



for your INFORMATION

Friends Of Residents In Long Term Care Newsletter

Winter 2005

Volume XIX

Issue Four

in this
ISSUE

Mission: Critical
Page 2

*Words from the
Board Chair*
Page 4

*Membership
Contributions*
Sept. - Nov. 2005
Page 5

*Special Focus:
Mixed Populations*
Pages 6, 7, & 10

*Who's Looking
Out for Mother?*
Page 11

and More...!!!



Events Committee Member Geri Cross, left, and other bidders listened eagerly as Fall Fun Fling Guest Emcee Bill Gaines announced the winners of the silent auction.

*Oh
What
A
Night!*

None of the 80,000 North Carolina adults who can't live independently walked through the Academy door on the warm fall night of November 4 – but their Friends did. About 100 of them enjoyed FORLTC's second annual Fall Fun Fling while raising more than \$8,000 on behalf of frail and disabled citizens, forgotten if not neglected by many, and those who care for them.

FORLTC Board Members came from as far away as Charlotte to help host an evening of food, fun and fellowship in the Raleigh building where Roger Manus, who chaired the board last year, has his office. There two dynamic members of his staff and other volunteers had set up elaborate displays sprinkled with colorful leaves for the silent auction. On the upper level, FORLTC Member Lanelle Davis, who donated her talent, performed with the other two members of her band.

Bill Gaines of Channel 17 took time out between his news broadcasts to volunteer as guest emcee. Board Chair Bill Lamb, after putting his mother into the hospital earlier in the week and running a hearing involving misconduct by a social worker in Chapel Hill that Friday, greeted guests and

continued on pg. 9

The mission of Friends of Residents in Long Term Care is to promote the highest quality of life for those who cannot live independently, and for those who care for them.

MISSION: CRITICAL

It's not Mission: Impossible. There's no self-destruct tape. There are no high-tech gadgets far beyond anything the world has yet seen. There are also no professional actors, imaginative screenwriters and gargantuan budgets enabling our heroes to succeed.

The mission of Friends of Residents in Long Term Care (FORLTC) is a real one addressing critical needs on behalf of vulnerable citizens. It resembles the fantasy in one respect: it's a mission few people are prepared to undertake. In North Carolina, FORLTC is the only independent, non-profit group working to promote the highest quality of life for those who cannot live independently, and for those who care for them.

FORLTC Board Member John Young warned our four new board members about the difficulty of this mission during their orientation. He explained that the overwhelming majority of people refuse to think about "our" issues until they absolutely have to. Many are then totally overwhelmed until the crisis ends or their loved one dies. Finally, they are too exhausted or simply too self-centered to want to be involved in helping others in long term care.

Our donors, board members, committee members, and other volunteers are the exception to this rule, and the board members, who donate their time, bring a special dedication. Most of them have had direct experience with a loved one in long term care, as many across the state have had, but most of these folks made an ongoing commitment before or after being personally involved with such a challenging situation. As 2005 ends, they continue to run the organization with just one half-time staff member and are making plans to continue to monitor and address ongoing and emerging needs in the field of long term care in 2006 and beyond.

This newsletter, a quarterly benefit of membership, has profiled some of them in the past and plans to do so in the future. This issue focuses both on key policy concerns and on the success of our second Fall Fun Fling for Friends.

Best wishes to all for happy holidays and a wonderful new year as we continue to partner together on behalf of those in need of our efforts.

Moving? E-Mail Address Changed?

If you have moved recently, or if your e-mail address has changed in the last year, please keep FORLTC updated. Just call us at 1-888-411-7571 with your new information. It's important to keep up with you! Thanks for your help.

For Your Information

The newsletter of Friends of Residents in Long Term Care

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Hillsborough Street, Raleigh, NC

For Your Information is published four times yearly and is a benefit of annual membership in Friends of Residents in Long Term Care.

NATIONWIDE HONORS: Two FORLTC Members Honored by NCCNHR

Two active members of Friends of Residents in Long Term Care have been honored by the National Citizens Coalition on Nursing Home Reform.

