BEHAVIOR-RELATED EXITS FROM LONG-TERM CARE BY PEOPLE WITH ALZHEIMER'S

FINAL REPORT AND RECOMMENDATIONS

DECEMBER 9, 2010

A PROJECT OF THE WEST VIRGINIA COMMUNITY VOICES INC. FUNDED BY THE CLAUDE WORTHINGTON BENEDUM FOUNDATION.

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We appreciate the contributions of each of the participants and their organizations in the roundtable meetings and the development of this report and recommendations.

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ISSUE OVERVIEW

The Alzheimer's Association, West Virginia Chapter received a grant from the West Virginia Long Term Care Partnership to initiate discussion concerning the problem of behavior related exits of those with Alzheimer's or a related dementia from West Virginia facilities due to "challenging" behaviors and elicit recommendations for change. The Association invited more than 25 stakeholders to participate in a series of three roundtable discussions. We worked to ensure inclusion of a wide variety of stakeholders who not only have expertise in this area, but who are impacted by this issue and the challenges created by current practice.

Alzheimer's disease is the most common form of dementia and is a neurodegenerative disease that progressively breaks down the functions of the brain. Alzheimer's disease results in memory loss, loss of ability to communicate and ultimately leads to death. Individuals with Alzheimer's disease need some degree of care throughout every stage of the disease; ultimately requiring around-the-clock supervision and care.

According to the *2010 Alzheimer's Disease Facts and Figures* from the national Alzheimer's Association, 44,000 West Virginians age 65 and older have Alzheimer's disease and an estimated additional 4,000 individuals under age 65 have early-onset Alzheimer's disease. The number of individuals with Alzheimer's is expected to rise dramatically as West Virginia's population ages, and a variety of care options are necessary to meet the needs of this growing group.

The unique challenges presented by Alzheimer's and other forms of dementia require not only patience but a significant understanding of the disease and caregiving best practices. Frequently, challenging behaviors associated with Alzheimer's disease create difficulties in the long-term care setting and can lead to staff turnover or resident exit. As the number of individuals with Alzheimer's disease increases in our state, the issues of adequate long-term care and best practices in care for individuals with Alzheimer's disease must be addressed.

The Alzheimer's Association, West Virginia Chapter's 24-hour Helpline frequently receives calls from families facing the immediate exit of their loved one from a West Virginia long-term care facility due to "behavior issues." Often the families are told that facilities in Ohio are the only option for their loved one. It also is not uncommon for discharge planners at West Virginia hospitals to inform families that due to behavior issues the only facility willing to admit the

individual is in Ohio. This geographic complication creates an additional burden for families who hope to keep their loved one nearby but do not have the ability to care for the person at home.

The reality of Alzheimer's disease or most of the related dementias is that long-term care is often the best option for the person with the disease. Yet the disease inherently may result in behaviors that are sometimes considered challenging. How do we provide safe and appropriate care for these individuals? As one member of the roundtable so succinctly said "We HAVE to have a place to put them."

DISCUSSION AND ANALYSIS

Presently, no mechanism exists to track the number of individuals with Alzheimer's who leave nursing facilities due to behavioral issues. Collecting this data is complicated for many reasons including often a resident experiencing challenging behavior may be sent to a local psychiatric unit in a hospital and then never readmitted to the facility. Consequently, the exact extent of the problem is unknown. All roundtable members, however, felt that these situations do arise with more frequency than they should and that this issue deserves action.

Prior to the initial meeting, the facilitator distributed a survey to participants to elicit general opinions about the relevant issues. Questions included: "What do you hope to accomplish in the roundtable discussions?"; "What is your definition of Alzheimer's 'behavior'?"; and, "Based on your expertise and experience do West Virginia nursing facilities (as compared to other states) have a higher frequency of discharges due to the individual having Alzheimer's or dementia?" Seventeen responses were submitted and their answers helped guide the overall direction of the roundtable discussions. The survey and responses are included in the Appendix.

The group elected not to focus on a specific definition of what constitutes challenging behavior. However, common examples of behavior that could lead to discharge include: wandering, shouting, inappropriate sexual behavior, and aggression toward staff and other residents.

Although individuals with Alzheimer's may live in other residential facilities such as assisted living, the group chose to focus just on issues and solutions for the nursing home environment in order to keep the project focused on similar facilities and the same regulatory rubric. Throughout this report the words nursing home, nursing facility and long-term care facility are used interchangeably.

During the first roundtable, the majority of the discussion centered on factors that could cause behavior that might initiate discharge from a long-term care facility. Members listed each of the issues below as potential causes of discharges. In subsequent roundtables, more detailed discussions surrounding the discharge process, training, and reimbursement were led by participants with particular expertise in those areas because the group felt that making modifications to those three areas might be the best way to address the overall problem.

Lack of Understanding of What "Behavior" Is

Several participants emphasized that "all behavior is communication," and that "all behavior has meaning." As a result, it is short-sighted and counter productive to assume that behavior is "just the dementia." Individuals with Alzheimer's communicate; but, they may communicate in new ways due to their diminishing abilities. Staff must take time to determine why the person is behaving in a certain way. Employing appropriate techniques, staff can eliminate or effectively manage many challenging behaviors. Integration of the philosophy of person centered care also may diminish unmanageable or challenging behaviors when implemented properly. In some circumstance, other acute illnesses actually may cause the challenging behavior.

Behavior as a concept deserves reframing. It may not be fair always to include the modifiers "difficult" or "problem" when describing behaviors. Instead, thinking about behavior as symptomatic may improve the way it is viewed and approached. Finally, behavior cannot be evaluated in isolation; instead staff should analyze what occurred directly before and after the behavior, as well as become familiar with the resident and his or her likes, dislikes, habits and personality in order to identify triggers.

Environmental Factors

Environment factors may more easily agitate individuals with Alzheimer's than other individuals. The affects of the disease frequently cause a heightened sense of hearing and/or difficulty filtering background noise. The individual experiences vision changes and often describes "confusion in the brain." Many West Virginia nursing facilities were constructed in the 1980s and since that time, our understanding of Alzheimer's has increased substantially. The physical design and practices such as lighting and long hallways, as well as overuse of alarms and intercoms or busy wall decorations, may trigger inconvenient or challenging behavior. Sometimes simply installing new lighting or using pagers instead of intercoms may decrease the amount of confusing stimuli and lead to fewer behavioral issues.

