

Giving Voice to Quality

*The National Citizens' Coalition for Nursing Home Reform consumer education project;
Funded by the Retirement Research Foundation*

EDUCATIONAL CONFERENCE CALL #3 IN OUR SERIES: “AFFIRMING DIGNITY AND INDIVIDUALITY: A LOOK AT RESIDENTS’ RIGHTS” TUESDAY, AUGUST 22, 2006 – 3PM (ET) [2PM CT / 1PM MT / 12PM PT]

EDUCATIONAL CONFERENCE CALL MINUTES

1. Welcome & Project Overview
 - This call series, on issues of quality in nursing homes, has been funded by the Retirement Research Foundation. The project began centered around the concept that while staff and professionals have access to information about nursing home quality care issues, family and residents often do not.
 - This project will help educate people by tapping into a national pool of experts. It will help inform families and residents on how to improve the quality of life and care in nursing homes they (or their family members) are in.
 - The calls have been successful. For example, we have seen people make connections across the country with people that have similar questions and issues. People are beginning to understand that they are not alone, and what types of progress are, possible, and are being made on issues.
2. Introduction of Robyn Grant the Conference Call Special Facilitator
3. Conference Call Overview – Robyn Grant
 - We welcome you, and are excited that so many have folks have been able to join us.
 - This call is "Affirming Dignity and Individuality: A look at Residents’ Rights" – our theme today is Residents’ rights
 - Residents' Rights is the foundation that is essential for quality nursing home living.
 - I would like to outline the agenda at this point. (Lists speakers' names and topics to be covered.)
 - Also later in the call we will look at a situation regarding residents' rights in a nursing home, and brainstorm together about ways to solve the issues. Throughout the call we will provide opportunities for you, the participants, to ask questions.
 - We want you to understand the logistics of the call. During speaker presentations the lines are muted. As mentioned earlier, after each speaker there will be an opportunity to ask questions, as the lines will be opened one by one.
 - The total time for the call is about 75 minutes. So please keep your comments and questions brief in order to provide enough time to respond.
 - One last detail before started – all the resources for this series are available on the NCCNHR website (www.nccnhr.org/consumervoice)
 - Remember the follow-up call for this topic is on September 7th. You will be able to ask more questions and we will provide technical assistance.
4. Speaker Introduction (Carol Scott)

- Carol has been the Missouri Long-Term Care State Ombudsman for the past 15 years.
- Carol served as the President of the National Association of Long-Term Care Ombudsman Programs (NASOP) from 2000 to 2004.
- Carol has extensive experience working at the state level as the former legislative liaison for the Division of Aging and a budget analyst for the Division of Medical Services (Medicaid Program) for two years.
- She serves on many boards and is a part of numerous membership organizations

5. **Expert Speaker Presentation: Carol J. Scott**

- Let me try, in just a few minutes, to talk about something that is very difficult to sum up. The topic of residents' rights is huge, and can take up days. Stop and think about the United States, and the populations that have struggled to be treated with respect and dignity. For example the Civil War, and the fact that it took a war for everyone to come to the consensus that all people are equal. Later woman voting was a struggle, and now we think, "how could anyone think that women couldn't vote." Civil Rights is another example; and how did it happen that all people weren't treated the same? In many years people will look back and think how strange it is that people in nursing homes had to have a law created to be treated with dignity and respect. Just because you cross the threshold of the nursing homes doesn't mean that you can't/shouldn't be able to express your own rights/wants. Just because you are meek doesn't mean you shouldn't know your rights – and be able to uphold them. We need to be like 3 year olds, and ask why.
- Let me ask you to pull out the law and look at what those residents' rights are.
- A good first step is to read the admissions agreement in a nursing home. This is a great resource to understand rights. For example: the right to know the charges; the right to choose the pharmacy/doctor; the right to know that you have 30 days notice, in writing, when a facility is trying to evict you, and they need to provide an explanation on the appeal process.
 - For example) There was a facility where the Mayor told the facility which pharmacy they should use. The administrator stood up and risked being fired and said he couldn't do that because it violated residents' rights.
 - Get a group together to look at the admissions agreement: does it follow the law, is it easy to read, does it express the quality you want.
 - For example) One right that may be important, but ignored is simply knocking on the door before entering. Remember when you were little and brothers and sisters barged in on your room – nothing changes when you're older. You like people to knock.
 - Read your packet of information available on this call. Try to understand why people don't speak up when they need to.
 - Let me refer you to the handout, "Airplane Metaphor and Residents' Rights" training strategy. Use this with staff, especially to understand what it is like to give up – when people enter a facility.

6. Participant Question and Answers

Q Which law do States need to follow first, federal or state residents' rights laws.

A Any facility that accepts Medicare/Medicaid must follow the Federal regulations. If in your state you have state regulations, typically those regulations cover "other" facilities (board & care, assisted living, etc.) So in one facility – you might have to follow both. The best advocacy there, is to try to get those two to be similar.