Carol Teal, past board member and executive director of FORLTC, was elected to serve as president-elect of NCCNHR at their annual meeting held in Washington, D.C., this past October. Carol was serving on the NCCNHR board of directors as a voting group representative member on behalf of FORLTC. She will begin her term as president at the NCCNHR annual meeting in October of 2006.

Ombudsman Debi Lee from Centralina Area Agency on Aging received the first Howard Hinds Award. This award was established in 2005 and honors an individual who has effectively advocated for long term care residents on the local level for many years. Debi received the award based on her diligent work to improve the quality of life for North Carolina long term care residents and her instrumental work in the formation of both the National Association of Local Long Term Care Ombudsmen and the North Carolina Regional Long Term Care Ombudsman Association.

Congratulations to both Carol and Debi. FORLTC has both a presence and an impact outside of North Carolina! We are proud of you both.

PENALTY REVIEW COMMITTEE: AN UNCERTAIN FUTURE

For some time, the nine-member Penalty Review Committee (PRC) has met monthly to consider penalties that were proposed for adult homes. FORLTC Vice Chair Beverley Wheeler faithfully attended many of these meetings, and we have devoted considerable space in this newsletter and on our website to publishing PRC findings.

Earlier this year, FORLTC helped block a move to abolish the PRC, but new legislation called for changes to be made. In September, FORLTC Public Policy Committee Member Christopher Ivy began serving on a Stakeholders Committee to consider the implementation of these changes. In his initial report to the FORLTC Board of Directors, he indicated that much confusion still exists; we expect to present a detailed report from him in a future edition of this newsletter.

In the meantime, the PRC met according to the previous format in September and October. Please check the FORLTC website for those findings as well as the archived findings from previous meetings. However, the new legislation states that the PRC “shall meet at least semiannually” and the implications of this are among those that are being considered.

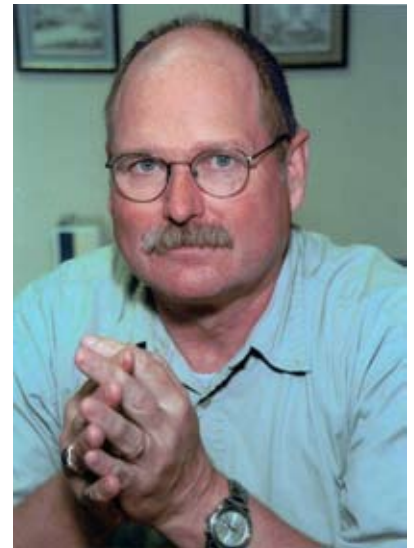
We can report, however, that at the October meeting the group decided not to meet in November and December. If you would like to inquire further regarding this matter, please give us a call at 782-1530.

Words from the Board Chair

By Bill Lamb

Creating a Family Council: A Group Bound for Success was the brain child of Carol Teal, former Executive Director of Friends of Residents in Long Term Care, who chose to make 2003 the “*Year of the Family Council*.” In honor of this designation she envisioned creating a state-specific manual to guide and direct families in assuring their loved ones receive quality care as they reside in long term care facilities.

In November of this year, I was finally able to take the finished product to our printers. A week later we received 1,000 copies available for distribution through the ombudsman program or through the Friends of Residents office for a nominal mailing and handling fee.



FORLTC Board Chair Bill Lamb

This manual is a culmination of many months of hard work and dedication by committed advocates for family empowerment. In addition to Carol Teal, I appreciate the time and expertise of all the individuals who contributed to this manual, especially those individuals on the initial planning committee: Pam Barger, Sherry Harris, Ruth Klemmer, Kathryn Lanier, Sharalyn Merritt, Nancy Murphy, Charlene Riedel-Leo, and Sharon Wilder. I also want to thank Sandy Spillman and Brookcare of North Carolina for helping to get the manual printed and distributed. If you want a copy, contact your regional ombudsman or contact the Friends office.