Solutions also may necessitate a bit of creativity on the part of facility staff. Many facilities do an excellent job of making these modifications and these best practice techniques need to be integrated into training across all facilities. Anecdotal examples include:

> A male resident frequently urinated in a potted plant in the entry area of a facility. Finally, the staff informed the daughter that her father must leave the facility for his behavior. Once his daughter explained that her father

had been a farmer for 50 years and was used to urinating in his fields during his work day, she suggested removing the potted plant might alleviate the problem. She was correct. Once the plant was removed the problem ceased.

In another facility a female resident continually entered the room of other residents. When a staff member would take her arm to guide her out of the room, the resident would resist and sometimes become "combative." This particular resident was born in Russia and immigrated to the United States as a child with her parents. In her disease state, she had regressed to speaking Russian and did not recognize herself as a married woman. Once a translator was secured who facilitated a discussion with the resident, she explained that she could not find her own room and merely was seeking to do so. She did not recognize her name on the door as it was listed as Mrs. "Smith." Once her name had been changed to her first name only, she stopped entering the rooms of other residents.

Special Care Units Versus General Units

Facilities in West Virginia operate 15 special care units, which provide care specifically for people with Alzheimer's. Ten are located within nursing homes and five are within assisted living facilities. The regulations governing these units differ from the general units. As an example, staffs in special care units receive 30 of hours of dementia training annually, while staffs in general units receive 2 hours. There is no standardized assessment that must be conducted to qualify a person for a special care unit. Instead, once a person is admitted, the facility applies its own assessment criteria to determine if placement in its special care unit is appropriate.

Participants who had worked in nursing facilities with special care units remarked that special care units typically experience fewer problems with worker retention and job satisfaction, and when a staff opening occurs in the unit, several general unit staff want to fill the spot. Managers attribute this phenomenon, in large part, to the specialized training these workers receive allowing them to be better prepared to handle situations and increase their feelings of investment in their work.

In West Virginia, it is estimated that 69 percent of individuals in nursing facilities have cognitive impairment. Since Alzheimer's is one of the most common forms of cognitive impairment, it is

reasonable to assume that a significant portion of nursing facility residents exhibits some symptoms of Alzheimer's. Further, due to the small number of special care units, most people with dementia who reside in a nursing facility in West Virginia live in a general long-term care facility. Some roundtable members felt that expanding the number of hours of training received by staff in general facilities might be helpful, while other members felt that taking a more hands on, mentoring approach, with existing training would be equally as effective.

Challenging behaviors will occur even in special care units. In any congregate setting there will be individuals who do not get along or tension between individuals will occur. The special care unit model assumes people with Alzheimer's living harmoniously in a congregate setting, so the introduction of one resident with challenging behaviors can sometimes tip the balance or bring out behavior in a previously peaceful resident. Thus, replicating what works well in a special care unit and infusing it into the culture of a general facility could be a helpful strategy, but probably does not provide a complete solution.

Quality of Training

Certified nursing assistants (CNAs) and licensed practical nurses (LPNs) provide the overwhelming majority of direct care in nursing facilities, but typically receive little training and overall tend to be much less educated. The target audience for any expanded or redesigned training is these two categories of staff.

Participants agreed that improved training would benefit staff in handling challenging behavior. But, to simply increase the number of hours may not be sufficient. Current training needs to be evaluated not just in terms of content and structure. Members remarked that training often is conducted by videotape, which may be outdated and does not guarantee that participants are paying attention. Others members felt that it was difficult to find quality training. Another challenge mentioned was scheduling training so that adequate numbers of staff receive the training while still ensuring sufficient staff remains on the floor to address resident needs. Finally, training that relies heavily on reading can pose challenges for staff with limited education.

By infusing elements such as mentoring, hands on components, and a competency test at the completion of training, staff would benefit more from current training requirements and in turn better handle difficult situations. In addition, it would be helpful to raise awareness of easily accessible training such as online trainings offered by organizations like the Alzheimer's Association that focus on quality dementia care.

Nursing Home Occupancy Rate

West Virginia's nursing home population is governed by a certificate of need (CON) process. At this time, a moratorium exists on new nursing home beds. Participants estimated that nursing home occupancy hovers around 90 percent, which makes it relatively easy for facilities to fill open beds and allows some facilities to be selective in admitting residents.

Because Alzheimer's affects the mind and because individuals with Alzheimer's may be more physically healthy than other nursing facility residents, they often are more mobile than other nursing home residents, but cannot be left alone for extended periods due to their cognitive limitations. Consequently, facilities frequently must dedicate increased staff time to these residents. When challenging behaviors occur, these situations only increase the burden for staff. At least one nursing home operator suggested that if given the choice, he would rather admit a resident with more predictable needs that are less draining on staff and present minimum exposure to liability than a resident with Alzheimer's. Due to the high occupancy rate, this philosophy undoubtedly could lead to individuals with Alzheimer's being unable to find placement.

It also was stated that unlike West Virginia, Ohio's occupancy rate is much lower, estimated at about 70 percent. Thus, one reason West Virginians may receive placement in Ohio is that its facilities have a greater need to fill beds and cannot be selective in admitting residents.

Increased Exposure to Liability

The mobility and behavior of a resident with Alzheimer's also may expose a facility to more liability than a resident with other needs. Sometimes the behavior is directed at staff or other residents or wandering will cause the resident to leave the facility grounds. All of these situations can subject a facility to legal action by a staff member, another resident, or even the family of the person with Alzheimer's. As one participant observed, "We're weighing the rights of one difficult resident with the safety of 100 other vulnerable residents." Another member said "Why should I take the risk of taking on this resident?"

Some of these incidents may constitute critical reporting requirements that facilities must report to regulators, which could expose them to fines. However, it also appears that facilities may

report issues such as wandering that they actually are not required to report because they do not want to be caught not reporting something they do need to report.

