

14-514

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INDEPENDENT REGULATORY
REVIEW COMMISSION

2249 Valley Hill Road

Malvern, PA 19355

September 15, 2008

In regards to: Regulation No. 14-514

2712

Ms. Gail Weidman
Office of Long-Term Care Living
Bureau of Policy and Strategic Planning
Box 2675
Harrisburg, PA 17105

Dear Ms. Weidman:

Assisted Living Regulations Reference No. 14-514

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REFER TO

This letter and attachment is in reference to your request for comments in regard to the regulations No. 14-514.

1. Wheel Chair Accessibility

It is very important that Assisted Living Facilities have room sizes that can be used by people with wheel chairs. If cost is the issue, it would be better to have many rooms large enough for two people and wheel chairs then have all single rooms with no wheel chair accessibility. It is not difficult to take down and put up walls in current facilities to meet the new standards. Instead of having fancy decorations it is better to have rooms sized for wheel chair accessibility.

2. Fire Safety

All facilities must provide fire safety provisions for all residents. Physical buildings must be built or modified with fire safety in mind. Also, staff must be trained and fire drills must be held often to make sure all can be safely helped out in case of fire.

3. Supervision

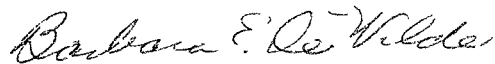
It is essential that medically trained supervisors are on staff. We have recently experienced the releasing of the Director of the Assisted Living facility. No temporary person has been put in his place for over a month. Now the supervisor of the Alzheimer's unit has left and no one is in charge of the unit. The quality of care and number of staff have become a problem.

My brother-in-law has had Alzheimer for over 10 years. Today, September 15 is his 67th birthday. My sister and brother-in-law have been dealing with this difficult disease for a long time. He has lived in over six facilities with many different levels of care. My brother-in-law broke his hip in one of the homes. Thirty nursing homes refused to take him. He is now living in an Assisted Living Alzheimer unit which has provided the best care of any facility. The good quality was due to the experience and quality of the supervisor of the Alzheimer unit. Unfortunately, she has been promoted and no one has taken her place and the care is now not as good as it was when she was there. The training of the staff is very, very important in the quality of the care received.

We are knowledgeable of the problems. We did work with the Alzheimer Association to make our concerns known. We did testify in West Chester when the Department of Aging asked for our input and we have gone to Harrisburg to speak with our representatives.

Thank you for the opportunity to comment. We are available to help with this cause. Please contact me at 610-827-7530 or dewilde2249yahoo.com.

Sincerely yours,

A handwritten signature in cursive script that reads "Barbara E. De Wilde".

Barbara E. De Wilde
Kathleen Stryker

Enclosure (1)

Comments by Kathleen Stryker and Barbara De Wilde in regard to the
Assisted Living Regulations Reference No 14-514.

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The following information was presented by Barbara De Wilde to the Department of Aging at their session in West Chester asking for input on Senate Bill 704. It was written by Kathleen Stryker and Barbara DeWilde.

Pennsylvania Senate Bill No. 704 Session of 2007

Recommendations for Assisted Living Regulations Pertaining to Alzheimer/Dementia Clients

SAFETY

1. The physical environment needs to be very carefully designed so that Alzheimer clients are not able to be harmed. The clients should not be able to leave unless escorted. The following conditions should be prevented:
 - a. **Eliminate exit doors which open automatically.**
 - i. An assisted living facility in Chester County had an automatically opening door. The facility was a short distance from a major highway. The Alzheimer client was given a device for his ankle which was to alert staff. Unfortunately, the staff was not often available. There was a known instance when an Alzheimer client walked out of the door in the winter

and broke a bone when falling in the ice and snow. Fortunately, he did not get to the major highway to be hit by a car and possibly killed.