As noted in this newsletter, we just held our second annual Fall Fun Fling for Friends. Since I am in the mood for “thank you’s,” I would be remiss not to thank the group who worked to put on this event: Dr. Leroy King, John Suddath, Helen Savage, Jim Ankeny, Sharon Wilder and June Bolton and particularly Rozanne Reynolds and Geri Cross. While the whole committee worked tirelessly on this event, Rozanne and Geri went above and beyond the call of duty. I also need to thank Roger Manus, former board chair, for his generosity in granting them time to work on this event. A great time was had by all.

This is my last column as board chair. (I know, I said that before; but this time I mean it.) I really have appreciated the opportunity to serve and will continue to support Friends of Residents as a board member and any other way I can be of help. This organization means so much to the lives and rights of residents in long term care facilities and to their family members. Families and friends of long term care residents should expect and receive quality of care and life for their loved ones. I can say that now as such a family member with a mother in a long term care facility -- a perspective that only heightens my passion for the issues involved.

Thanks so much for your membership and support. You make the voice of residents heard in the legislature and governmental offices. In the public policy debates about regulations and resources, Friends of Residents is the sole organization independently representing the interests of residents and their family members. It is a voice that needs to continue to be heard first and foremost. If you have not renewed your membership for 2006, now is the time to do it and please consider increasing your contribution. We need it and so do the residents in our facilities.

Membership Contributions from September through November 2005

Thank you to these contributors for helping continue our mission!

BENEFACTORS AND SUPER FRIENDS

(\$1,000 and up)

Brookcare of North Carolina

Anne Duvoisin

Daniel Hudgins

Dr. J. LeRoy King

William E. Lamb

Roger Manus

Sara M. Ratchford

Michael Schafale

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Dr. Paul and Mrs. Tiffany Woodard

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Bill Lamb and Roger Manus

By Carolyn King

IN MEMORY OF

Mrs. Dale Rosenbloom Fuerst

By Charlene Riedel-Leo

ADVOCATE

(\$100-249)

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Community United Church of Christ

Brenda H. Compton

Woody Connette

Eastern Carolina Council

Marge Eckels

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Carol Kepler

Mr. and Mrs. Thomas King

Ruby Lamb

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By Anne L. Schmitt

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Anne Denmark Beaty

Ellen Beidler

James and Annette Epps

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Dana Courtney

Janet Downs

Barbara Jackson

Jeanne Ledbetter

Carolyn Register

Maria Riemann

SPECIAL FOCUS ON A 2005 FORLTC ADVOCACY

Mixed Populations in Adult Care Homes: A Personal View

By Polly Williams

“I was elected President of the World,” the elderly woman said to me, “but I have never been able to serve.” I was visiting in her adult care home, and she was explaining to me why I needed to help her get off her medications. She wanted to go to Washington to assist the President.

As a member of the volunteer county advisory committee, I was supposed to respond to complaints, but this was not one I could handle. Over time, however, I became good friends with this woman, who would show me her letters to the President. Once when a television anchor mentioned that most people were not aware that June 14th was Flag Day, I was amused — my friend knew well that it was Flag Day and had already written the President a letter about it.

Our meetings were taking place in an assisted living facility where many of the frail elderly residents had cognitive problems as well as physical ones. My friend Doris fit in very well there, and the aides got along with her, more or less.

On the other hand, in that same adult care home, I talked with a much younger woman who had recently been discharged from a psychiatric hospital and who was bitterly unhappy. She was horrendously bored, with no activities that suited her and no one to whom she could really talk. She was well able to carry on an intelligent conversation, but many of the other residents were not. Most of the aides spoke little English. A resident at another time was a young man who had been dumped in the adult care home to rid himself of a substance abuse problem. He spent time working in the vegetable garden to relieve his frustration with this place where he thought he did not belong.

More and more persons who are not elderly or physically disabled but have some form of mental illness are sent to live in adult care homes under the pretense that in this way they are being returned to the community and that they have chosen this environment. Supposedly special accommodations in the way of activities and treatment are provided for them, although often they are not.