Medicaid Reimbursement Rate

Approximately 80 percent of nursing facility residents in West Virginia are Medicaid eligible. Thus, the Medicaid reimbursement rate for people with Alzheimer's and behavior is an important factor. Surprisingly, while individuals with Alzheimer's generally require more care and attention, they are not considered a high acuity patient, and thus, facilities typically receive one of the lowest reimbursement rates for their care. Paradoxically, facilities must dedicate extra resources for those patients, but cannot seek a higher reimbursement rate for their efforts.

By increasing the reimbursement rate for the care of Alzheimer's patients, especially those individuals with challenging behavior, facilities would receive more appropriate compensation for the care they currently provide, and for facilities which presently prefer not to accept challenging cases, the increased reimbursement rate may incentivize them to admit and retain residents with behavior.

Family Attitude and Involvement

Families want their loved ones to receive high quality care, but their expectations of facilities sometimes may be unrealistic. In a nursing home environment, it is unlikely that the family member will receive the constant hands on care that many families expect.

Additionally, conversations with families concerning behavior issues need to occur sooner. Often these conversations do not happen until after a major incident at which time the facility may feel they no longer can meet the resident's care needs.

Families often may experience some denial concerning their loved one's condition and do not understand clearly the disease. This may cause some confusion and lack of receptiveness when the facility staff conveys the issues surrounding the challenging behaviors. For the family, it may be more comforting to assume the behavior is caused by the facility and the care provided.

By supplying families with more information about the disease (such as referring families to the Alzheimer's Association's Web site or free 24-hour Helpline) and improving dialogue between facilities and families so that conversations concerning problems occur sooner, families and

facilities can collaborate to identify potential solutions that may allow the resident to remain in the facility.

Shortage of Medical Providers With Expertise

Occasionally, facilities need access to the expertise of a geriatrician, and most especially, a geriatric psychiatrist, in working with a resident with challenging behaviors. West Virginia possesses some wonderful geriatric providers; however the number with this expertise is very small. As a result, many facilities lack easy access to these few clinicians with expert understanding of addressing behavioral issues.

Short-stay placement in geriatric psychiatric facilities is available in at least three psychiatric facilities across the state. Many participants viewed this tactic only as a temporary fix. It is not uncommon for a resident to stabilize at a psychiatric facility and then return to the nursing facility only to have the behavior reappear because the environmental trigger still exists.

Other states have employed strategies such as loan forgiveness and enhanced focus on geriatrics and geriatric psychiatry in medical school curriculum and residency opportunities to attract clinicians to these fields. The West Virginia Geriatric Education Center is the state's leader in developing some of these strategies, but more attention and focus on this area is needed.

WORKING GROUP RECOMMENDATIONS

With the goal of diminishing, and ultimately negating, the discharge of individuals with Alzheimer's and related dementias from long-term care facilities due to adverse behaviors, the following changes are recommended. In some cases, the recommendations are policy based and require changing law or regulation. Other recommendations are best practices that facilities may wish to adopt. The recommendations below are separated into these two categories.

Policy Change For State Government to Adopt

1. *Explore the creation of highly specialized units or stand alone facilities for individuals with severe behavior issues.*

> Rationale: Often the needs of people that exhibit challenging behaviors cannot be met in traditional long-term care facilities or even special care units. These individuals may be transferred to a psychiatric facility, but these units can be used only for short-term placement. Further study should occur to determine the feasibility of opening a facility to provide longer-term specialized care to individuals with severe behavioral issues.
>
> Additionally, innovative new types of facilities such as green houses could be utilized to provide highly specialized care in more focused setting to individuals with Alzheimer's. A pilot project could be undertaken to determine the feasibility of developing such a facility.
>
> Issues to consider include whether the certificate of need moratorium could be lifted to build such a facility for individuals with highly specific needs, whether such a unit could be established by converting beds at an existing facility, and whether increased reimbursement could be secured.

2. *Revise the content of state policy mandating dementia training in long-term care facilities to incorporate best practices to enhance the quality of training provided.*

> Rationale: West Virginia currently requires direct service workers in long-term care facilities to receive a certain amount of dementia training annually. Often times this training is conducted by watching an outdated video tape or in lecture format. Research shows training that incorporates techniques such as mentoring, hands on modules,

competency testing, and recognition for completion of training results in both better employee understanding of dementia care and improved morale among workforce. Current policy governing dementia training should be evaluated and revised to infuse innovation into existing requirements.

3. *Reconfigure the current reimbursement rate for Alzheimer's patients in long-term care to reflect more accurately the amount of staff time facilities must dedicate to the care of residents with Alzheimer's and behavior.*

Rationale: The base rate for Medicaid reimbursement of a patient with impaired cognition and challenging behaviors is currently set among the lowest of base rates. Yet it is estimated that more than one-half of residents in a nursing home have Alzheimer's or a related dementia, a complex disease that inherently causes behavior challenges. Due to their care needs, it is reasonable that residents with Alzheimer's should be classified as a higher acuity level, possibly equal to the clinically complex, and thus, receive higher reimbursement. One experienced geriatric physician in the group said it well, "At some point we need some clinical truth as we look at reimbursement rates." With an improved reimbursement rate, all facilities could then afford to provide the consistent, individualized care necessary to manage Alzheimer's and challenging behaviors.

4. *Explore applying for a Medicaid Waiver for assisted living to make assisted living a viable option for lower income individuals with Alzheimer's who need to live in a residential care setting, but do not yet require the skilled care of a nursing facility.*

Rationale: Assisted living level of care is often an ideal choice for people who do not yet require nursing home level of care but need or desire 24 hour support and/or care. This is especially true for people who do not have or lack the ability to maintain a private dwelling. It is almost always less expensive than nursing home care. However, currently in West Virginia assisted living level of care is paid for almost entirely out-of-pocket by the people who live there. Practically, this means that this level of care is not accessible to most middle and low income West Virginians. Until some type of financial assistance, *e.g.*, Medicaid waiver, is available WV has a marked gap in our continuum of care.

Due to the course of the disease and the burden it places on family caregivers, residential care often is the most appropriate option for people with Alzheimer's. At the same time, many individuals do not have care needs that require highly skilled nursing home care.

The assisted living environment would offer a safe, supervised living situation, as well as personal care services for people with Alzheimer's.

Identifying funding for the program is a major challenge, but the establishment of a waiver through Medicaid would allow for a significant contribution of federal matching dollars.