- Q** Federal law supercedes state law. Some federal law lets the states make the decide. Some residents take advantage of other residents,
- A** One of the things about RR regs – is that Facilities are obligated to make sure that they are getting information from everyone. There are ways to get around that. Mike’s presentation will touch on this more.
- A** What you have is a balancing of rights as well. Ombudsman often get involved in a dispute between residents.
- Q** Residents have some idea of their rights, but they are afraid to say anything because they are afraid of the retaliation. It won’t do any good to be protected by law, because residents say, “You don’t know how they will get even with me.”
- A** In facilities where residents are expressing fear of retaliation – residents should come together as a group (even ad hoc) and advocate for more than themselves – it’s harder to know who to retaliate against.
- A** Get people to sit down to talk (staff and residents) and openly talk about how things are, is the first step to getting some understanding.
- A** Often the administration is not aware that there is retaliation –and need to pay closer attention to the direct care staff.
- A** If there really is a climate to fear, and residents are banding together, it’s good to bring in an outside party to prompt the conversation. Once it’s out in the open it’s easier to deal with.
- Q** What is the order of reporting if you see something is out of order? The nurses' station?
- A** Ombudsmen always check to see who has been approached by the resident. Because sometimes residents tell someone that can’t do anything about it. Calling the ombudsman is always a good option.

7. Speaker Introduction (Mike Connors)

- For the past 28 years, Mike has worked across the country, in California, New Orleans, and Michigan trying to improve choices and care for people, especially those who need long term care.
- Mike works for the California Advocates for Nursing Home Reform (CANHR) as a member of its advocacy team.
- Mike has served as:
 - Director of the Detroit office of Citizens for Better Care (CBC)
 - Michigan Protection and Advocacy
- He has a Bachelor of Arts degree in political science from Michigan State University.

8. Expert Speaker Presentation: Mike Connors

- Thank you for joining us. I think I've been asked to talk about 'complaining,' which often gets a bad name, because I'm often thought of as a complainer! (joke)
- I believe complaining is not only a good thing – it’s practically a civil duty.
- If you don't speak up, nothing will change
 - Necessary to complain or problems won't get fixed
 - Not only is there risk to complaining, there is often greater risk to doing nothing
- There are lots of ways to complain, within and outside the nursing home
 - Take into account your style, and how you handle concerns.
- Usually, best to try solving rights violations within the facility. It's direct, and should often be done first (unless, for example, you are being evicted.)

- Talk to: Staff; find out about how to use the Facility Grievance System; meet with the Administrator or Department Heads; seek out and participate in Care Planning Meetings; work with Resident and Family Councils; and go up the Corporate Ladder.
- The rules of thumb on where to direct concerns are:
 - Find out where people in your nursing home go to get problems fixed.
 - Learn about the nursing home's grievance procedure
 - If problem not too serious, voice concern to the staff who are directly involved.
 - If problems are serious or longstanding, use formal grievance process, notify administrator, and seek allies
- The trick is to find out which approach works best in your facility in your situation.
- You can always complain outside the Facility if the nursing home does not respond to your concerns and anytime a resident is harmed or put in serious danger due to neglect or abuse.
 - Use your ombudsman, the State Survey Agency, or the Attorney General Elder Abuse Units
 - If you are not already aware, the role of the ombudsman is to advocate or guide and support residents as they need. They are experienced and effective, and can persuade the facility, can speak up on your behalf.
 - State inspection agencies have different names in each state, but every state has them. They are responsible for completing annual inspections and investigating complaints. It's a good idea to contact a state inspection agency because it creates a public record. But they are not often very good at helping you solve your problem.
 - Talk to your inspector when they are in your facility.
- For more information on how to complain effectively, you should review the NCCNHR fact sheet on resolving problems in nursing homes.
- Remember though, pick your battles, and don't try to solve too many problems at once.
- Speak up when the problem happens or soon afterward
- Be respectful, non-confrontational and assertive when you voice your complaint
- Be specific
- If possible, put serious concerns in writing
- Strength in numbers
- Depending on situation, seek support of direct caregivers
 - One issue to address with staff as your ally is the problem of short staffing. This is a problem for staff and residents, and directly affects the quality of care in the facility. This is an area to ally yourself to staff as you try to solve problems.

9. Participant Question and Answers

- Q** Question about right for individualized care. I've been trying to advocate for my mother. But from the top down, there is resistance to put it in writing because it commits the facility.
- A** Heart of all the reform laws – want people to be treated like individuals instead of individualized
- A** In a lot of facilities the laws get lip service. She is breaking new ground in her facility.