Adult care homes are required to provide activities for their residents, but these often consist of bingo, Bible study (offered by a local church member), and videos of old Western movies. Exercises are performed sitting down. “Current Events” may consist of a discussion of the day’s advice column. The alternative is daytime TV. Books and up-to-date magazines may be hard to come by. A young, active person may be bored to tears, or to worse behavior.

Even more serious than the lack of appropriate activities is the lack of adequate training for aides in the home. Staff members may not know how to monitor side effects from the psychotropic drugs they are handing out. Aides also may not be well trained to manage challenging behaviors that can sometimes be associated with mental illness. They may not be alert to problematic behavior changes, and they may not know when to intervene in a particular situation before it becomes disruptive.

And that’s the other side of the problem — the way it is viewed by advocates for the elderly. While advocates for persons with mental illness object to the inadequacies of life in an adult care home for those they are concerned about, advocates for the aging object to the potential risks of abuse — verbal, physical, or sexual -- for the frail elderly and physically disabled residents.

A woman I knew was beaten up by another resident. Because she was blind, she didn’t know how badly she was bruised. After one look, a friend who had come to take her to church took her to the police station instead.

continued on pg. 10

PRIORITY AND ONGOING CONCERN

Mixed Populations: A FORLTC Policy Perspective

By Roger Manus

North Carolina law currently provides separate licensing standards for various types of long term care facilities that house persons with mental illness. To a greater or lesser extent these licensing standards require practices and staff training designated to meet the needs of persons with mental illness.

Yet about 5000 adults with mental illness live in the generic adult care homes instead of the more specifically licensed facilities. These residents account for about a fifth of the population of these adult care homes. Many of these persons with mental illness are under the age of 60, i.e. younger than their co-residents. Most of them live in adult care homes that serve primarily low-income residents (a.k.a. "rest homes"). In many cases, they have been discharged to the rest homes directly from state psychiatric hospitals. This is a disservice to the facility residents with mental illness and to the facility residents who are old and frail.

Disservice to Facility Residents

Persons with severe and persistent mental illness need the support of staff who are specifically trained and skilled -- staff who speak in ways that are reassuring instead of inciting, staff who can notice when the person's prescribed antipsychotic medication(s) might be doing more harm than good, staff who can understand and follow the behavior support aspects of a care plan. Persons with severe and persistent mental illness need support persons and activities (in and out of a resident's facility) that engage them in a meaningful and ongoing way. They do not get this in most rest homes. Instead, they often get a regimen of TV, coffee, cigarettes, and wandering -- an exacerbation of demoralization.

Often facility residents who are old and frail fear their younger co-residents who have severe and persistent mental illness. Usually, this fear is misguided, but sometimes it is not. Recent instances of sexual assault and homicide illustrate the danger.

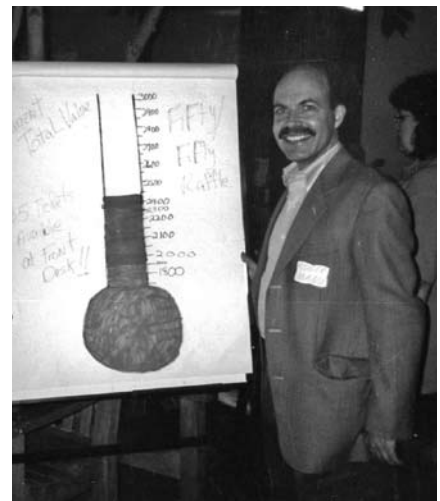
Why Does It Happen?

Why does our state allow and even perpetuate this dangerous and neglectful practice? Money. It is cheaper to funnel persons with severe and persistent mental illness into generic rest homes than to develop appropriate non-institutionalized services to truly meet their needs. When the executive branch of the state government does not frankly and boldly proclaim the need, it is easier for legislators to kid themselves and the public into believing that tax resources should go for corporate giveaways and even more tax breaks for the wealthy. We advocates must find a way to pierce this cloud of complacency.

