted to testify in the Maryland General Assembly House and Senate chambers for a Dental hygiene bill to provide preventive dental hygiene services, without restrictive supervision provision to residents. The nursing home administrator had her transported (two separate occasions) and he accompanied her along with an aide. One of the days was a very snowy day but Mary was there and did an excellent job of speaking with the health committees of the House and Senate on Dental hygiene concerns. The profession of Dental Hygiene is working very diligently with the legislators to expand oral health services to residents of nursing facilities as well as assisted living facilities. The bill did not pass through the chambers, but the legislators were given valuable information coming from a resident of a facility.

Submitted by: Susan Polydoroff, RDH, Coordinator Senior Dental Program
Montgomery County Health & Human Services (MCHHS)

I want to start by telling you a little bit about a certain elder that lives here. Her name is June Miller and she is 90 years old. She has lived here for about two years now. She has a roommate named Miss Muffin (her cat) that has been here with her since shortly after she moved in. June has got one of the most delightful personalities of anyone I have ever taken care of. She has been a schoolteacher all of her life.

After being here for a short while June started looking for things to do and noticed that our library was in need of a little TLC. Actually as June puts it "I was out rolling around and noticed these big bookshelves, I was looking at the titles and didn't see any interesting ones. After spending some time observing, I never noticed anyone around the library; it didn't seem anyone was in charge. So I talked to the activities director and started asking her questions about the library. In one of our many conversations about the library she asked me if I would like to be the librarian. I told her I knew nothing about being a librarian. She told me that I would make a fine librarian being a schoolteacher and all. June is now our librarian. They spread the word that the library was up and running and June was in charge of things and soon the books came pouring in. She was happily surprised at the number of books she received. She inventories all of the books and alphabetizes them by author. Every day she spends at least an hour straightening things up, arranging the books and putting in new ones. She has a check out sheet on a table in the library. Lots of people check out books including other residents, family members and staff members. You better make sure your book is back on time because she will hunt you down to get it back.

Submitted by: Chandra Wilson, a CNA/QMA, Provena Sacred Heart Nursing Home, Avilla, Indiana.

Residents of the Calhoun County Medical Care Facility in Battle Creek, Michigan care about their community, both in the nursing home and out. After hearing of the devastation and aftermath of Hurricane Katrina in Louisiana last fall, the resident council voted to contribute \$500 to the Louisiana Long Term Care Foundation. This summer they chose to contribute another \$500 to the *YES for Seniors* Millage campaign for the renewal of the Calhoun County Medical Care Facility Millage and the Calhoun County Senior Millage, both that serve seniors in need throughout the county.

On a nursing home community level, residents gather daily for activity and casual conversation. Residents Rose, Helen, Grace, Irene, Dollie, Linda, and Uncle Bud roll napkins daily for 120 residents for both lunch and dinner. It becomes a social time for them, where they reminisce about days gone by. They enjoy the stories shared by everyone in the room. Another group of residents fold and put address labels on 140 facility newsletters each month. Another resident, Helen, is a former missionary, and has empowered herself to lead a Bible Study group for other residents two times each month. In addition, each Sunday the facility offers a church service at which a long time facility resident, Maria, leads with the assistance of the Activity Staff. She chooses the material to be used and the scripture to be read each Sunday.

These are just a few of the many things residents and the Resident Council of the facility are doing that allow their lives to be and feel dignified, important, and meaningful while a resident of the Calhoun County Medical Care Facility.

Submitted by: Sally Dull, CTRS, Activity Director, Calhoun County Medical Care Facility, Battle Creek, Michigan

In 2005, Ten residents of the Gino Merli Veterans Center participated in the Pennsylvania's Empowered Resident Experts (PEER) program. This group began to move toward empowerment advocating for themselves and the other residents of this nursing facility. The group was instrumental, serving on a food committee where they are working with facility staff to improve the quality of meals served and were able to immediately restore condiments to the menu that they had not had for several months.

This group also worked with staff to resolve an issue of caregivers using cellular telephones while providing care to residents. The residents expressed that this was upsetting to them and that they did not feel they were getting personal treatment with the phones being used while care was being given. This resulted in a new facility policy about the use of cellular telephones during work hours—staff are now permitted to use cellular phones during break times.

This group has also been working with the activities director to increase the number of activities available to residents. Ombudsman posters have been erected on every floor of the facility with the name and room numbers of all PEER graduates so that all residents of the facility have easy access to PEER advocates if there is a problem or they need assistance. The group has also started a welcoming committee, which includes new admissions in the facility, and explains the PEER program. This group also participated in the National Residents Rights poster contest during October 2005.

The group received the 2006 Annual PEER Award, which was held in May, Harrisburg, Pennsylvania. Ron Grabowski, the Therapeutic Activities & Certified Activities Director at Gino Merli Veterans Center said it best:

“The PEER program in itself is one of the most invigorating programs I've been associated with. It brought new life to the residents and a shining light to the facility. Our PEER group has become a new path for residents to express their concerns with positive results. In addition, it has also boosted morale and self-esteem for the group and other residents.”

Submitted By: Kimberly Shetler, Regional Ombudsman Coordinator, State of Pennsylvania