Best Practice Change For Facilities to Implement

1. Ensure widespread physician education and use of a diagnostic/assessment tool so that people receive a diagnosis of the correct form of dementia and ensure all health providers are trained to differentiate between the different types of dementia in order to deliver appropriate care.

Rationale: Although Alzheimer's is the most common form of dementia, several other types of dementia exist such as frontotemporal lobe dementia, Creutzfeldt-Jakob disease, and Pick's disease. Because these types of dementia are less common, a person often is diagnosed with Alzheimer's when in fact they suffer from another condition. Further, the symptoms and severity of certain symptoms are different, and thus, the course of care for each of these diseases varies. Through improved education and the consistent use of a diagnostic tool, physicians can improve the accuracy of diagnosis and ensure the patient receives appropriate care.

Dementia-based training requirements already exist for long-term care facilities. It is important that these training include as part of their curriculum the different forms of dementia, as well as appropriate behavioral interventions, and when absolutely necessary, medication use.

2. *Upon diagnosis, family members consistently must receive more comprehensive, quality training about Alzheimer's and the long-term care system.*

Rationale: Families should receive information that prepares them for the course of the disease including the potential for challenging behaviors. Improving families' Alzheimer's literacy will allow for better informed discussions with care providers about the most appropriate care options for loved ones. For example, referrals can be made to the Alzheimer's Association free 24 hour Helpline, educational materials, care consultations, and Web site.

Families also need education regarding certain operating principles of long-term care facilities. Unrealistic expectations, e.g., the notion that individuals who are demonstrating adverse behaviors can receive prolonged one-on-one care, can lead to escalation of families' frustrations, thus worsening already difficult situations.

2. *Implement steps to improve the timing of the intervention by the facility and the family to address the behavior and ensure sufficient screening occurs upon admission to identify potential challenges.*

Rationale: Often intervention occurs too late in the process. Facilities and families should become more proactive in seeking modification or beginning the conversation that the current placement may not be best for the individual *before* the challenging behavior pinnacles, so that alternative placements may be located.

The processes for initial admissions need to be explicit in their assessments of whether individuals are appropriate for certain facilities at the outset, so that individuals are matched with facilities that can meet their needs.

3. *Utilize Civil Monetary Penalty Fund to assist in funding training initiatives*.

Rationale: Civil Monetary Penalty Fund is money collected from survey violations occurring in Medicaid participating nursing homes. Any Medicaid participating nursing facility can apply to receive a portion of the funds and use them to invest in projects related to quality improvement in nursing homes. Additionally, outside entities also may apply to receive these funds to conduct similar activities within nursing facilities. These funds cannot be used for permanent projects, but could be used by facilities to help offer improved training opportunities or make other quality improvements

4. *Launch a pilot project to develop a Crisis Intervention Team, which facilities could utilize to assess a resident exhibiting challenging behaviors*.

Rationale: Until consistent statewide dissemination of education exists and for situations that escalate too rapidly for local care providers to handle, regional Crisis Intervention Teams could be formed and deployed to address short-term behavior issues. The teams would be charged with investigating situations reported to them and exploring alternatives, much the way that Ethics Committees consider situations in various care settings.

This system would allow for independent on-site assessments of individuals in their own environment. Often issues causing behavior are environmental or can be addressed without moving an individual out of facility or to a short-stay psychiatric hospital. Each team would include experts like geriatric clinicians, long-term care administrators, patient advocates, and representatives from organizations like the Alzheimer's Association.

5. *Maximize the use of activity staffing in facilities*.

Rationale: Facilities are reimbursed by Medicaid for a variety of categories of operation using a cost-based method that has a standard, set by an average of overall statewide facility spending. If a facility exceeds the standard in its spending, it still only receives the standard rate in reimbursement. If the facility spends under the standard, it is only paid what it spent.

For certain categories of spending, an "efficiency incentive" exists encouraging facilities to spend less than the standard. Activities program spending in nursing facilities is not one of those categories. Thus, facilities could be encouraged as a best practice to spend the maximum of the allotted standard rate in their activities department. By maximizing activity spending, facilities may increase their utilization of activity staff and direct these staff towards using this time to provide individualized or small group care to residents with Alzheimer's.

Due to the timing of reimbursement, if a facility currently is spending below the standard and increases its costs spent in the activities department, it will not see any heightened reimbursement for a period of nine months. "Front ending" this money for a facility may pose short-term financial challenges, but also hopefully would result in improved care for residents with Alzheimer's, and in turn, prevent the onset of most behavior.

REFERENCES AND RESOURCES

1. 2009 Alzheimer's Disease Facts and Figures. Alzheimer's Association, 2009. Available at: http://www.alz.org/national/documents/report_alzfactsfigures2009.pdf

2. Case Mix Classification Worksheet.

APPENDIX

Working group member survey responses on roundtable issue background, process and expected outcomes (October 2010)

Alzheimer's Association - West Virginia Chapter Roundtable Meeting Edit

Default Report + Add Report

Response Summary

Total Started Survey: 17
Total Completed Survey: 16 (94.1%)

Show this Page Only

PAGE: GENERAL QUESTIONS

1. How well is West Virginia doing to address the following issues involving long term care patients with Alzheimer's disease. Create Chart Download

	Not very well	Okay	Average	Above average	Doing a great job	Rating Average	Response Count
Providing appropriate care settings	**73.3% (11)**	6.7% (1)	13.3% (2)	6.7% (1)	0.0% (0)	1.53	15
Diagnosis of the disease	30.8% (4)	**46.2% (6)**	15.4% (2)	7.7% (1)	0.0% (0)	2.00	13
Education of LTC staff about the disease	**46.7% (7)**	20.0% (3)	33.3% (5)	0.0% (0)	0.0% (0)	1.87	15
Training of LTC staff about behaviors	**50.0% (7)**	35.7% (5)	7.1% (1)	7.1% (1)	0.0% (0)	1.71	14
Adequate payment to address services needed	**42.9% (6)**	35.7% (5)	14.3% (2)	7.1% (1)	0.0% (0)	1.86	14
Providing advocacy resources for families	**46.7% (7)**	26.7% (4)	26.7% (4)	0.0% (0)	0.0% (0)	1.80	15
Regulating the discharge process	**35.7% (5)**	21.4% (3)	**35.7% (5)**	7.1% (1)	0.0% (0)	2.14	14
Regulating the admission process	26.7% (4)	26.7% (4)	**40.0% (6)**	6.7% (1)	0.0% (0)	2.27	15
Managing the discharge process	**35.7% (5)**	21.4% (3)	**35.7% (5)**	7.1% (1)	0.0% (0)	2.14	14
Hide replies What other issues would you like to see this group rate?							8