- b. **Reduce loud buzzers that go off whenever anyone leaves or enters the unit.**
 - i. An entryway can be designed which requires people to go into an enclosed foyer first. Then, use an internal code which will not give off the loud buzzer.
 - c. **An Alzheimer client should be prevented from access to the elevator when a guest is leaving.**
 - i. There should be a coded door which closes quickly and then a separate entrance and code for the elevator.
 - d. **Dishes, glasses and cups should be made out of non-breakable materials. Knives should not be given to Alzheimer's clients.**
 - i. Advanced Alzheimer clients may throw glasses, plates, etc. at others. Broken glass and pottery is more dangerous than non-breakable.
 - ii. At an advanced facility, an Alzheimer client was found naked on a bed with no sheets except a urine-coated sheet on top of him. A plate containing his breakfast and a fork was next to his head. The fork in that environment could have been a dangerous utensil.
2. **A positive environment fosters safety.**
- a. Supervisory staff offices should be within the Alzheimer Unit with visual access to the areas where the staff and clients spend most of their time.
 - b. Clean, pleasant surroundings are conducive to a good feeling on the part of staff, Alzheimer clients and visitors.
 - c. Calming, positive music should be played, especially from a time period when the clients were young. Clients will often be able to sing the words to the songs and get joy from the beautiful sounds. Live music is wonderful because the person playing the music can help to get the Alzheimer client involved.
 - d. Birds, fish or other appropriate animals enhance the positive experiences of the clients.
 - e. Provide a safe area outside where the clients can wander themselves. Walking is one of the few activities that Alzheimer clients still enjoy. Fresh air and the activity of walking will enhance their health, including their sleeping habits.

STAFFING

A well-trained, compassionate staff is the one most important factor that determines the quality of the Alzheimer client's experience. The following list gives suggestions on how this can be achieved:

1. The facility needs to have as their main goal the constant striving to provide the highest quality of care. The state of Pennsylvania should have legislation in place to constantly monitor Assisted Living Alzheimer Units so that the desire for the highest profit does not replace the goal of providing the best quality of care.
2. The head administrator of the Alzheimer Unit needs to be compassionate and have the ability to lead the staff to constantly strive to provide the best care. This person has to be

very well-trained and experienced in working in such a unit. This administrator must be a hands-on person and have their office within the unit with windows so that all can be constantly supervised.

3. The background of prospective staff needs to be carefully investigated. A background check of all people working with clients should be required.
4. Both men and women should be hired. Clients will respond differently to a man or woman, especially since many of the clients need help with the basic needs of life, including bathing. This can reduce the physical outbursts of the clients. It is very important to have enough staff to meet the needs of the Alzheimer clients.
5. Staff training needs to be provided constantly. The Alzheimer's Association has training available.
6. Part of the evaluations and raises for the staff should be based on their ability to carry out the quality of care addressed in the classes.
7. Staff should be augmented by individuals coming in to provide music and activities for the clients.
8. College and High School students should be encouraged to provide community service by visiting the Alzheimer unit.
9. Visitors should be welcomed and encouraged to visit.

MEDICAL ISSUES

1. Medications should be given by a medically trained staff member such as an RN or LPN.
2. Over-medication should not be used to control the actions of the Alzheimer client. Trained staff can best reduce negative actions.
3. Trained medical staff should evaluate and make the decisions when a client should be sent to the hospital. The family needs to be notified immediately.
4. Means should be provided so that the client can be easily seen by a physician.
5. Family, staff and physicians need to work together and communicate to provide the highest quality of care.
6. Medical records need to be carefully maintained. The family should have a copy of the records. The family needs to review carefully the contents of the medical records. Family members who are not medically knowledgeable must have access to someone in the state of Pennsylvania Department of Aging to discuss the medications and other health issues.

FAMILY RECOURSE

1. Families should be provided with written information from the state of Pennsylvania about the laws in Pennsylvania which govern the rights of the patient and families.
 - a. Some Alzheimer Assisted Living facilities have been asking family members to give up their right to sue if it turns out that the care is not adequate.
 - b. A detailed booklet should be provided for each Pennsylvania County giving the name and phone number of the ombudsman. The booklet should contain the procedure to follow if there is an issue with the care given at the Assisted Living facility. Many older family members do not have access to the internet to get this information.

2. The family should have to sign a form stating that they have received the information about the state laws when they sign the paperwork at the Alzheimer Assisted Living facility entrance conference.
3. The state of Pennsylvania should have the Department of Aging go out to Senior Centers, libraries and other locations to educate the senior population about their rights.

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