- A Family Council and Resident Council are not effective: I advocate for my mother and others as well. I have a good regional ombudsman but we are surprised by the lack of cooperation.
- A Not all councils are effective in every situation – have to find the person or the place of who can help you.
- A In every state there is an effort to have facilities look at culture change, and individualized care. Have the ombudsman identify other facilities that are doing this – and offer those as example to the facility with the mother – so they can link up and find a solution. You can always go to the owner.
- Q Is going up the chain of command perceived as confrontational?
- A I'm feeling frustrated, and I want to give one more shot – I'm not going around you to get you in trouble, but because I'm not seeing a change.
- A Demeanor and how it's done can be seen as confrontational – but if done right, then it is just means.
- A You can consider filing alternate complaints. Because the issues around your mothers' care are important.
- Q Even though residents have a choice of doctor, the facility recommends doctors. Doctors that are paid by the facility might have a conflict of interest. And Doctors may use medications that the nursing home wants the residents to be on – not what is best for them.
- A These are issues that need to be tracked, and people need to be educated about what options there are.
- Q Residents being left out, when one resident is a stronger leader. She is the resident council president. We try to stick up for all the residents, although not an ideal facility we have tried to look more at residents that can't stick up for themselves, and speak up for them.
- A Does the facility respond to the council as they advocate for other residents?
- Q Yes – the administration does respond. We are working on culture change, and have a good activities department.
- A When you advocate for those that can't there is trickle down.

10. Speaker Introduction (Kriss) – Robyn Grant

- Kriss Schaffer lives in Charleston, Arkansas
- He graduated with a Bachelor of Arts from the University of Arkansas, with a major in Political Science and English.
- He also graduated with top honors in Applied Science and Nursing from Ulster County Community College in Stone Ridge, NY.
- Currently he is the Administrator and owner of the family owned and run Greenhurst Nursing Center in Charleston, Arkansas
- He has three daughters: Alexis, Molly Rose, and Madison Susanne.

11. **Presentation: Kriss Schaffer (Best Practice Provider)**

- Thank you for having me on the call. I echo Mike, I've always been a complainer, and I'm the owner/administrator.
- In fact, the reason I'm here is because years ago I complained to the advocacy group in AR that was only saying that all nursing homes were horrible. One day they showed up at my facility, and they liked it.

- In my facility, it is made quite apparent to the family and the resident from the initial visit (whether it be shopping for a home or actually coming to the home) that the Administrator's Office is the bottom line.
 - I explain the admissions pack, which includes going over all Resident Rights Information; Restraint Policies; Rules and Regulations; Voter Registration; when Family Council and Resident Council Meetings are, etc. The family and the resident are assured if they have ANY problem my door is always open.
- Each shift has a CNA supervisor: she does nothing but supervise. She does scheduling and problem solving.
- The facility has a tremendous family council. The president is a retired family nurse. They meet twice a month, and invite him to the meeting (2x a year.) The resident council complains often (ex. Wants fried chicken livers, now get them twice a week) and is always willing to give feedback.
- When a new staff person is hired I sit with each hire and explains the "camp experience." I say that even though when we were kids and enjoying camp, we had to do things on a schedule. In a nursing home, it's like camp, but people don't often get to go home. We have to be sensitive to the changes, and what we would want for ourselves.
- Administrators must be visible to the residents. The bottom line has never been money – the main thing is to do right by people.
- Being a good citizen is the essential piece.

12. Participant Question and Answers

- Q** We are proud of AR. I have visited Kriss' building, and as we entered the building it was clean, with uncluttered wide hallways, the rooms were decorated, there were no unanswered call lights, and residents wanted to hug and give kisses to Kriss. The history of a facility is a valuable indicator.
- Q** Concerned about residents that can't advocate for themselves: often given less than respect and dignity. How should I step in and what is my role?
- A** One theme of the call is how to help residents that can't advocate for themselves. Finding one of these groups or trying to organize a group. However, if something doesn't exist – try to ID staff and residents that make decisions – and approach those folks for meetings on issues you've seen.
- A** Find out when an in-service is on residents' rights and attend that meeting.

13. Discussion of Advocacy Strategies

- We will be having a follow-up call on Residents' Rights on Sep 7th. So if your question did not get asked, or if you'd like to offer more insight to the conversation please plan to join us.
- On this call you've heard about rights, and strategies for upholding your rights. Such as:
 - Talk to the staff involved
 - Talk to the social worker
 - Take the issue to the next care plan conference
 - Ask for a special care plan conference.
 - Talk to the department heads.
 - Talk to the administrator
 - Find out what the grievance policy is.
 - Residents and Family councils – strength in numbers

- Ombudsman and Citizen Advocacy groups can assist in starting/strengthen councils.
- File a complaint with the agency.
- Don't give up, and you're not alone.
- Nothing comes from nothing. – and if we do nothing than we send the message that poor care is alright.
- Let us issue some quick challenges.
 - Identify one right that you'd like to see promoted or improved in your facility. Make a plan on how you can educate others about that right, and make a change. Remember, you have the capacity to make changes and make a difference.
 - Don't forget that Residents' Rights Week is Oct 1-7th. And is an opportunity to celebrate/share information about residents' rights. Think of an activity that you can plan. Ideas are available from NCCNHR's Residents' Rights Week Packet.

14. Closing, Wrap up, Announcements

- Please fill out the evaluations you will receive via email and mail. Please make sure that if people joined you on the call, that you are able to get them an evaluation and have it returned.
- The next Educational Call on September 13th on communication with staff and facilities. You need to register separately for that call, and all future calls, if they are interested.
- We ask that ombudsman try to have at least one or two active family members or residents with them on these calls.
- Thank you for your time. Good afternoon.