1. I am afraid that I do not know what the above questions are meant to ask in several questions, and therefore hesitate to provide answers in this format. I will be willing to answer once clarified during the roundtable. Tue, Oct 12, 2010 2:31 AM Find...

answered question	**15**
skipped question	**2**

1. How well is West Virginia doing to address the following issues involving long term care patients with Alzheimer's disease. Create Chart Download

2.	* The # of facilities with Alzheimer's Specific Care Programs. * Rate of behavior related discharges from facilities with Alzheimer's Specific Care Programs vs. general TLC * Training types = inhouse with vidoe/book review vs. hands on/ classroom training. * Is dementia training part of healthcare cirriculum for med. school, nursing, CNA and how many hours?	Mon, Oct 11, 2010 11:12 AM	Find...
3.	The role mental health care plays in the SNF setting and the lack of it and why.	Mon, Oct 11, 2010 7:58 AM	Find...
4.	Better education given to family care givers.	Mon, Oct 11, 2010 5:28 AM	Find...
5.	Benefits and limitations of medication vs non-pharmaceutical treatment apporaches	Mon, Oct 11, 2010 5:08 AM	Find...
6.	The problems that arise for families on fixed incomes or lower incomes who must either quit their jobs to care for their loved one at home or either place them into a nursing home.	Mon, Oct 11, 2010 3:06 AM	Find...
7.	What are West Virginia's future plans for the increase in the number of persons with Alzheimer's Disease?	Sun, Oct 10, 2010 2:24 PM	Find...
8.	Training of the staff. They are reviewed to see that they are offered at least 2 hour of Dementia Specific training annually an upon hire, but no one looks at the materials offered or who is doing the training. Dementia type for addmissiona nd how much staff and the corporate people know about the disease type. Admitting for census recovery instead of meeting the need of the resident. Logging which facilities routinely discharge for behaviors and upgrading their education and reviewing why.	Sun, Oct 10, 2010 1:22 PM	Find...

answered question	**15**
skipped question	**2**

2. What do you hope to accomplish as a participant in this roundtable discussion on Alzheimer's disease related behavior issues. Download

	Response Count
Hide replies	14

1.	Gain a better understanding of what the "behaviors" are, what the obstacles "actually" are, and what our action steps ought to be.	Tue, Oct 12, 2010 7:44 AM	Find...
2.	Be a part of a positive change.	Tue, Oct 12, 2010 5:51 AM	Find...
3.	Develop a model that supports better training for all LTC providers.	Tue, Oct 12, 2010 2:31 AM	Find...
4.	My goal would be to come together as a group to join minds and talents to make the care of Alzheimer's patients better understood and reimbursed in the state of WV	Mon, Oct 11, 2010 1:04 PM	Find...
5.	To inform other members of the group about the increase occurrance of discharges from facilities for behavior related issues. To increase peoples knowledge of the importance of dementia training and education to support facility staff and residents. to establish a need for education and auditing that will increase support and decrease discharges.	Mon, Oct 11, 2010 11:12 AM	Find...

25 responses per page

answered question	**14**
skipped question	**3**

2. What do you hope to accomplish as a participant in this roundtable discussion on Alzheimer's disease related behavior issues. Download

6.	Contribute to the future direction of the provision of care for our geriatric patients diagnosed with dementia.	Mon, Oct 11, 2010 7:58 AM	Find...
7.	A definitive plan for solutions to provide adequate long term care for those with Alzheimer's in an appropriate and effective manner.	Mon, Oct 11, 2010 7:24 AM	Find...
8.	Awareness of the need for more Demenita/Alzheimer Units in WV. Colaboration.	Mon, Oct 11, 2010 5:35 AM	Find...
9.	Better understanding of a complex problem	Mon, Oct 11, 2010 5:28 AM	Find...
10.	Improvement of both families' and LTC staff members' understanding of dementia.	Mon, Oct 11, 2010 5:08 AM	Find...
11.	Better care models or options for families who care for their loved ones with alzheimer's disease as well as other dementias.	Mon, Oct 11, 2010 3:06 AM	Find...
12.	An answer as to how West Virginia plans to address the related behavior issues.	Sun, Oct 10, 2010 2:24 PM	Find...
13.	Eliminate or lessen the occurance of resident being discharged for managable behaviors. Covering Behavior as Communication - a mandatory requirement for all staff in nursing homes and assisted living.	Sun, Oct 10, 2010 1:22 PM	Find...
14.	A greater sense of urgency as to the importance of providing a greater range of appopriate services for those individuals with denentia.	Sun, Oct 10, 2010 8:08 AM	Find...

25 responses per page

answered question	**14**
skipped question	**3**

3. What "one question" would you like to ask the roundtable group to discuss - but are afraid to ask? Download

		Response Count
	Hide replies	12

1.	Why do people think if you have an Alzheimer's unit you take residents with any kind of behaviors?	Tue, Oct 12, 2010 5:51 AM	Find...
2.	Do designated "Alzheimer's disease units" in assisted living and nursing home facilities really improve care outcomes, or are they just marketing ploys and opportunities to charge higher prices for care?	Tue, Oct 12, 2010 2:31 AM	Find...
3.	I don't think I would be afraid to ask any questions that I might have.	Mon, Oct 11, 2010 1:04 PM	Find...
4.	None..."i'm not afraid." :0)	Mon, Oct 11, 2010 7:58 AM	Find...
5.	Will the leaders of WV State government be willing to actually address this very crucial issue instead of ignoring it?	Mon, Oct 11, 2010 7:24 AM	Find...
6.	Reimbursement for specialty Alzheimer Units.	Mon, Oct 11, 2010 5:35 AM	Find...
7.	What is the real future of the disease.	Mon, Oct 11, 2010 5:28 AM	Find...
8.	Do families know there are no "magic bullets", medication-wise, which will universally calm behaviors and yet cause no side effects?	Mon, Oct 11, 2010 5:08 AM	Find...