FORLTC's Position

In response, FORLTC adopted the following position:

- Meet adequately the needs of medically diverse populations in appropriate settings and appropriate groupings through appropriate reimbursement structures, resulting in adequate assessment, diversion, and specialized services for such populations.
- Address the need for mental health facilities for those who cannot live at home.
- When a person's mental health needs override physical care



Past Board Chair Roger Manus shared in the excitement as the 50/50 raffle pool grew at the Fall Fun Fling for Friends. See page 9 for the announcement of the Winner.

continued on pg. 9



**Some
Friends
of
“the least
of these”**





Bert Lamb and Ashley Campione



**Event Committee Members
Helen Savage and Rozanne Reynolds**

continued from page 1

worked closely with Mr. Gaines to announce winners throughout the evening. Though the ticket stubs were well shuffled, two consecutive stubs were chosen at different times; consequently Bud Frank went home with an autographed copy of Board Member John Suddath’s book while Mara Frank won a tote bag. Jennifer Eckersley, John Little, Darren Stover and Kelly Taft also won door prizes.

FORLTC committee members and former staff were among those donating and bidding on a wide variety of items for the silent auction. Bidders circled around the bid sheets for hotly-contested items such as a gift certificate for housecleaning, while others relaxed with beverages and gourmet treats such as Apple Cream Cheese Tarts and Chocolate Truffles.

A very pregnant Charlene Riedel-Leo took time off from finalizing the Long Term Care 101 curriculum and with her husband won a bottle of fine wine for an upcoming celebration. Other silent auction winners and finally the “big winner” of the 50/50 raffle (see below) were announced, and a good time was had by all on behalf of some of “the least of these” in our society.

Charlotte Attorney Wins Big



Woody Connette

When Woody Connette decided to buy 20 tickets for the Fall Fun Fling for Friends 50/50 raffle from Past Board Chair Roger Manus, Roger had already sold so many that he could only fill out 10 stubs. The 10 additional stubs were filled out in the FORLTC office and included in the drawing, and Woody’s check for \$100 was actually deposited on the very day of the event. Many more tickets were sold prior to those 20 and during the event as excitement mounted right up until Bill Gaines reached in to draw the big winner, but it was one of Woody’s tickets that won the \$1,375 payout.

Woody practices law in Charlotte and has a long history of public interest legal work including law reform cases on behalf of persons with mental disabilities. He told FORLTC he was pleased to win, noting that this was the first time he had won anything since winning a baseball in the sixth grade.

Woody made arrangements to donate a portion of his winnings back to FORLTC, adding, “I really am tickled to win the lottery, but more than anything I appreciate the work that you are doing.” We heartily congratulate Woody and welcome him as an Advocate Member.

continued from page 6

The police may not be well schooled in how to handle such situations, however. In this case the woman was simply moved to another home.

In a family care home in Burlington, NC, an 88-year-old woman was murdered by a fellow resident, a 25-year-old man with a previous record of assault. (A family care home has two to six residents living at close quarters.) The woman was strangled and stabbed in the chest; her assailant was found not competent to be tried.

One problem in this case was the lack of adequate pre-admission screening of residents. Other problems where populations are mixed involve drug or alcohol abuse in the homes, the insufficiency in health care and mental health treatment offered to younger residents, and punishments for “bad” behavior (as determined by staff members) that violate residents’ rights.

All in all, a young, aggressive person, just discharged from a psychiatric hospital, is not well located in a home filled with tottery old folks. Every case is not so clear-cut, however. Doris may live with a fantasy about her world presidency, but she does no one any harm and quite likes life in the adult care home except that they don’t take her shopping often enough. Some persons with mental illness or other cognitive disabilities may do well there; others will not. A sorting-out process must be developed whereby screening and assessment before admission will allow placement in homes in which residents can get care suited to their needs. And more and better homes are needed for younger persons whose needs are too often neglected.