25 responses per page

answered question	**12**
skipped question	**5**

3. What "one question" would you like to ask the roundtable group to discuss - but are afraid to ask? Download

9.	Why did the WV Bureau of Senior Services purposely exclude Medical Model Adult Day Care from the next 5 year Aged and Disabled Waiver when THIS option would help families care for their loved ones at home.	Mon, Oct 11, 2010 3:06 AM	Find...
10.	I'm not afraid to ask the question. When is West Virginia going to realize the seriousness of Alzheimer's Disease especially with the large number of elderly persons that live in West Virginia.	Sun, Oct 10, 2010 2:24 PM	Find...
11.	How many hours of dementia specific training has each of them had? How many hours have each of them spent working with residents who have dementia?	Sun, Oct 10, 2010 1:22 PM	Find...
12.	I am not afraid to ask but the question I keep asking is why do long-term care facilities, especially nursing homes, that are supposed to be experts in caring for people with dementia, along with other medical needs, often reluctant to take individuals who have demential but exhibit acting out behaviors that are common to the conditon,	Sun, Oct 10, 2010 8:08 AM	Find...

25 responses per page

answered question	**12**
skipped question	**5**

Show this Page Only

PAGE: EXPLORIATION OF BEHAVIORS WHICH RESULT IN EXIT/DISCHARGE

1. Please share your definition of Alzheimer's disease "behavior" that results in a need to discharge an individual. Describe the types of behaviors involved and what policy or treatment modalities may help to alleviate the need for a discharge. Download

		Response Count
	Hide replies	13

1.	If one resident is combative or abusive and hurts another resident for example, breaks an arm or pushes them down and they break a hip.	Tue, Oct 12, 2010 6:00 AM	Find...
2.	In my personal opinion, staff in LTC facilities does not know the residents well enough to avoid (or defuse) behaviors such as refusal of any type of care (which escalates to combativeness) and behaviors that may be perceived by others as being sexually inappropriate. Often, the residents' behaviors are not the problem - the staff's responses to the residents' behaviors are the problem.	Tue, Oct 12, 2010 5:54 AM	Find...
3.	Long term care facilities should be able to handle almost all types of Alzheimer's disease behavior within the facility, given that it may affect more than half of their residents. If they can't take care of patients with Alzheimer's disease, then they seem to be in the wrong business. Occasionally, a patient becomes delirious and obviously sick and may need to be transferred out for more thorough evaluation than can be accomplished in the LTC setting.	Tue, Oct 12, 2010 2:36 AM	Find...
4.	Typically the only type of Alzheimer's behaviors that pose a huge challenge would be violent behaviors or excessive wandering to the point of usafe elopements on a frequent basis.	Mon, Oct 11, 2010 1:08 PM	Find...

25 responses per page

answered question	**13**
skipped question	**4**

1. Please share your definition of Alzheimer's disease "behavior" that results in a need to discharge an individual. Describe the types of behaviors involved and what policy or treatment modalities may help to alleviate the need for a discharge. Download

5.	When I train staff for dementia care, I refer to Webster's dicitonary - the word "Communication is defined as a behavior that sends a message. It can be in the form of words, symbols, gesture, signs, etc. SO if communication is a behavior - than people working with people with dementia need to view behaviors as communication that is sending a message. Unless someone is at risk of harming themselves or others AND cannot be redirected, they should not be dischraged. Many times the discharge or labled behavior is the result of 1 instance that is mismanaged by hourly staff who are under trained and over used (at least that is how they often feel). Admissions of people with dementia, Alzheimer's type or otherwise should be screened and assessed by the facility care team prior to placement. A family history, life history of the individual, baseline needs, behaviors, routines, lifestyles must be gathered and reviewed pre-admission. The facility needs to be sure that they can accommodate this disease process as they would any other disease process, AND if the placement is not going to accommodate the disease and will put the person with dementia at risk, than do not admit. It is OK to say that the facility is not able to adequately accommodate the disease and that it would not be fair to admit the person. Admission Policy needs to be upgraded to include more specific screening. Discharge Policy needs to be upgraded to include steps that must be taken and documented prior to permanent discharge. Changes in behavior should be looked at, documented, and tracked. Changes need medical review that "Rules Out All Other Known Causes" just like when diagnosing for Alzheimer's disease itself, and the behavior should not be listed as caused by dementia. There should be a person in every facility who is the "go to" for all residents with dementia. All residents with dementia should be well documented, and revisited by a monitor/ mentor who can ask about, observe and care plan with satff and family for this person.	Mon, Oct 11, 2010 12:10 PM	Find...
6.	Behavioral problems that may require 1:1 staffing or psychological/psychiatric treatment. Aggression, depression (severe), disorganization that places the individual a danger to self or others.	Mon, Oct 11, 2010 8:07 AM	Find...
7.	There should be no behavior that leads to discharge. Is there a reason why cancer patients are discharged?	Mon, Oct 11, 2010 7:26 AM	Find...
8.	Resident to resident altercations. Falls. Wandering. Proper placement of residents with Alzheimer's Disease.	Mon, Oct 11, 2010 5:39 AM	Find...
9.	Danger to self or others.	Mon, Oct 11, 2010 5:32 AM	Find...
10.	Mostly such behaviors are those which grossly interfere with the staff providing care for the patient or those in which patients endanger other patients.Loosening of rigid behaviors by staff - "this is my assignment today and I must do it in this order"-types of approaches never work. Families' expectations that their family member will be PERFECTLY cared for ALL the time have to be loosened as well.	Mon, Oct 11, 2010 5:08 AM	Find...
11.	Any behavior that could possibly lead to a injury of another resident within the facility.	Mon, Oct 11, 2010 3:10 AM	Find...
12.	Severe aggressiveness, extreme behaviors are two generalized behaviors that come to mind. I'm not sure what treatment modalities could be used in facilities that do not distinct Alzheimer's units. You can't drug the residents and you constrain them.	Sun, Oct 10, 2010 2:45 PM	Find...
13.	I am not sure of a definition but they appear to be those behaivors which require more staff invovlement and oversight. these include wandering, shouting or yelling and aggessive behaviors toward others.	Sun, Oct 10, 2010 8:22 AM	Find...

25 responses per page

answered question **13**

skipped question **4**

2. Based on your expertise and experiences do West Virginia long term care facilities (as compared to other states) have a higher frequency of discharges due to the individual having Alzheimer's disease or dementia. Create Chart Download

	Response Percent	Response Count
Yes	25.0%	4
No	25.0%	4
I don't know	50.0%	8
Hide replies Why?		9

1.	I know the problem is prevalent in other states. However, the nature of our job exposes us to more problems than successes. Other states may be doing better than WV, but those aren't the situation we tend to hear about.	Tue, Oct 12, 2010 7:49 AM	Find...
2.	I think we do everything possible to keep them in our facility, such as re-evaling meds, using programming for redirection.	Tue, Oct 12, 2010 6:00 AM	Find...
3.	They wait until a resident's behavior increases in frequency and intensity such that it becomes a survey issue, and then instead of training staff to address they behavior, they discharge the resident.	Tue, Oct 12, 2010 5:54 AM	Find...
4.	It seems like it. But WV facilities are not set up to accommodate people with dementia. General populations are often too big, over stimulating and lack cues and supervision that allows these people to live comfortably and successfully. When I worked in LTC and Assisted Living Care(1985 - 2008) for those with dementia, discharges for behavior was not part of any plan. Discharges for behaviors were few and far betwwen and were always a last, last resort!! I can recall very few(3 - 5) cases where the resident was not able to return to the facility following a hospital/medical review.	Mon, Oct 11, 2010 12:10 PM	Find...
5.	Need for alternative placement.	Mon, Oct 11, 2010 5:32 AM	Find...
6.	I don't know the statistics but I doubt there is much difference.	Mon, Oct 11, 2010 5:08 AM	Find...
7.	I'm not familiar with what other states experience.	Sun, Oct 10, 2010 2:45 PM	Find...
8.	Limited staff training and limited facilities designed and managed to accomodate the changes that occur and the needs of those with dementia.	Sun, Oct 10, 2010 1:27 PM	Find...
9.	I wish I knew but I suspect some of it has to do with the fact many of our facilities have a high occupancy rate and do not need to fill their beds with individuals who require more staff intensive intervention.	Sun, Oct 10, 2010 8:22 AM	Find...

answered question	**16**
skipped question	**1**

3. What are the barriers or problems, if any, that exist in West Virginia that result in the discharge of individuals with Alzheimer's disease or dementia. Download

	Response Count
Hide replies	15

answered question	**15**
skipped question	**2**

3. What are the barriers or problems, if any, that exist in West Virginia that result in the discharge of individuals with Alzheimer's disease or dementia. Download

1.	Most NHs do not have any trouble filling their beds so there is no incentive for them to change this practice.	Tue, Oct 12, 2010 7:49 AM	Find...
2.	There isn't anywhere appropriate to send them.	Tue, Oct 12, 2010 6:00 AM	Find...
3.	Lack of understanding of the disease process at highest levels in LTC management - any "undesirable" behavior can escalate to the point of combativeness if the resident feels threatened or frustrated. Lack of efforts to provide appropriate training to front-line staff (and to reinforce that training on a daily basis). While increased casemix reimbursement would be helpful, this does not explain why facilities have not invested in training their staff appropriately.	Tue, Oct 12, 2010 5:54 AM	Find...
4.	Lack of education and training for LTC staff and clinicians.	Tue, Oct 12, 2010 2:36 AM	Find...
5.	There is really no better senario or system to send these patients too. The specialized units are small and far between.	Mon, Oct 11, 2010 1:08 PM	Find...
6.	* Facilities want heads in the beds and often don't take the time to review adequate information or information is sketchy. *LTC facilities do not have defined admission criteria for dementing illnesses. *LTC facilities do not gathered detailed life histories stating baselines and life patterns and life styles. *Hospitals often forget to tell about concern areas if they know it may be a problem *drugs are used during hospital stays that once eliminated - behaviors return.	Mon, Oct 11, 2010 12:10 PM	Find...
7.	If a patient is discharged/"kicked out" of a facility due to aggression or other behavior problems no other facility will give them a second chance.	Mon, Oct 11, 2010 8:07 AM	Find...
8.	the biggest barrier is that they "can" be discharged for behavior issues.	Mon, Oct 11, 2010 7:26 AM	Find...
9.	Lack of Alzheimer Units in WV.	Mon, Oct 11, 2010 5:39 AM	Find...
10.	Lack of senior mental facilities.	Mon, Oct 11, 2010 5:32 AM	Find...
11.	Insufficient gero-psychiatry expertise.	Mon, Oct 11, 2010 5:08 AM	Find...
12.	Lack of knowledge and or skill set needed to deal with individuals who exhibit less than desirable behaviors within the residential setting.	Mon, Oct 11, 2010 3:10 AM	Find...
13.	Most facilities are not equiped with special units for Alzheimer's residents. You can't blame them when the reimbursement for Alzheimer's residents in nursing homes is so low.	Sun, Oct 10, 2010 2:45 PM	Find...
14.	Poor staff knowledge. Poor support in the facility management. limited facility (physical plant) modifications to accommodate.	Sun, Oct 10, 2010 1:27 PM	Find...
15.	1.. Lack of proper training of staff. 2. HIgh occupancy rate that leave little incentive to take more difficult to care for residents. 3. Poor labor pool including limited number of direct care staff available. 4. Hospitals not always up front with receiving facility as to the conditon of the indiviudal to be served.	Sun, Oct 10, 2010 8:22 AM	Find...