Legislators are becoming aware of this troublesome situation but are having difficulty keeping up with funding for programs already in existence. Concern must grow into specific plans for better community support and housing choices for persons with mental illness, as well as additional requirements for those facilities that accept them.

continued from page 7

- needs, the person should be served in settings licensed by G.S. 122-C, administered through the State Mental Health Commission. (122-C facilities are also called 24-hour treatment facilities.)
- When a person’s physical care needs override mental health needs, an adult care home or nursing home should serve that person.
 - To meet the needs of aggressive persons or sexual offenders, a Pre-Admission Screening and Resident Review (PASARR)-type evaluation should be conducted to determine how best to meet that person’s needs.
 - Define clearly the meaning and operation of special care units.
 - Where locked units or groupings of patients with Alzheimer’s or related dementias exist, require that the locked units be deemed special care units so that all such units will be required to have enhanced staffing, training, and activities to meet the needs of the residents.
 - Use Medicaid and Special Assistance funding to improve the reimbursement structure for those units that meet the higher standards, thus enhancing the safety and health of residents, increasing staffing, and improving availability.

Recent Developments

The General Assembly recently required the Department of Health and Human Services (DHHS) to work with providers and advocates to study the problem and make recommendations. FORLTC Board Member and Ombudsman Jill Passmore represented FORLTC in that effort. Some industry representatives urged that adult care homes continue to admit persons with a primary diagnosis of mental illness, and be allowed to restrict rights currently recognized by the Residents Bill of Rights. This proposal was reportedly blocked. DHHS has asked for an extension until January, 2006 to report its findings and recommendations to the North Carolina Commission on Aging.

Who's Looking Out for Mother?

By Polly Williams

Nursing homes and adult care homes (rest homes) have different types of supervision. If your mother is in a nursing home, her care is monitored by the state — namely, the Division of Facility Services (DFS) in the Department of Health and Human Services — under federal regulations. If she is in a rest home, the monitoring agency is the county Social Services Department (DSS), under state regulations. When county monitors discover violations that require penalties, they call in DFS, which may change the amount of the penalty.

Why not combine these two kinds of monitoring, take the burden of oversight off the counties, and let the state agency do it all? Every few years this proposal surfaces again, and once again those concerned about the well-being of residents in adult care homes must explain that **this is a really bad idea**. Those who most favor the change would like a chummy relationship between monitors and administrators. This sort of relationship develops most readily between state agency employees and the representatives of nursing home and assisted living trade associations and trickles down to state monitors and facilities' administrators. It doesn't make for good supervision.

State monitors, moreover, are required to visit nursing homes only once a year, whereas adult care home specialists show up every two months to give a thorough inspection of the facility. Because the adult home specialists are nearby in the local DSS Office, they can be on the spot quickly when they receive a complaint or learn of an emergency.

Also, they are acquainted with community resources. Consequently, help is at hand, not in Raleigh, in cases of injury or abuse or other violations. A DSS representative attends the monthly meeting of the county adult care home advisory committee, made up of volunteers who visit homes regularly to monitor whether residents' rights are observed. The ombudsman from the regional Area Association on Aging attends as well, and a great deal of information on improvements, problems, violations, and administrative changes in homes is exchanged at these meetings. The county adult home specialists often know where problems are before they surface; they are familiar with both management and residents of the homes in their locality.

Proponents of a change to monitoring by DFS cite the uneven application of regulations from one county to another and lax supervision in some counties. The answer is not to shift to a system of even less supervision but to a system of comprehensive training for county adult home specialists. Over the years, staff throughout the counties have been doing a better job of supervision and can certainly do even better with some help from the state. Were the responsibility for monitoring turned over to the state, the system would not only be less efficient but also less cost effective, since the state would have to hire more inspectors, while county staff would become case managers.

Considerations of efficiency and cost are extremely important; nevertheless, quality of care is the most important consideration of all. With frequent changes in administration and much more frequent turnover of caregivers, quality of care in any adult care home can change dramatically in a short time. Once-a-year inspections cannot guarantee that the good care residents and their families expect can be maintained.