25 responses per page

answered question	**15**
skipped question	**2**

4. Please rate the effect of each of the following on exits or discharges of residents with Alzheimer's disease or other dementia issues from assisted living or long term care facilities. Download

answered question	**16**
skipped question	**1**

4. Please rate the effect of each of the following on exits or discharges of residents with Alzheimer's disease or other dementia issues from assisted living or long term care facilities. Create Chart Download

	No Effect.	Little Effect.	Some Effect.	Significant Effect.	Substantial Effect.	Rating Average	Response Count
Facility Staffing	6.7% (1)	6.7% (1)	20.0% (3)	**40.0% (6)**	26.7% (4)	3.73	15
Facility Resources	6.7% (1)	0.0% (0)	20.0% (3)	**53.3% (8)**	20.0% (3)	3.80	15
Facility Characteristics	6.7% (1)	13.3% (2)	33.3% (5)	**40.0% (6)**	6.7% (1)	3.27	15
Facility Workload	0.0% (0)	6.3% (1)	18.8% (3)	**50.0% (8)**	25.0% (4)	3.94	16
Regulation	6.3% (1)	25.0% (4)	**43.8% (7)**	25.0% (4)	0.0% (0)	2.88	16
Legal/Liability Concerns	0.0% (0)	6.7% (1)	13.3% (2)	**66.7% (10)**	13.3% (2)	3.87	15
Family Concerns or Dissatisfaction	0.0% (0)	0.0% (0)	30.8% (4)	23.1% (3)	**46.2% (6)**	4.15	13
Caregiver Education	0.0% (0)	0.0% (0)	28.6% (4)	28.6% (4)	**42.9% (6)**	4.14	14
Lack of Statewide Plan	7.1% (1)	0.0% (0)	**42.9% (6)**	28.6% (4)	21.4% (3)	3.57	14
Reimbursement	6.7% (1)	13.3% (2)	**46.7% (7)**	20.0% (3)	13.3% (2)	3.20	15
Behavior Issues	6.7% (1)	6.7% (1)	13.3% (2)	13.3% (2)	**60.0% (9)**	4.13	15

Hide replies Describe any others? 2

1.	Accuity Level vs. Staff Hours for the 24 hour day. There is no accommodation for increased staffing for Mental Accuity/Memory Impairment. Yet 70 % of all nursing home residents have dementia.	Mon, Oct 11, 2010 12:10 PM	Find...
2.	I tried clicking on many of the above areas and when clicking on one it would erase the one I clicked on previously. I think all of the above have at least some effect althought I sometimes think some , like reimbursemnt. are used as excuses that are not accurate	Sun, Oct 10, 2010 8:22 AM	Find...

answered question **16**

skipped question **1**

Show this Page Only

PAGE: ADEQUACY OF STAFF TRAINING

1. Please rate whether Staff members are properly educated on the nature, stages and treatment of Alzheimer's disease and related dementias? Create Chart Download

	Strongly Disagree.	Disagree.	Not sure.	Agree.	Strongly Agree.	Rating Average	Response Count
Select from the following:	26.7% (4)	**53.3% (8)**	13.3% (2)	6.7% (1)	0.0% (0)	2.00	15

answered question **15**

skipped question **2**

2. List examples of areas of education that you would like to see developed in West Virginia to help improve the care for individuals with Alzheimer's disease or other dementia. Download

		Response Percent	Response Count
Show replies	**1.**	**100.0%**	**11**
Show replies	**2.**	81.8%	9
Show replies	**3.**	45.5%	5
Show replies	**4.**	36.4%	4
Show replies	**5.**	36.4%	4

answered question **11**

skipped question **6**

3. Share and describe the most creative or innovative program, plan, policy, caregiver technique, or education that you have experienced or seen related to improving the care for Alzheimer's disease or dementia. Download

	Response Count
Hide replies	11

1.	therapuetic programming, home style dining, roundup (gathering them in the kitchen for shift change so they don't see the shifts coming and going)	Tue, Oct 12, 2010 6:03 AM	Find...
2.	Sensory rooms for use with patients on a daily basis	Mon, Oct 11, 2010 1:14 PM	Find...
3.	I have been involved with planning and implimentation of some outstanding Social Models of care that were supported and monitored and worked beautifully. These do not happen overnight and must be championed by the facility staff, management, owners. Philosophy cannot just be on paper, but in practice - every day, 24 hours per day. Staff education and training is paramount, but daily monitoring and mentoring of care plans, individual residents and staff interventions are what makes it work. Residents in these care centers need to be closely	Mon, Oct 11, 2010 12:31 PM	Find...

25 responses per page

answered question **11**

skipped question **6**

3. Share and describe the most creative or innovative program, plan, policy, caregiver technique, or education that you have experienced or seen related to improving the care for Alzheimer's disease or dementia. Download

	monitored, because of their limited ability to communicate and staff need to be continuously communicated with to remind them to focus on what the resident can still do and to look beyond the dementia - especially where behavior is involved. It is well documented that 95-99% of all behaviors that result in concern are the result of the caregivers/care team not planning well. We always need to be one step ahead. Setting an appropriate stage, otherwise we set the person with dementia up for failure. People working in the facilities will often say "we don't have that kind of time", I say "it takes more time to mend the bridge once it is broken."		
4.	sensory stimulation; cognitive enhancement; physical exercise; "fractal" therapy - exposure to nature and art	Mon, Oct 11, 2010 8:08 AM	Find...
5.	The Alzheimer's Association training on behaviors and communication is excellent.	Mon, Oct 11, 2010 7:35 AM	Find...
6.	Monthly case studies training.	Mon, Oct 11, 2010 5:41 AM	Find...
7.	Continuity of care givers. Same people taking care of same residents.	Mon, Oct 11, 2010 5:36 AM	Find...
8.	Specialized units - which need improvement but still work better than not having them. In NH's without special units, in-facilty "adult day care"-type programs for the demented patients often work.	Mon, Oct 11, 2010 5:10 AM	Find...
9.	I believe the hands on training approach works best with front line staff who may have limited knowledge base as to the scientific and medical issues related with dementia but focuses on the hands on techniques used to appropriately care for those who suffer from dementias.	Mon, Oct 11, 2010 3:15 AM	Find...
10.	I have not seen a really good, creative program, plan or policy that relates to improving the care for Alzheimer's Disease.	Sun, Oct 10, 2010 2:55 PM	Find...
11.	It is not so much that the training is not available as the fact the training usually is not made available to direct care staff and is not often realted to the uniquenss of each individual being cared for. Instead, administrative staff attend the trainings and they often are not adequate in their ability to traing other staff.	Sun, Oct 10, 2010 8:29 AM	Find...

25 responses per page

answered question	**11**
skipped question	**6**